Module 5: How to Stay Healthy

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What Can You Do to Stay Well?

With the right precautions, people with sickle cell disease can do most of the stuff others do. To stay as healthy as possible, take these steps:

- Eat a balanced, healthy diet.
- Take medications, including folic acid supplements and hydroxyurea, as prescribed. Pack some medications if you are traveling or even just staying overnight away from home.
- Avoid extreme cold or heat. Dress in layers when the weather is changing. Layers can also help when you might go from hot weather into a cold air-conditioned room.
- Exercise regularly, but in a balanced way. Exercise is important for staying healthy, but doing too much can cause pain, particularly if you become dehydrated, overheated, or exhausted.

What Else Can You Do to Stay Well?

- Avoid alcohol, street drugs, and smoking, which can aggravate sickle cell disease and its symptoms. Some people with sickle cell disease are actually at risk for lung problems, so smoking is risky and must be avoided.

- Avoid places low in oxygen. For example, it's not a good idea to go hiking at high altitudes (over 8,000 ft elevation) or spend lots of time swimming under water.

- Prevent serious infections by contacting your doctor as soon as illness symptoms start. Be sure to get any immunizations (such as pneumococcal and flu vaccines) that the doctor recommends, and always call your doctor if you have a high fever (over 101.4°F, 38.5°C).

- Learn as much as you can about the disease and see your doctor regularly to help prevent more problems.

Water!

Water is extremely important to anyone who has Sickle Cell. Dehydration can cause a lot of problems, so it’s best to avoid it. The best way is to drink plenty of fluids! For an adult, drink at least 2-3 liters (70-100 oz) of water daily (equals about 4-6 bottles of water).

Your teachers and/or supervisors should know that you could become dehydrated quickly if you are not allowed to have ready access to water, either from a water bottle at your desk or from a nearby water fountain. They also need to be aware that you will need to visit the restroom more often as urination is more frequent than normal due to poor kidney function.

Other Health Considerations

- Stress management. Stress can lead to or worsen pain crises or increase pain episodes among people with sickle cell. Anyone with sickle cell should learn the signs of stress and take appropriate actions to manage high stress levels, such as regularly exercising and relaxing

- Get plenty of rest: Sleep 8-9 hours every night

- You also need to know your limits. People with sickle cell disease should avoid certain activities. However, remember the list of things that you can do is much longer! If you have any questions about a specific activity, ask your doctor. You know your body best, so with experience, you will find what activities are best for you.

Preventive Doctor Appointments

As someone with sickle cell, prevention can help you manage your condition better. It's a good idea to schedule appointments at least every 6 months in order to have regular checkups with your doctor.

PREVENTIVE CARE offers you several benefits:

- You can receive immunizations or antibiotics to prevent infection.
- You can get screening tests for early detection and preventive care of stroke, vision loss, lung, heart, kidney etc.
- You can get a prescription for pain medications.
- You can get a prescription for Hydroxyurea.
- You can Chronic transfusion.
- You can prevent iron overload.
- You can learn and keep track of pain triggers like menses, sleep apnea, asthma, gallstones etc.
- You can keep up to date with the most recent pain management techniques.
- You can have forms completed for your school or employer.
- You can learn about the latest news of sickle cell events and advances in research, and changes in health insurance or policies.
- You can check the accuracy of what you might have learned on the Web or social media.
- You may even help your condition by getting a Bone Marrow or Stem Cell Transplantation.

Be Careful Which Doctor You Visit

You might be surprised to know that many American doctors don’t know much about sickle cell disease. It is complex and not every doctor has had the opportunity to learn about how sickle cell can affect many parts of the body. Some doctors might have seen a lot of sickle cell patients many years ago but have not kept up to date on progress in treatments.

So, when you have Sickle Cell, it’s very important that you always check with your hematologist. If you don’t have the option to visit him/her for whatever reason, you need to have your medical records with you, which keep track of your previous tests and/or medications. This allows you to be more careful with a new doctor and gives you more knowledge about what is and is not okay for your health.

It’s important that you are not prescribed medication that might interact with the medication you’re currently taking or are allergic to. It’s also important that you don’t have repeat tests like x-rays. Even more importantly, DO NOT have surgery without talking to your hematologist first. He/she will know your health the best and will know if a certain surgery may have negative consequences.

