Transitioning Medical Care

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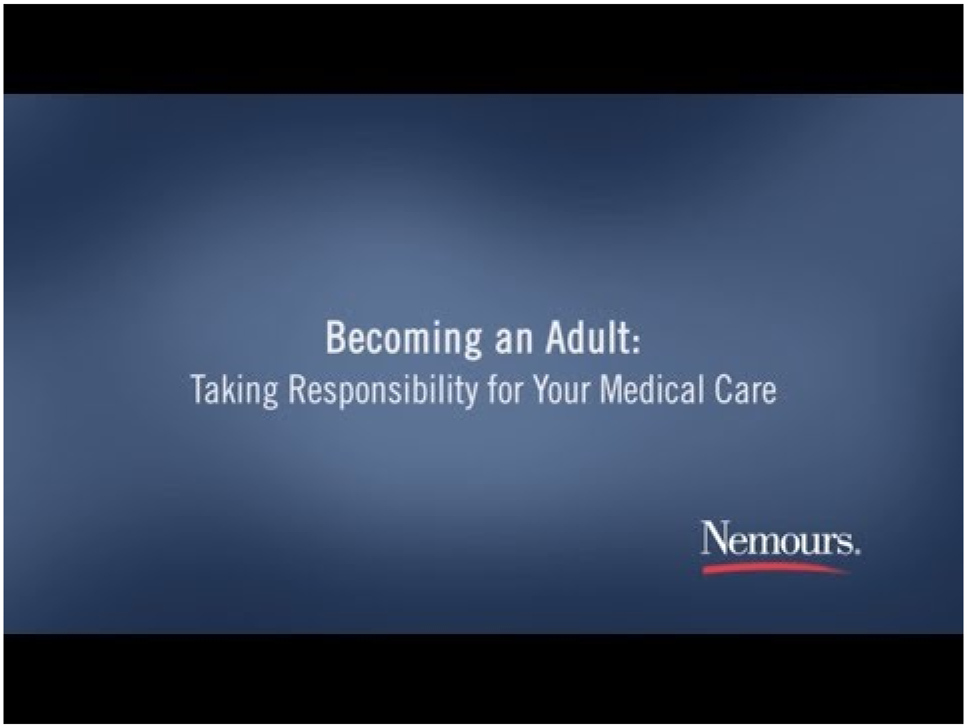
What is Transitioning?

Transition means changing or moving from one stage or place to another. Everyone goes through transitions in life - like when you graduated from elementary school or started a new job. Transition can be exciting and involve new experiences, but transition can also be difficult and scary, especially when you are not prepared for it.

An important transition in your life will be moving from child to adult healthcare for your sickle cell disease. As you get older, you have to become responsible for your health and you need to be able to take the steps that will ensure that you stay as healthy as possible. This transition is different around the country depending on your sickle cell program, but it usually involves changing your sickle cell doctor and hospital from ones that specialize in child care to ones that specialize in adult care. Transition also involves other important aspects like:

- Understanding sickle cell disease
- Answering and asking questions at your medical appointments
- Making your own medical decisions
- Taking your medicines on your own
- Speaking up for yourself

Here’s a great video that explains transitioning from Nemours:



When Does Transition Occur?

Transition does not happen all of the sudden, rather it is a step-by-step process that you, your family, and your doctors work on over time. Transition can be made simple by starting early and taking the time to get used to the new responsibilities that you will be having. It is never too early to start thinking about transition because being prepared can make it easier in the long-run. It is a good idea to start creating a transition plan with your healthcare team before age 14. The earlier you start, the better, because then you will be able to work on your plan for a few years before you move to a different doctor or hospital.

It is important to know that some pediatric hospitals have different practices and rules regarding care of older patients. For example, at some places patients over the age of 21 cannot be admitted to the pediatric hospital. At other places the age limit is 18 or 22 years. Ask your doctor about the policies at your hospital.

Why Do You Need to Transition?

Transitioning is important because it prepares you to become a successful, independent adult. Some of the responsibilities that come with transitioning can be scary, but just remember that with these responsibilities you are also gaining more freedom and privileges. Through transition, you earn the freedom to be in control of your own life.

Transition can be difficult because you might be leaving a pediatric doctor or healthcare team that knows you well and that you feel comfortable with. These individuals, however, are often not trained to treat adults. Treating adults and children with sickle cell disease can be very different so it is important that you are ready for the changes to come.

Are You Ready for Transition?

Change can be a scary thing but there are ways to be prepared for it. There are some checklists that can help you figure out whether you are ready to transition or not. The following checklists review all the information you would need to know:

- Understand your Medical History
- Know Medical Knowledge about Sickle Cell
- Have Medical Skills to deal with your condition
- Have certain Educational Skills
- Understand Health Benefits
- Have the proper Social Support

Review the following checklists. If you can answer "YES" to most topics, great-you are ready to transition soon. If you answer "NO," to a statement, use this checklist and talk to your doctor for help related to that topic.

