



SPARK

SICKLE CELL CONVERSATIONS

A brochure that can help you get the best care for you

KEVIN

Living With Sickle Cell

INTRODUCTION

As a person living with or caring for someone with sickle cell, **it is important that you get care that works for you and your family.** Whether you already have a treatment plan in place or you're just beginning to put one together, you've likely asked the question: how do I get the best care possible for myself or my loved one? **This guide aims to help with that and includes resources on the following:**



BUILDING a care team



DEVELOPING a stronger partnership with your doctor and their practice and/or hospital



NAVIGATING the healthcare system



CREATING a personalized long-term treatment plan with your care team



ASKING your doctor questions about symptoms, complications, and potential treatment options tailored to your individual needs and goals

This guide aims to give you some tools to evaluate and strengthen your care plan in partnership with your care team. If you feel your care plan isn't working for you, there may be some information here to help you try a new approach.

A good care plan goes beyond managing immediate symptoms like pain. Guidelines suggest monitoring and managing your overall health, **which may help you set and achieve your long-term goals.**



BUILDING A CARE TEAM

Building a team of health care providers that understand you as a person and as a patient can be challenging for anyone. It can be even more challenging for someone living with a condition like sickle cell. As someone with sickle cell, or as a caregiver of someone with sickle cell, you may have experienced medical bias or discrimination. You may even have feelings of mistrust toward the healthcare system as a whole. Despite this, you still need a healthcare team that can give you the care you need and deserve.



Finding the right healthcare team for you at a practice or hospital that you can trust may take time.

You could start by finding a primary care physician (PCP) or hematologist with whom you feel comfortable. Depending on your healthcare needs, your care team may also include other specialists, such as a cardiologist, ophthalmologist, nutritionist, or even a mental health professional. Once you find a PCP or hematologist you trust, you can ask them to help you fill out the rest of your care team. In certain situations, you may also need help from healthcare professionals who aren't familiar with sickle cell. You can ask your care team for guidance on how to navigate these conversations.

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“I have a closer relationship with my nurse practitioner because we talk about everything.
I have a habit of saying, ‘I’m fine,’ even though I’m not fine. So when she comes in, I’ll say, ‘Oh, I’m fine.’
And she’ll respond, ‘You’re not okay. What’s going on?’ She knows from the start.”

-Jemela, Living With Sickle Cell

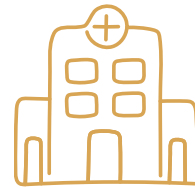
DEVELOPING A STRONGER PARTNERSHIP

Living with sickle cell is challenging. And although people with sickle cell show a tremendous amount of strength and courage, sickle cell can't be managed alone. Your care team is there to support you!

Receiving the support you need will require being open and honest about how you're feeling emotionally and physically. This kind of vulnerability may not be easy for many people. It may even feel uncomfortable at first, but, as you build trust and develop a stronger relationship with your doctor, these conversations can get easier. If you need some help starting conversations about how you are feeling today, **think about how you would complete the following sentences:**



Lately, I've been struggling with
(anxiety, fatigue, etc)...



How can I best prepare for
(regular appointments,
emergency room visits, etc)...



I'd like to know more about
(new treatment options, research, etc)...



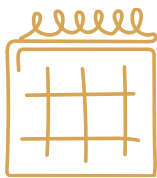
I currently manage my sickle cell by
(red blood cell transfusions, pain
medications, herbal supplements, etc)...

MY DISCUSSION NOTES

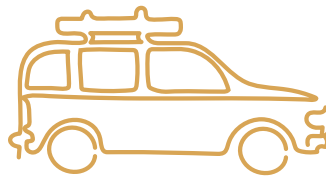
DEVELOPING A STRONGER PARTNERSHIP (CONT.)

Because sickle cell is a lifelong condition, you might want to think about how it will affect you beyond today and into the future. This includes the kinds of treatments you are currently receiving, as well as any life changes that you are expecting. It's important to think about long-term goals and how you and your doctor can start planning for them now.

If you need some help starting conversations about your future, **think about how you would complete the following sentences:**



I want to start planning
(travel, cross-country
move, etc)...



I'm nervous about
(my transition to adult care,
going away to college, etc)...



