



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](#)