

Taking Charge of Your Health

A Guide for Teens & Young Adults Living with Sickle Cell Disease

As you get older, you'll naturally take on more responsibility for managing your own health. This can feel like a lot, but this guide is here to help you build the confidence to manage your condition on your own terms

KNOW YOUR CONDITION

Understanding sickle cell triggers—like dehydration, cold, or stress—helps you manage pain and know when to seek help. If anything is unclear, ask your healthcare provider; being informed empowers you to manage your condition effectively.

SPEAK UP FOR YOURSELF

Build communication skills by speaking directly with your healthcare providers. Ask questions about treatments, share symptom changes, and voice concerns openly. Your input is vital; speaking up ensures your team understands your experiences and provides the best care for your needs.

MANAGING YOUR HEALTH

Build daily habits to manage your condition: stay hydrated to avoid pain crises, prioritize rest, and strictly follow your prescribed treatment plan. Using apps or reminders can help you stay organized and consistent with your medications and daily health needs.

KNOW EARLY WARNING SIGNS

Identify changes early to prevent complications. Monitor for worsening pain, unusual fatigue, fever, or any physical shifts. Acting before symptoms intensify helps manage your condition effectively. Paying attention to your body's signals is a vital tool for long-term health.

BALANCING YOUR ACTIVITIES

Participate fully by planning ahead for rest and avoiding overexertion. Communicate your needs to teachers or employers when appropriate. Prioritizing your health isn't a limitation; it's the foundation that makes your academic, professional, and social goals possible.

TRANSITIONING TO ADULT CARE

Prepare for the shift to adult care by learning your medications and keeping personal medical records. Start asking your provider about the transition early and attend appointments solo when ready. This gradual process ensures you're ready for independent health management.

YOUR MENTAL AND EMOTIONAL WELL-BEING

Living with a chronic condition can impact emotional health, causing stress, anxiety, or isolation. These feelings are valid. Speak with a trusted friend, family member, or counselor when needed. Remember, prioritizing your mental well-being is just as vital as managing your physical health.

WHEN TO SEEK MEDICAL HELP

Seek medical attention if you experience:
Severe or unusual pain
Fever (38°C / 100.4°F or higher)
Chest pain or difficulty breathing
Sudden weakness, confusion, or trouble speaking
When unsure, it's always better to seek help. Trust your body.