Medical History Checklist

As you get older, you become fully responsible for your health and living your life with Sickle Cell Disease. Make sure that you are able to answer ALL the questions below to ensure that you know everything possible to live as healthy as you can.

1. know what type sickle cell disease (hemoglobin SS, SC, etc) you have?
2. I know my baseline hemoglobin level?
3. I know my baseline pulse ox level?
4. I know all of my medication names and doses?
5. I know what all of my medications are for and what they do?
6. I know all of my drug allergies?
7. I know all of the surgeries that I have had?
8. I know I have developed antibodies because of past blood transfusions?

1. PERSONAL STATEME
Has a proposal for insurance
with certain provisions, e.g. a

2. MEDICAL HISTORY
Have you, or have you ever
2.1 Disorder of the heart

Medical Knowledge Checklist

As you are transitioning into adult care, you will find that your doctors, especially your hematologists will expect you to know more about your SCD than you are used to.

They won't expect you to know everything, but they will expect that you have a basic understanding about living with SCD.

Because you are transitioning, it is likely that your parents or guardians have been keeping track of your health, but you have reached the age where it is your turn to take care of yourself. Ask your doctors and parents to go through your medical records with you so that you can have a better understanding of SCD. Go through the checklist below and see what you understand on your own and make sure you ask for help for the items you do not fully understand.

1. I understand behaviors and triggers that can cause a pain episode.
2. I know why drinking a lot of fluid is important for people with sickle cell disease.
3. I understand the importance of a healthy diet as it relates to sickle cell disease.
4. I understand how I got sickle cell disease.
5. I understand how I might pass sickle cell disease on to my child.
6. (For females) I understand how sickle cell disease could affect my health if I got pregnant.
7. I know about serious complications in sickle cell disease (acute chest syndrome, stroke, priapism, etc.)
8. I know what is considered an emergency related to sickle cell disease and what to do.
9. I know how the use of tobacco, alcohol, and other drugs can affect my sickle cell disease.

Medical Skills Checklist

Having Sickle Cell Disease means that you need to understand your body better than others and be prepared to handle complications that can happen because of your SCD. It is important that you are able to do ALL of the following to better ensure that your health is at its best at all times. Go through the following items and see what you are able to do on your own and get help for the items that need work.

1. I can tell someone what sickle cell disease is and how it makes me feel.
2. I know how to use a thermometer and what to do if I have fever.
3. I answer my doctor's questions during my clinic visits.
4. I ask questions during my medical appointments.
5. I know how to schedule a medical appointment.
6. I keep track of my medical appointments using a calendar.
7. I can get myself to my medical appointments.
8. I know how to get my prescriptions filled.
9. I have or am working on a medical transition plan when I leave pediatrics

Importance of a Primary Care Physician

Another medical aspect you need to make sure to understand when you are transitioning to adult care is knowing which doctor to go to at which time. As a sickle cell patient, you have a hematologist who cares for all things related to your disease.

If you deal with other types of sickness like asthma, allergies or even nutrition issues, you will need to make sure you are going to another doctor for those issues. Your hematologist is only meant to treat you for your sickle cell condition, not other medical problems. The best way to make sure that you can coordinate your care is to have a primary care physician who you see to connect you with the right doctor for the issue that you may be having that is not related to sickle cell disease.

Education and Employment Skills Checklist

It is important to know the options available to you to make sure that you get the most out of your education and employment. Look through this checklist and make sure that you are prepared in all aspects of life to better handle having Sickle Cell Disease.

- I have a 504 Plan or Individualized Education Plan (IEP).
- I participate in my 504 or IEP.
- I plan to graduate from high school / vocational school or obtain a GED.
- I have been thinking about the kind of career I would like as an adult.
- I have talked to my school counselor or a teacher about my educational / career goals.
- I know what type of training I might need for the career I want.
- I know the types of work situations that could cause problems related to sickle cell disease.
- I have practiced my job interview skills.
- I know how to write a resume.
- I know where to find information about job training and opportunities.
- I know where to find information about educational scholarships.
- I have talked with my parents about my vision for my future.

Health Benefits Checklist

Make sure that you are able to check yes to these points to make sure that you are prepared to manage your health and receive the best care for your Sickle Cell Disease.

1. I know what kind of medical insurance I have.
2. I understand the different types of health benefits that are available to me.
3. I know how my age can affect my health benefits.
4. I carry my own copy of my health insurance card.
5. I have a plan for the future regarding my health benefits.