Medical Records and Health Passport

Every time you see your doctors or go to the hospital, they keep detailed notes in writing or on computers about your health history. These are your medical records. Doctors look up your records to remember what happened to you in the past so that they can understand better how to treat you today. Your family probably has been keeping track of your medical records since you were born.

Many families choose one or more of these options:

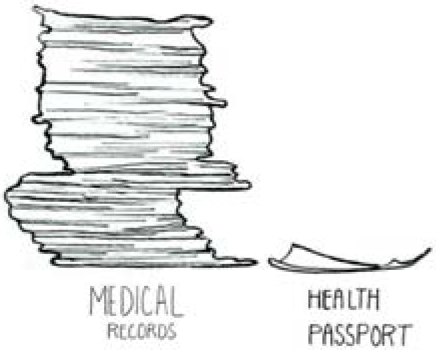
- Keep a copy of the most important papers that summarize your medical history.
- Write notes in a notebook and bring it to all medical appointments.
- Memorize the most important information in your medical history.
- Read your medical records online through electronic “Patient Portals”

All of your medical records will stay together as long as you keep going to the same doctor and hospital. When you go to a new doctor or hospital, one of the first things you will be asked is to remember all of your medical history until they can get a copy of the medical records from your other doctor or hospital.

Another time that you might need to have your medical records is when you travel—to camp, on a long field trip, or other trips.

A special set of medical notes can include guidelines written by the doctors who know you best, like suggestions for a doctor in the Emergency Department to treat your pain, fever, or other condition. This type of medical summary is sometimes nicknamed a health passport because it is an important set of papers, just like a passport is an important document to prove your citizenship when you travel.

New options for medical record sharing use the computer networks and “electronic medical records.” You will probably be asked to use these more than paper medical records in the near future.



Without Medical Records or Health Passport

What happens if I do not have medical records or a health passport?

Without your medical records, you may get incorrect or delayed treatment, including:

- a duplicate test or injection
- a medicine that triggers an allergic reaction
- a transfusion that triggers a transfusion reaction
- a waste of time trying medication doses or treatments again that did not work for you in the first place
- delay while the doctors or hospital ask you to remember your medical history and ask for a copy of medical records from the other doctors or hospital

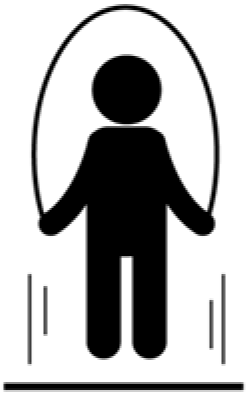
You might ask the new doctors to contact your previous doctors to talk about your care and what’s worked for you in the past.

Benefits of Exercise

Being physically active can help with improving and maintaining overall good health. Here are the top reasons why it is beneficial:

1. Strengthens the cardiovascular system—heart, lungs and blood vessels
2. Reduces the risk of persistent illness.
3. Increases muscle strength.
4. Helps you become more flexible.
5. Increases endurance and stamina-gives you energy for a longer period of time.
6. Increases natural pain killers (called endorphins) in the body's nervous system, which help control pain.
7. Helps with weight control.
8. Helps to improve quality of sleep.
9. Helps balance and coordination.
10. Reduces fatigue and increases energy.
11. Reduces muscular tension, stress and depression.
12. Helps combat depression and anxiety.
13. Helps you keep a positive outlook.
14. Helps to prevent constipation.

People with sickle cell disease can become physically active – just be smart about how you do it. Start up an exercise program gradually and take little rest breaks and always drink plenty of water.



Tips for Exercising and Playing Sports

People with Sickle Cell who participate in competitive or team sports (i.e. student athletes) should be careful when doing training or conditioning activities. To prevent illness, it is important to:

- Set your own pace and build your intensity slowly.
- Rest often in between repetitive sets and drills.
- Drink plenty of water before, during and after training and conditioning activities.
- Keep the body temperature cool when exercising in hot and humid temperatures by seeking the shade.
- Immediately get medical help when feeling ill.
- Tell your coach or gym teacher that you have Sickle Cell, so that they can understand why you are taking a wise and cautious approach to exercise.

