

Health Smart:

Teens with Sickle Cell Disease Moving from Pediatric Care to Adult Care



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This document is not intended to take the place of the care and attention of your personal doctor. Our aim is to promote active participation in your care and treatment by providing information and education. Questions about individual health concerns or specific treatment options should be discussed with your doctor. For more general information on sickle cell disease, please visit our Web site at www.stjude.org/sicklecell.

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Teens with Sickle Cell Disease Moving from Pediatric Care to Adult Care

Moving from pediatric (children's) care to adult care can be one of the hardest changes you will face as a patient with sickle cell disease. As a family you must find a balance between concerned parents who want to handle all the details and teens who want to be completely independent.

Many issues must be considered when moving from a pediatric hematologist (sickle cell doctor) to a hematologist who treats adults.

This booklet will help you address some of these issues. Feel free to ask the St. Jude staff questions you might have about making this transition (change).

At the back of the booklet are several pages for you to write notes and questions.

You will also find a glossary of terms that you might encounter during this time of change.



Making a transition to adult care means changing from your pediatric hematologist to a hematologist who treats adults.



*Why do I need
to change doctors?
I like my
hematologist.*

Changing from a pediatric doctor to an adult hematologist needs to happen for many reasons.

- Most children's hospitals do not treat anyone older than 18.
- At age 18, you are legally an adult.
- Your body is changing; caring for a child is much different than caring for an adult.



*How do I
transition to
adult care?*

You need to be **HEALTH SMART!**



What is
**HEALTH
SMART?**

HEALTH SMART is being able to make decisions about your medical care. You should know:

- How sickle cell disease affects your body;
- How to ask questions about your treatment;
- How to make it through the health care system as an adult; and
- How to get support when you need it.



Your doctor and nurse case manager can help you understand.

- You can begin by knowing your medical history.
- Know what type of sickle cell disease you have, and what complications you have had in the past.
- Know what medicines you take and why.
- Keep a copy of your medical record for your files.



You need a copy of your medical record for several reasons.

- You need to know what is in your medical record.
- You need to make sure your medical record is complete.
- You need to give your adult hematologist a copy of your medical record.
- Your adult hematologist cannot make informed decisions about your care without a complete medical history.



*How will I know if
my medical record
is complete?*

Your medical record should have the following information:

- | | |
|-----------------------------|-------------------------|
| Name | Transfusion History |
| Date of Birth | Recent Labs |
| Type of Sickle Cell Disease | Allergies |
| Recent Medical Problems | Current Medicines |
| Ongoing Problems | Immunizations |
| Past Medical History | Family & Social History |
| Past Surgeries | Physical Exams |

Don't forget to add to your medical record each time you visit your health care provider.



What else do I need to have to make the transition to adult care?

You should have the following documents:

- A medical identification (ID) card
- A durable power of attorney for health care
- A health insurance card
- An up-to-date immunization record



*What is a
medical ID card?*

A medical ID card is a card that you carry in your wallet. You should carry it with you at all times. The medical ID card should contain the following details:

Name

Date of Birth

Type of Sickle Cell Disease

Allergies

Average Hemoglobin

Emergency Contact
Information

Name of Hematologist

Other (for example,
current treatment of
major complications)

Information current as of: _____



What is a durable power of attorney for health care?

A durable power of attorney for health care is a document that allows someone to make health care decisions for you if you are unable to make them for yourself. This can be a spouse, parent, or friend who is 18 years or older. Before choosing someone to name in your durable power of attorney for health care:

- Discuss your medical views with the person; and
- Make sure that the person you choose is comfortable making medical decisions for you if you cannot make them for yourself.

Give a copy of your durable power of attorney for health care to your doctor and the hospital whenever you are admitted.



Your insurance carrier will issue you a copy of your insurance card. Give them a call if you do not have one. Carry your insurance card with you at all times. Also, learn the terms of your insurance policy:

- Do you have a co-pay for office visits and visits to the emergency room?
- Which hospitals take part in your insurance plan?
- What happens if you are traveling out of town?
- How does your insurance handle payment?
- Do you need pre-approval for surgery or specialist care?



