



## Roadmap of Resources For Sickle Cell Disease (SCD) Caregivers

[Sick Cells](#) in partnership with the [Caregiver Action Network](#) (CAN) developed this **Roadmap of Resources** to support sickle cell caregivers, improve their quality of life, and reduce their stress. The resources listed below were compiled to help address the common challenges and barriers caregivers face.

### What Is SCD?

*A wealth of information about SCD*

- [CDC Materials & Multimedia](#)
- [SCD Therapies Fact Sheets](#)
- [Sickle Cell Trait](#)
- [Rethink SCD](#)
- [SCD Silent Damage](#)
- [Ask the Hematologist](#)

### Caring for Someone with SCD

*Information about complications and treatment*

- [Caring for Common Complications of SCD](#)
- [A Parent's Guide to Managing SCD \(UK\)](#)
- [What to Know about Blood Clots](#)
- [Steps to Better Lung Health](#)
- [Steps to Better Kidney Health](#)
- [Stroke Prevention Guidelines](#)
- [What Your Dentist Should Know](#)

### Clinical Guidelines

*Evidence-based recommendations that can help educate your care teams*

- [ASH Clinical Guidelines](#)
- [NHLBI Clinical Practice Guidelines](#)
- [Project ECHO](#)
- [Treatment Fact Sheet](#)
- [CDC Tips for Emergency Providers](#)

### Community Resources

*Toolkits and resources from community-based organizations (CBO)*

- [Sick Cells' Advocacy Tools](#)
- [SCDAA Find a Local CBO](#)
- [SCD Coalition Community Resources](#)
- [SCD 101 Sicklepedia](#)

### SCD Storytelling

*Elevating the voices of the SCD community*

- [Faces of SCD](#)
- [Sickle Cell Speaks](#)



### **Transition from Pediatric to Adult**

*Resources to help prepare for the change in care during adolescences*

- [St. Jude's STEP Program for Teens with SCD](#)
- [Hopkin's Sickle Cell Transition Program](#)
- [Peer-To-Peer Mentoring](#)
- [Transition Materials for Providers](#)
- [Transition Toolkit for Families \(en Español\)](#)

### **Emergency Rooms and Hospitalizations**

*Resources to assist with the hospital setting*

- Being Your Own Advocate in a Medical Setting: [Part 1](#) and [Part 2](#)
- [How Do We Approach Racism in Care](#)
- [SCD Management in the ER: What Every ER Nurse Should Know](#)
- [What to Know Before You Go \(ER Tips for Families\)](#)
- [Tips for Communicating with Your Loved Ones' Doctor](#)
- [Patient File Checklist](#)
- [Medication Checklist](#)

### **Emotion Health and Wellbeing**

*Resources to help caregivers live well*

- [Wellness Fundamentals](#)
- [Be The Match free counseling services for SCD warriors, caregivers, and family members](#)
- [UC Berkeley Resources to Find Your True Fulfillment and Joy](#)
- [Caregiver Telephone Support Group \(English + Español\)](#)
- [Mental Health Tests](#)
- [10 Tips for Family Caregivers](#)

### **Financial and Legal Resources**

*Grant programs, financial support, and legal advice*

- [HealthWell's SCD Treatment Fund](#)
- [PAF's Co-Pay Relief](#)
- [Engaging with Insurers: Appealing a Denial](#)
- [Legal Advice for When a Child Turns 18 Years Old](#)

### **Caregiver Employment and Family Coordination**

*Resources to help the family unit*

- [A Guide to School Policy \(June 2016\)](#)
- [MARAC Template Letter for Employers](#)
- [CDC "Tips for Supporting Students with Sickle Cell Disease"](#)
- [Support for Siblings of SCD Warrior](#)
- [Tips for Traveling](#)
- [Tips for the Employed Caregiver](#)