Click here to watch a video that gives you some tips from Billy Garrett, Jr., who is a DePaul University basketball star that has sickle cell!

Your Health at School/Work

What can I tell my teachers and/or other school staff members so that they can help me to stay well? You and your family can tell your school many things about sickle cell disease. Make sure you at least share these key points:

- Sickle cell disease is an inherited disorder of the blood. It is a lifelong condition that can be treated, but it has no cure except bone marrow transplantation. It is not contagious.
- Sickle cell disease can cause some medical emergencies as well as hidden daily problems. However, the challenges of sickle cell disease can be very different for any two people.
- Physical activity - The low red blood cell counts (anemia) of sickle cell disease can cause decreases in endurance.
- Teachers should encourage your participation in physical education but allow rest breaks if you feel tired or short of breath. Stop if you have pain or weakness.
- Some people may have bone pain or bone damage that impairs mobility, so they may have difficulty moving quickly between classrooms or on stairs.
- It may be helpful for your school to provide an extra set of textbooks for you to keep at home in order to decrease the physical stress of carrying a heavy backpack.

More About Your Health at School/Work

Here are some other points to share with teachers and/or bosses:

- Fluids - Silent kidney damage increases both peeing and the chances of dehydration. Dehydration can lead to increased pain.
- Temperature - Extremely hot or cold temperatures can trigger a painful episode.
- Physical appearance - Most people with sickle cell disease appear normal.
- Your teachers/supervisors should allow you to drink plenty of fluids throughout the day. Doctors recommend allowing you to carry a water bottle with you. Going to the water fountain or cooler is also fine.
- You should be allowed bathroom breaks whenever necessary.
- You should limit outdoor activities when the weather is excessively hot or cold.
- Be sure that you dress right for the weather (including fire drills). Dressing in layers permits flexibility when weather conditions change.
- Take care to avoid excessive chilling from air conditioning or wet clothing.
- Request bus transport when it is too hot or cold to walk to school.
- Jaundice (yellow eyes) can be caused by the products of increased broken red blood cells.
- Delayed growth and puberty appear to be caused by chronic anemia and organ damage.

Educational Resources

Some students need special arrangements and accommodations at school, such as a 504 plan, an individualized educational plan, and maybe tutoring.

At some point during your education, you may need to be hospitalized and miss school. Or you might miss parts of days for appointments with the doctor. You might be in the hospital for a few days for pain management or longer if other problems come up. After you are discharged, you may miss a few additional days of school to manage pain at home.

Give your school the telephone number for your doctors, and tell your school that these websites have additional information:

- www.SCInfo.org
- www.SickleCellKids.org
- www.cdc.gov/ncbddd/sicklecell/documents/SCD%20factsheet_9steps.pdf

What else does your school need to know? Most schools have a form for your doctor to complete. You can help by completing a health passport and review it with your doctor to be sure it is correct.

Air Travel with Sickle Cell Disease

Most people with sickle cell disease adapt well to air travel, but some can run into difficulties. Unfortunately, it is not always possible to predict if you will do just fine or be among those who have trouble flying. For this reason, it helps to know about potential problems so that you can take preventive measures or deal with them head-on if they should occur.

Commercial jets fly at an altitude of around 30,000 feet, where the oxygen is extremely low, but their cabins are pressurized to keep the oxygen level equivalent to that at 8,000 feet. While this oxygen level is adequate for most children with sickle cell, you may need more. To play it safe, call the airline ahead of time to find out what procedures are in place for the use of supplemental oxygen. Keep in mind—even if you do experience complications from the low oxygen level, it does not mean you will have a problem with every flight.

The air both in airports and on planes tends to be dry, so you will need to drink more than usual to avoid becoming dehydrated. This is easy enough to prevent—just pack an empty travel mug or sports bottle in your carry-on bag. After you pass through security, fill the mug or bottle for use. Oxygen generators are starting to be substituted for oxygen tanks in flight.

Great job! You’re another step closer to finishing the CHECK Sickle Cell Online Program. Hopefully you now know more about how you can stay healthy with sickle cell.

Now you can move on to the next topic, which talks about sexual health and sickle cell.