Yes, usually health coverage changes when a patient turns 18.

- If you are covered by a state health care plan, you will have to re-apply at 18 years of age.
- If you are covered by your parents' health insurance, coverage may stop at 18 unless you attend college.
- If you attend college, you may be able to get discount health insurance through your school.
- If you purchase health insurance, make sure it does not have a pre-existing condition clause.
- If you begin working, you may be covered under your employer's medical plan.
- Talk to the social worker if you have questions about insurance coverage.



What immunizations do I need before I transition to adult care?

In addition to your childhood immunizations, you should have the following:

- | | |
|-----------------------|------------------------------|
| Hepatitis A | MMR Booster |
| Hepatitis B* | Polio Booster |
| Pevnar* | Tetanus-diphtheria-acellular |
| Pneumococcal Vaccine* | Pertussis Booster |
| Influenza vaccine* | Meningococcal Meningitis* |

Optional:

- Varicella (chickenpox)
- HPV vaccine (if you are female)

You can get the vaccines marked above with * at the St. Jude Sickle Cell Clinic. You can receive the other vaccines at your primary care doctor's office.



*How do I
choose a hematologist
who treats
adults?*

Your nurse case manager can help.

- Your case manager will give you a list of hematologists in the area who treat adults.
- Your case manager will invite you to take part in a teen transition tour of adult hematology offices in the area.
- Your case manager can help you schedule your first appointment.
- With your consent, your records will be sent to your new hematologist's office before your first visit.
- Make a list of questions to ask during your first visit.



This is a tour that visits two adult hematology offices in the Memphis area.

- It is provided free of charge.
- Teens and their parents are welcome to attend.
- Transportation is provided.
- It is a half day tour with free lunch at the end.
- There is a discussion period during lunch to answer your questions.
- The tour is scheduled one (1) time every 3 months.
- Your case manager will schedule you for a tour shortly before you turn 18.

Ask your teen case manager for more details.



At 18 years old, you are a legal adult.

- You have to give permission for your parents to see your medical records or to talk to your doctor about your treatment.
- At age 18, you have to sign all medical documents. Your parents cannot sign for you.
- You will have to begin to show your independence by taking responsibility for your health.




*What if
I am not ready to
take on all of this
responsibility?*

You will not lose your support system!

- You will start becoming independent at 18, but your parents can help you until you are comfortable making decisions on your own.

Your current support system is still in place:

- Family
- Friends
- Social workers
- Your minister
- Your doctor and health care team



*What are
some of the differences
between pediatric and
adult care?*

You will become your own self advocate.

- Adult hematologists will not schedule or re-schedule appointments for you. That is your responsibility.
- Doctors who treat adults may not be able to spend much time with you. Write down what you need to tell your doctors in advance.

Make sure your care is coordinated:

- Ask your hematologist to send a copy of the dictation to your internal medicine doctor. The dictation is the note written in your medical record after each visit. You should ask the hematologist to do this every time you visit.
- Ask your hematologist to mail you a copy of the dictation after each visit for your medical record file at home.



Why do I need an internal medicine doctor if I see an adult hematologist?

You need an internal medicine doctor to take care of non-sickle cell health issues.

- Your insurance policy may require an internal medicine doctor to give you a referral to a hematologist and other specialists.
- The internal medicine doctor will give you annual physicals.
- Your internal medicine doctor usually will coordinate care between all of your specialists.
- It is like having a pediatrician and a pediatric hematologist.



*How do I
become a
self advocate?*

By being **HEALTH SMART!**

- If you follow the transition information in this booklet, you are well on your way to becoming a self advocate.
- Do not neglect your health. Continued care is important.
- If you wait until you have a problem, it might be too late.
- As an adult, you have to think ahead and try to prevent problems before they occur.
- See your new hematologist on a regular basis.

**Do Not Take Your Health for Granted –
Be **HEALTH SMART!****



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