

# Module 3: Healthcare Tips

## Contents

- Be a Wise Healthcare User
- Becoming a Partner with Your Child's Healthcare Team
- Preventive Care
- Being a Medical Advocate
- Hospital Visits
- Questions to Think About for Hospital Stays
- Other Helpful HealthCare Tips

## Be a Wise Healthcare User

Another important area that you need to learn as much as possible about is healthcare and how to use resources in the best way possible for you and your child. Here are 5 key points to remember:

1. At the beginning of an appointment, always tell any doctor or medical person that your child has sickle cell.
2. Try to avoid seeing too many doctors at different places. It's better to keep consistent with the doctors your child sees. That way, those doctors are building a complete picture of your child's health. If you take your child to different doctors, each doctor will only be getting one chapter of your child's health.
3. Avoid going to MinuteClinics or Drugstore Clinics with fever or other medical issues. These basic health centers do not have people who are trained in complex health problems like sickle cell disease. It's like if you took a racecar to a local quick oil change shop for an engine problem. They wouldn't know what to do! Even many community hospitals cannot handle the scope of problems that a child with sickle cell can have.
4. Select insurance coverage VERY, VERY carefully. You need to make sure you choose a healthcare plan that won't charge you big copayments or send you to a hospital far away. If you need help, you can always talk to a hospital social worker.
5. Plan ahead for travel or living somewhere new. It's important to plan ahead whenever your child goes on a trip. Make sure to pack medicines with a paper that talks about your child's medical conditions. Many times, people won't know what to do so it's always helpful to travel with information.



## Becoming a Partner with Your Child's Healthcare Team

The best patient-doctor relationships are partnerships. You and your child's doctor can work together as a team to address your child's medical problems and keep your child healthy.

Your first step is to find a main doctor (your child's hematologist and/or primary care doctor) that you feel comfortable talking to. He or she will help you make medical decisions that suit your values and daily habits and will keep in touch with any other specialists you may need. So, spend some time finding a doctor you can trust and with whom you can talk openly.

Try drawing up a basic plan to help you make the most of your appointment. This can be for a new doctor or with the one your child has seen for years. Before your child's appointment, make a list of the things you want to discuss:

- Does your child have a new symptom?
- Are you concerned about how a treatment is affecting your child's daily life? Feel free to ask about different treatment options.
- You should bring either a complete list of everything your child takes or the actual medicine and supplement bottles. This includes over-the-counter medicines, vitamins, and herbal remedies or supplements.
- Bring up any problems or concerns you might have, whether or not the doctor asks about them.
- If you have more than a few items to discuss, put them in order with the most important ones first.
- If you're not comfortable or unable to do these things yourself, consider bringing a family member or friend and let them know in advance what you want from your visit.

During your visit, make sure to ask questions if anything is unclear to you. Take an active role in your child's health care. Do everything you can to get the best care possible.

The [National Institutes of Health](#) offers a great website with lots of other health tips.

## Preventive Care

Don't only take your child to your doctor when they are sick! You can help your child stay healthier by making sure you visit your hematologist on a regular basis. By checking in with him or her, there are a lot of benefits for your child. Here are just some of them:

- Your child can receive immunizations or antibiotics to prevent infection
- Your child can get screening tests for early detection and preventive care - stroke, vision loss, lung, heart, kidney
- You can learn about new pain medications or treatment options
- You can learn how to reduce triggers for pain by understanding menses, sleep apnea, asthma, gallstones
- You can learn about community events and support resources like summer camp, parties, conferences, scholarships



## Being a Medical Advocate

Another form of prevention is being an advocate for your child's health. This means making sure you take steps to speak up for your child. Some doctors may not understand the complexities of sickle cell. Here are some key things to remember:

- Watch out for overlapping and contradicting treatment
- Learn to understand medical forms and get counseling about your child's rights as a patient: Americans with Disabilities Act, FMLA, etc.
- Understand any plans for surgery. This means do not let a doctor allow your child to get anesthesia without them having the proper medical understanding and approval. This includes surgeries related to gallbladder, hip, tonsil, dental, spleen, Port, bypass etc.
- Try to keep all of your child's medical records together and bring them with you so that you can avoid or reduce repeat testing
- Make sure you know your child's medication allergies and let healthcare providers know
- Make sure you know your child's blood transfusion reactions and all antibodies and always tell the healthcare provider know



## Hospital Visits

Hospital stays can be difficult times for your child and your family. Many hospital admissions for children with sickle cell disease are unplanned and occur because they have become suddenly ill. This adds to the stress of being in the hospital and may make parents feel they have no control over what is happening. This is normal, but you should let a social worker or your child's nurse or doctor know what you are feeling.

The best way to prepare for future hospital stays is to learn about what will happen there. At your routine doctor visits, ask about what to expect at your child's first hospital stay. Often, your hospital will have information, which can help you and your child. They may have a brochure that explains the resources they have to help children and their families.

For children up to age six, try to have a parent spend the night. At night, your voice or touch can comfort your child. During the day, if a parent can't be there, the hospital may have volunteers who can sit with your child for short visits to keep him busy. If you don't think that you will be able to spend time at the hospital, talk this over with the hospital staff. They may know of resources to help you and your child.



## Questions to Think About for Hospital Stays

Here are some things to think about when your child needs to stay at the hospital:

- Who will take care of your child?
- Who will visit your child and how often?
- Who will watch your other children when you are at the hospital?
- How will you deal with hospital costs?

Talk to the social worker at the hospital if you need help with these plans.

Keep in close contact with your child's nurses. A good way of doing this is to set up a schedule for phone calls and visits so that the nurse knows when to expect you. She or he can then give you an update on your child's progress and make sure that your child is available when you come.

It is important that you understand what the doctors have decided about your child's illness and that you understand what medications and treatments are being given. If you do not understand what the doctors are talking about (this is very common) ask them for more explanation so that you are able to understand.

## Other Helpful HealthCare Tips

### Tips on Organizing Medication Refills

Depending on your child, you may have a lot of medications to keep organized. There are a few things that might help:

- Keep track of medication refills by adding a reminder to your calendar
- You can set up a reminder in your cell phone
- You can even post a note on your refrigerator

### Keeping Track of Appointments

You may have to go to a lot of doctor's visits with your child and it can be hard to remember them all. Here are a few ideas that may help:

- You can add all of the upcoming appointments in a calendar that you see everyday
- You can use a refrigerator magnet with a post-it or a white board to remind you
- You can even use your cell phone to program a reminder to pop up and give you a notification at any time before the appointment, even a few days ahead of time

Here are a couple of smartphone apps that can help you schedule reminders:

- [Medisafe Meds and Pill Reminder for Android](#)
- [Pillboxie for iPhone](#)





Congratulations! You have just completed the CHECK Sickle Cell Online Program!

Even though you are finished, you can always go back to any module to review any information!

