

# Caregiver Support Guide

## Supporting Someone Living with Sickle Cell Disease

Caring for someone with sickle cell disease involves navigating daily routines and health challenges. Your role is vital, and being informed builds confidence. Sickle cell disease affects how red blood cells transport oxygen; blocked flow causes pain crises, fatigue, and infection risks. Because symptoms vary daily, understanding these fluctuations helps you provide steady support. This guide covers practical assistance, recognizing warning signs, and the importance of prioritizing your own well-being while caregiving.

### HOW YOU CAN PROVIDE DAY-TO-DAY SUPPORT

To provide day-to-day support, maintain consistent routines by encouraging regular fluid intake, healthy meals, and adequate rest while managing medications as prescribed. Stay alert for early warning signs like fever, breathing difficulties, or behavioral shifts; identifying pain early can prevent serious complications. During a pain crisis, remain calm and offer reassurance while assisting with their care plan, fluids, and comfort measures like warmth. If symptoms worsen, seek medical care immediately. Act as a healthcare partner by scheduling appointments, tracking refills, and maintaining organized records. Finally, provide emotional support by listening without judgment, encouraging open conversation, and reducing unnecessary stressors, as emotional well-being is as vital as physical care.

### TAKING CARE OF YOURSELF

Caregiving is meaningful but demanding, making your well-being essential. Take breaks, request help from your community, and access available support services. Prioritizing your physical and mental health ensures you are better equipped to provide the care others need.

### WHEN TO SEEK HELP

#### SEEK EMERGENCY HELP FOR THOSE YOU SUPPORT

If they have a fever (38°C / 100.4°F or higher), chest pain, or difficulty breathing. Watch for severe, worsening pain or signs of stroke, such as sudden confusion, weakness, and speech trouble. When any unusual change occurs, it is always safer to seek professional medical care.

#### Working with Healthcare Providers

As a vital care team member, advocate for the patient by sharing symptom observations & asking questions to clarify the care plan and instructions.