Social Support Checklist

Make sure that you can check yes to these questions to ensure that you have the best social support to help manage your Sickle Cell Disease.

1. I have a good support system of family and/or friends.
2. I understand what self-esteem is.
3. I understand the difference between being sad and being depressed.
4. I understand what "healthy relationships" are.
5. I have hobbies or activities that I enjoy.
6. I have a person that I can talk to about sickle cell disease.
7. I have a positive vision of my future.

University of Illinois Hospital and Health Systems has ongoing support group events where families who have members with sickle cell can connect with others. Visit the website to find out more.

The Sickle Cell Disease Association of Illinois is a way for families to connect all around Chicago. Visit their website to find out their events and ways to learn more about sickle cell.

What Exactly Is Health Insurance?

Another important thing you have to know about when you are going to be part of adult care is health insurance.

Health insurance is a plan that people buy so they can pay a fixed amount of money for a range of medical care including doctors' appointments, emergency room visits, hospital stays, and medications.

Health insurance is now required for everyone in the United States. People who don't have insurance have to pay penalties that get more expensive each year.

The Kaiser Family Foundation offers a great video to explain the basics:

What Kind of Health Insurance Do I Have?

Because you are part of the CHECK Program, this means that you are receiving health insurance through the state of Illinois. You get a type of government-funded health insurance that is available only to certain people, like low-income adults and people with disabilities. It is called Medicaid. Many people with sickle cell qualify for Medicaid. Some children with sickle cell qualify for coverage under programs for Special Healthcare Needs.

Important Health Insurance Tips

Pay close attention to any mail or phone calls from your medical insurer.

1. Sometimes you only get one warning to send in paperwork or else your insurance coverage will end.
2. Sometimes a bill is wrong and you only have a short time to fix the mistake.
3. Bills that are not paid might quickly be sent to a collection agency.

Make sure that your medical insurer has the correct mailing address and contact information for you. If you miss one key notice because your mail went to an old address, you might end up with a very large mess.

Where Can I Get Help?

Trying to figure out how to transition to the right health insurance can seem very complicated. The good news is that there are people who you can talk to in your community to figure out what to do.

Illinois Department of Human Services has resource centers all across Illinois to help people figure out which health insurance they should have and how to apply for it. There are different locations depending on where you live.
Click on this link to find the one that is closest to you. Here are a few examples:

DHS Family Community Resource Center in Cook County -
Calumet Park Family Community Resource Center
831 West 119th Street
Chicago, IL 60643
Phone: (773) 660-4700
TTY: (866) 439-3713

DHS Family Community Resource Center in Cook County -
Englewood Family Community Resource Center
5323 South Western Avenue
Chicago, IL 60609
Phone: (773) 918-6700
TTY: (866) 214-9360

DHS Family Community Resource Center in Cook County -
Humboldt Park Family Community Resource Center
2753 West North Avenue
Chicago, IL 60647
Phone: (773) 292-7200
TTY: (866) 439-3721

There is also a general helpline you can call to ask questions: For more information about medical benefits, call the Health Benefits Hotline: In Illinois: 1-866-468-7543

What Other Kinds of Health Insurance are there?

In the future, you may be in a situation where you will be getting a different type of health insurance. Here are some examples of different kinds:

- The Health Insurance Marketplace.
  This option allows people who need to buy health insurance on their own to choose the best insurance to meet their needs. It's also sometimes called a Health Insurance Exchange. Get Covered Illinois is the official source to shop for health insurance online:
  https://getcoveredillinois.gov/explore-coverage-options/

- Student health coverage through a college.
  These provide only a little basic health coverage while you are enrolled in a college, but generally are not going to cover enough services for people with chronic medical condition like sickle cell disease. Students with sickle cell who choose these coverages often report their surprise that the student health insurance did not cover some basic blood tests, hydroxyurea medications, and sickle cell clinic visits – they were stuck with large medical bills to pay out of pocket

- Employer plans.
  This is the way a lot of people in the United States get their health insurance. It is also usually the least expensive option, since employers often help pay for part of the insurance. Some employers offer health insurance coverage on your first day of work. Others may make you work a period of time first (30, 60, or 90 days).

- Parents' plan.
  In the United States, kids can stay on their parents' health insurance plan until age 26. This is true even if you're married, live somewhere else, and have a job.

Where to Find More Information

Got Transition is a great resource that offers a lot of information all about transitioning along with comments from youth like you.

Great job!!

You’re another step closer to finishing the CHECK Sickle Cell Online Program. Hopefully you were able to learn how you transition from your parent taking care of everything to having your own health insurance and seeing an adult doctor.

Now you can move on to the next topic, which shares stories about how other people deal with their Sickle Cell Disease.