

# GENERATION SICKLE CELL

## Taking Control of Your Sickle Cell Care Transition

Actual Generation S Members.

A resource to help educate, empower, and engage young adults who are transitioning to adult care

# Sickle Cell Disease Care Transition Guide

## Small Steps to Help Prepare for a Big Step

Moving from pediatric to adult care is an important time in your life. Many people are involved in the process including you, your parents or caregivers, and your health care team. Transitioning from pediatric to adult care is something your pediatric care team may ask you to start thinking about as young as 12 years old!

### Adult care may feel different than pediatric care.

Your visits may be quicker and you may have less time with your doctor. It will be helpful to be well-prepared to make the most of each visit. This may seem overwhelming but have confidence in yourself as you begin to take more responsibility for your care—you've got this!



**Sickle cell taught me that I was a rare breed and how important it is to fight for what you want.** I learned how to be determined from facing sickle cell disease-related pain. It was important for me to not compare myself to other individuals, and despite my irregular hemoglobin, I was capable of achieving my dreams and desires. Sickle cell disease is a challenging disease to live with, but that doesn't mean I'm unable to achieve my dreams especially when challenges are an opportunity for growth.

**Kadeem G.**  
Actual Generation S Member.

# Be Empowered

## This information may help you get ready to move from pediatric to adult care

This section is designed to help you prepare for your move to adult care. It includes information and helpful tips for people 12-15 years old, 16-17 years old, and 18 years old and over.



**Graduating high school was a huge accomplishment for me.** Graduating was amazing because I did it without being left behind once. I fought through the missed days and countless hospital visits, and I made it. And if I can, then anyone can. You...can do whatever you want. No illness can stop you. Don't let it fight your dreams.

**Kierra M.**  
Actual Generation S Member.

# Ages 12-15

At this age, your parents or caregivers are likely still managing most of your care. This is a great time to **start asking questions and understanding how to care for yourself**.

**Check out the categories below for tips on starting to take an active role in your care**

## Sickle cell disease



- Know the type of sickle cell disease you have (this is very important)



- Understand how sickle cell disease can affect different parts of your body

## Pain crisis



- Know what triggers your pain crises



- Know how you make yourself feel better during a pain crisis

## Health care team



- Know the names and contact information of your doctor, nurses, and social worker

## About you

- Tell your health care team how you are feeling and/or if you are having trouble in school or with friends



**Parents and caregivers:** Work with your teen to help them understand the information on this page. You can help him/her successfully move to adult care down the road.

# Ages 16-17

Because sickle cell disease is different for everyone, management is too. At this age, your doctor may encourage you to **become more involved in your care and get ready for the move to adult care.**

**Once you know the information on page 4 [Ages 12-15], you can then move on to this list of helpful tips**

## Sickle cell disease



- Understand what it is and the science behind it
- Know your medicines and health history

## Pain crisis



- Know what can cause it and what your triggers are
- Track your pain crises and keep your pain management plan with you at all times

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## Health care team

- It is recommended that you talk to your pediatric health care team about transitioning and begin to look for an adult doctor
- Remember/write down the names of the other health care specialists you see and why you see them
- Start scheduling your own appointments



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## Health insurance



- Learn if you can stay on the same health insurance plan after you turn 18 years old
- Learn about how and when to apply for your own health insurance

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## About you

- Tell your health care team if you feel anxious or depressed
- Talk to your health care team if you are sexually active or thinking about becoming sexually active



**Set a goal for your move to adult care** and tell your health care team how you are getting ready for it. Ask for any help you need from them.

# Ages 18 and Older

By now you likely understand your sickle cell disease, your health care, and how to talk to your health care team.

Moving to adult care is an important step. Talk to your health care team and work with them to make a plan.