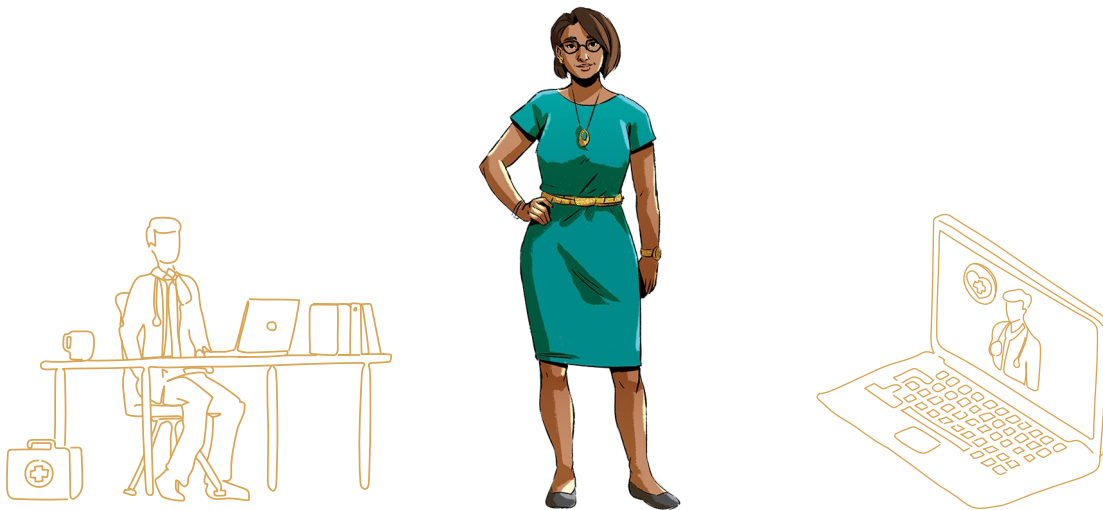
My long-term goal is to
(go to college, have kids, etc)...

MY DISCUSSION NOTES

These conversations will allow your care team to better understand the **different ways sickle cell impacts your life on a daily basis** and may make it easier for them to help provide suggestions for your care. Your care team can only work with the information you give them, so make sure you discuss the goals you want to achieve with their help.

NAVIGATING THE HEALTHCARE SYSTEM

Care for sickle cell can look a little different for everyone. Because good care can include regular monitoring and management, your appointments may go beyond traditional in-office visits with your doctor.



IN-PERSON VISITS

Your doctors may be located at a variety of healthcare institutions, depending on where you live, including a private practice, an academic hospital, or a sickle cell specialty center.

Other members of your sickle cell care team, in addition to your doctor, may include:

- Nurses
- Nurse practitioners (NP)
- Medical assistants/Office managers
- Physician's assistants
- Social workers

You may even meet with some of these care team members before being introduced to your doctor, as their role is to manage healthcare delivery in hospitals and clinics.

TELEMEDICINE OR REMOTE VISITS

Outside of in-office visits, you may communicate with your doctor and other members of your care team using telemedicine. Telemedicine includes any virtual communication you have, such as a phone call, video call, or messaging through a patient portal. Using telemedicine can allow you to communicate with your doctor more often, notify them of any new concerns or questions you have, and help with ongoing monitoring and management of sickle cell complications. **Frequent communication with your care team helps to build and sustain your relationship with them.**

NAVIGATING THE HEALTHCARE SYSTEM (CONT.)

If you ever have an emergency (like a pain crisis) that requires a visit to the emergency room (ER), you will likely see doctors outside of your regular care team. **It may help to:**



- **Call your primary sickle cell care office** on the way to the ER because they can provide the ER doctors with guidance for your care



- **Have a list of your medications, conditions, and other key information** on a piece of paper that you can provide while requesting emergency care. Doing so can help make sure you receive the treatment you need



- **Have information ready to share with your ER doctor in case of an emergency**, such as your after-visit summary sheet or wallet card from your patient portal.

Any information you provide to your care team will be relayed to your doctor. It could be helpful to **develop a strong relationship with them**, as they can become powerful advocates for you and your care.

NAVIGATING THE HEALTHCARE SYSTEM (CONT.)

Mapping out how you, your doctor, and your other care team members will communicate in different situations is an important part of your care. For every situation, it's good to know **who you will talk to and how you can get in touch with them.**

EXAMPLES OF SITUATIONS IT MAY HELP TO PLAN FOR

What is the situation?	Who can I talk to?	How can I get in touch with them?
Having an emergency	_____	_____
Experiencing a new symptom or if you are unsure it is an emergency	_____	_____
Following up after a visit	_____	_____
Getting a referral to a specialist (like an ophthalmologist or social worker)	_____	_____
Needing a refill	_____	_____

Your care team is there to offer any assistance they can. You should feel free to get in touch with them about any questions you might have about sickle cell or your care.










