

Sickle cell disease: Transition



What is sickle cell transition?

Transition is the period of evolving from a teen to an adult. You will begin to prepare for transition around 13 years of age. Transition is:

- A normal part of growing up.
- Preparing you for adult healthcare, one step at a time.
- Learning and gaining independence to take care of your health and manage your sickle cell disease.

Why is sickle cell transition needed?

- By the time you finish high school or by the time you turn 18, you should be ready to transfer your routine sickle cell care to an adult sickle cell provider of your choice.
- Adult health care providers are trained and specialized in treating sickle cell issues and concerns that may happen during the late teen years and into adulthood.

In order to stay healthy and have a successful transition to adult care, you must learn to be responsible for your own health and for your own body. You must learn about the healthcare system and your own health needs. This means:

- **Become informed** – know about your specific sickle cell type, your usual lab values and past issues you have had due to your sickle cell disease.
- **Find an adult sickle cell provider** – talk with your pediatric sickle cell provider, and ask for help with this. Your care team has a list of local adult sickle cell providers and can also help you find out-of-state providers.
- **Learn to make your own clinic appointments** – know the right provider to call when needed.
- **Take charge of your daily medicines** – make sure you know the names of the medicines you take and each medicine's purpose, dose, frequency (how often to take it) and side effects. Also know when and how to get refills.
- **Know your local sickle cell resources** – learn about the types of resources in your area and how to access them. Your sickle cell care team can help you find these.
- **Know about your insurance** – make sure you have proper insurance coverage for all of your medical needs. There are resources to help you with this. Insurance is required to get medical care and prescription coverage.
- **Learn to manage finances** – know how to pay for your sickle cell care, living costs, medicines, and getting to and from appointments.
- **Plan your career** – set goals to finish high school, possibly go to college or a vocational program, earn a living, and begin a career.

How do I prepare for sickle cell transition?

- Sickle cell transition is not always easy. It needs to be planned and needs to happen over time.
- Leaving your pediatric sickle cell providers is a huge life change. Your Children's Healthcare of Atlanta Sickle Cell team will help you and your family prepare for your journey.
- We have many programs and community resources to help with this process.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Sickle cell disease: transition, continued

At Children's, we offer the **Teen Scene** activities listed below.

Clinic Education Program (Teen Clinic), which:

- Helps prepare you and your family for the transition process while in your usual clinic setting.
- Is encouraged for patients 1 to 2 times each year from age 13 until ready for transition at about 18 years of age.
- Gives you a special time to meet and talk with other teens with sickle cell disease and their families in separate teen and parent groups.
- Gives your sickle cell providers time to discuss your sickle cell disease and care plan, and also spend time reviewing the skills you need to prepare yourself for transition and adult care.
- Helps you learn about transition in small amounts every year during your teens. This will help you feel confident, prepared and ready when the time comes for transition.

Transition Education Day (for 17 and 18 year olds), which is held 2 times a year for teens and their families at a local adult sickle cell facility. At this event, you can:

- Get a list of local adult sickle cell providers. You may also meet some local adult sickle cell providers and get a tour of an adult clinic.
- Meet other adults with sickle cell disease. You will learn about how they moved to adult care and how they live with sickle cell on a daily basis.
- You can discuss tips for successful transition and other life topics, such as reproductive and sexual health, social and emotional challenges, college-career options, and lifestyle concerns for adults living with sickle cell.
- Hear social workers discuss topics, such as getting and maintaining health insurance, social security, community resources, planning for college-vocation, scholarship opportunities and financial planning.

Ask your sickle cell provider for details about these programs and events.

Where do I go for adult sickle cell care?

- Talk with your sickle cell provider about adult care in your area.
- If you plan to go to college away from home, you must plan ahead.
 - Ask for a referral to an adult sickle cell provider near your campus.
 - Ask the Office of Disability Services at your college to help you.
 - Get a letter from your sickle cell provider to give to the Office of Disability Services.

You are not alone. Your doctor, nurse, social worker, parents and the rest of your healthcare team are here to help with your transition to adult medical care. You will be in charge of your healthcare as an adult so be strong, ask questions, and be part of the plan.

ALWAYS tell any new healthcare providers, especially emergency department (ED) doctors and staff, that you have sickle cell disease. For more details on sickle cell disease and services, visit the Children's Healthcare of Atlanta website at choa.org/sicklecell.

This teaching sheet contains general information only. Talk with your child's doctor or a member of your child's healthcare team about specific care of your child.

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