## The tips below can help you take control of your care

### Sickle cell disease

- Know about long-term problems of sickle cell disease and what you can do to stay healthy
- Practice healthy lifestyle choices



### Pain crisis

- Make a pain management plan with your adult health care team and ask them to add it to your electronic medical record
- Continue to track your pain crises



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### Health care team



- Identify who your new adult doctor is and set up an appointment with him/her
- Ensure all medical records from pediatric office have been transferred to new adult doctor
- Know who to call after office hours if you need medical attention or advice

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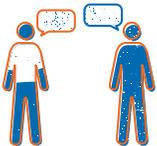
### Health insurance

- Carry your health insurance card with you
- Make sure your new adult health care team takes your insurance
- Know what number to call with any questions



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### About you



- Think about your future, your goals, and dreams
- Apply for jobs or enroll in college
- Talk with your health care team about future family planning
- Speak with other people who have sickle cell disease and support each other

# Be Your Own Advocate for Your Transition Story

Think about these questions as you transition to adult care. Use the notes section below to write down the answers and/or add your own questions.

**How do I take care of myself/what do I do when I am having a pain crisis?**

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**Why and how might my sickle cell disease affect my future?**

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**How am I keeping myself healthy?**

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**What should I take with me to my first appointment with my new adult care team?**

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**What are my future plans like college, a job, and planning my own family?**

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**What are my other goals for the future?**

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# Some questions you may want to ask your adult health care team

Think about these questions as you transition to adult care. Use the notes section below to write down the answers and/or add your own questions.

**How will I know if major organs in my body are being damaged?**

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**Is there anything I can do to help maintain a healthy life?**

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**Who can I call if I have to go to the emergency room (ER) for a pain crisis?**

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**If I need medical help, and your office is closed, what hospital should I go to?**

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**Will you put my pain management plan into my electronic medical record so hospital staff can see it?**

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**What other types of doctors should I see? Will you help make the appointment?**

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# Now That You Are Transitioning to Adult Care

Once you move to adult care, with this new status comes more responsibility. Here are some tips to consider once you transition to adult care.

## 1. Be prepared



- Make sure nothing gets lost in the move. Your adult health care team should have all of your medical records
- Have a pain management plan for pain crises. Know who to call if you have a pain crisis after office hours

## 2. Say what's on your mind and ask questions



- If you do not understand something your health care team says, ask them to explain it
- Tell your health care team about any problems you are having, especially if you have had any pain crises at home or in the hospital
- Tell your health care team if you are having trouble with work or school

## 3. Make sure your care is covered by your insurance



- Find out how this change in doctors may affect your health insurance coverage
- Find out if you can get insurance through your job or government-funded insurance, like Medicaid

## 4. Focus on the future



- Follow your dreams. Be your own advocate, and share your story with others
- Go to support groups to help others move to adult care

### Did you know? There are 2 main types of health insurance:

**Commercial insurance** comes from your job; you can also buy it. There are many different types of plans you can choose from. It is important to find out about different types of commercial insurance plans. Some may only let you see certain doctors or only pay for a certain amount of care each year.

**Government-funded health insurance** is for people who qualify based on a disability or the amount of money they make. Each state has different rules.

# Transition Timeline Tips



Ages  
**12-15**

Start learning more about sickle cell disease to ask your doctor questions



**Keep track of important things, like:**

- What type of sickle cell disease you have
- What medicines you are on and the phone numbers of your health care team

Use **“My Health Information Card”** on pages 13-14 to write down all of your medical information.



Ages  
**16-17**

Get comfortable taking an active role in your care, and begin searching for an adult health care team

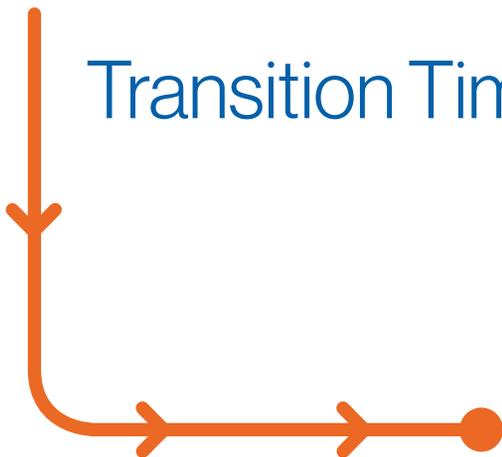


**Stay on top of pain**

- Know your pain crisis triggers and how to manage them!
- Tell your doctor when you have a pain crisis
- Keep track of the pain crises you have at home and in the ER

Use **“My Pain Crisis Tracker”** on pages 15-16 to keep track of your pain crises.