"I'm very optimistic. You know, one of the biggest things that I really think we should do is to **start taking charge and try to get everybody together.**"

-Cory, *Living With Sickle Cell*

CREATING

A LONG-TERM TREATMENT PLAN

Your care team is responsible for providing comprehensive care that goes beyond pain management and helps to monitor and manage your symptoms and complications before they progress. Even if you aren't currently experiencing symptoms, working with your doctor and care team to develop a long-term treatment plan can help you in the future. **A plan may include:**

-  **Scheduling and going to appointments consistently.** Regular monitoring of all organs, including kidney and lung function, as well as measuring blood counts and hemoglobin levels, may help to manage the silent effects of sickle cell
-  **Tracking symptoms or complications.** A daily journal that details the ways sickle cell impacts your body and your life may help your care team better understand what impacts you most
-  **Developing a communication plan.** Regular check-ins using telemedicine (video calls) or a patient portal (messaging) may help to keep your care team informed
-  **Transitioning care.** Making plans for specific life events, like switching from a pediatric to adult hematologist or going away to college, may help you maintain a consistent level of care after college or moving to a new area
-  **Preparing for ER visits.** Have a plan for who you will call, what you will say, and who will send notes to the ER so that you can receive the treatment you need
-  **Monitoring mental health.** Getting a mental health professional involved in your care may help to alleviate conditions like stress and anxiety that are related to sickle cell. Sickle cell pain and complications can have an emotional effect on people with sickle cell, which is why managing it is so important
-  **Discussing treatment options for sickle cell symptoms,** such as pain, and treatment options for underlying sickle cell disease will allow you and your doctor to make the best choices for you. It may be helpful to have these discussions on a regular basis, as well as when you're approaching different milestones in your life

Staying up to date on treatment options may also help you have more meaningful conversations with your doctor. You can find more information on available treatment options at sparksicklecellchange.com/treatment.

ASKING YOUR DOCTOR ABOUT YOUR CARE

Symptoms and complications of sickle cell may worsen with time. These changes may require additional care or different treatment options. Because of this, it's important to check in with your doctor on a regular basis.

Here are a few questions you may ask them:

Are there things I can do to prevent painful events?

What can I do to protect myself from an unpredictable crisis?

What complications are common for someone my age?

Can we develop a plan so I can receive the best care in an emergency situation?

How might sickle cell affect my life in 2 years? 5 years? 10 years?

Are there other treatment options you think I should consider now or in the future?

What are the risks and benefits of these options?

Are there specific screening tests I should have to better evaluate my health?

When and how often should I get these tests done?

What changes to my daily habits do you recommend (diet, exercise, etc)?

Is a stem cell transplant (bone marrow transplant) an option for me?

How will my ability to have children and family planning in general be affected?



Taking an active role in your care is important. No one knows your body, your wants, or your needs better than you do. **If your personal needs change** or you believe you're experiencing a new symptom, you should **reach out to your care team** right away. **This can give them a better opportunity to address your needs** and manage any symptoms or complications you may have.

LET'S SPARK CHANGE IN SICKLE CELL


Every step, no matter how small, can Spark change. It's important to take that first step. Try using some of these points in a conversation with your doctor during your next visit to advocate for the care you need and deserve.



CORY
Living With Sickle Cell

**"I had a doctor who knew a lot about sickle cell,
and she taught me a lot about how to take care of myself,
what I needed to be doing."**

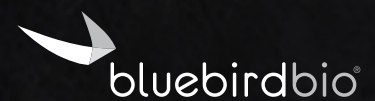
—Cory

A microscopic view of sickle cells, showing several elongated, curved, and pointed cells against a dark background. The cells are illuminated from the left, creating a bright, glowing effect.

Sign up at sparksicklecellchange.com to stay connected through email with resources, support, ways to connect with others, and more information about sickle cell.

A heartfelt thanks to the patients, families, allies, and sickle cell community who have helped make Spark possible. We hope that their experience helps to inspire you and your family as we continue to Spark change in sickle cell. This brochure was created through the collaborative efforts with the sickle cell community and hematologists who specialize in sickle cell disease.

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