# Transition Timeline Tips (cont)



Ages  
**18+**

**Identify your new adult care team and be prepared for your first appointment**



## **Make and keep track of your appointments**

- Use a calendar (print, phone, computer, or app) so you don't forget
- When making appointments, make sure you have transportation on that date/time



## **Answer your health care team's questions yourself**

- Tell your parents or caregivers before the appointment that you will answer questions
- They can always help if you get stuck



## **Consider ways you can get support**

- Choose who you want your support team to be (family, friends)
- Look to support groups for people living with sickle cell disease

# Be Engaged

## Stay involved in your care

Use the trackers on the following pages to help you keep track of your medical information. Be sure to share this information with your new adult care team.

A portrait of Dominique G., a woman with dark hair, smiling. The image is semi-transparent and overlaid on an orange background.

**Sickle cell disease is pain and anger and loneliness and heartache.** But it is also love and community and strength and enlightenment and a better you. If it wasn't for me having sickle cell I don't think I would be this caring, wise, and thoughtful person. I say proudly that sickle cell disease has made me the woman I am today.

**Dominique G.**  
Actual Generation S Member.

# My Health Information Card

My Name:

Address:

Home Phone:

Cell Phone:

Email:

Emergency Contact and Phone Number:

Allergies:

## Adult Health Care Team

| Name                | Phone/After-Hours Phone | Affiliation (Hospital or Health Care Network) |
|---------------------|-------------------------|---|
| Hematologist        |                         |   |
| Primary Care Doctor |                         |   |
| Social Worker       |                         |   |
| Other               |                         |   |

## Previous (pediatric) Health Care Team

Doctor's Name:

Phone Number:

## Health Insurance (you can find this information on your health insurance card)

Provider:

ID Number:

Account Number:

Phone/Fax:

Website:

## Pharmacy

Name:

Phone Number:

Address:

Hours of operation:

## My Medical Information

Type of Sickle Cell Disease:

Blood Type:

Major Surgeries:

Total Blood Transfusions:

Current Transfusion Schedule:

## Current Medicines

| Name | Dose | When Do You Take It? |
|------|------|----------------------|
|      |      |                      |
|      |      |                      |
|      |      |                      |
|      |      |                      |
|      |      |                      |



# My pain crisis management plan

Use this page to record how you are managing your pain crises. Be sure to share this information with your adult health care team.

| Type of Medication   | Name | Dose | How often can you take it? |
|--|------|------|----------------------------|
| <input type="radio"/> over the counter<br><input type="radio"/> prescription |      |      |                            |
| <input type="radio"/> over the counter<br><input type="radio"/> prescription |      |      |                            |
| <input type="radio"/> over the counter<br><input type="radio"/> prescription |      |      |                            |
| <input type="radio"/> over the counter<br><input type="radio"/> prescription |      |      |                            |
| <input type="radio"/> over the counter<br><input type="radio"/> prescription |      |      |                            |
| <input type="radio"/> over the counter<br><input type="radio"/> prescription |      |      |                            |

**What else helps to relieve your pain? (check all that work for you)**

- Rest  
  Drinking lots of fluids  
  Heating pad  
  Massage  
  Distraction (watching TV, listening to music)  
  Other \_\_\_\_\_

**Who do I call if I am having a pain crisis?** \_\_\_\_\_



# GENERATION S

SICKLE CELL

Actual Generation S Members.

Your story can help inspire others who are living with sickle cell disease. With your parent's or caregiver's permission, share your story with Generation S at [www.JoinGenS.com](http://www.JoinGenS.com).

