



SICKLE CELL DISEASE CAREGIVER HELP DESK FINAL PROJECT REPORT

Table of Contents

Abstract	1
Background	1
Methods.....	2
Overview	2
Challenge Areas for SCD Caregivers.....	2
Journey Map of a SCD Caregiver	3
Roundtable on Resources for SCD Caregivers	3
Roadmap of Resources	3
Results and Evaluation.....	3
Discussion.....	5
Conclusion	6
Acknowledgements	6
Appendix A: The Journey Map of the Sick Cell Caregiver.....	7
Appendix B: Roadmap of Resources	12

Abstract

Sick Cells partnered with the Caregiver Action Network (CAN) to strength their Caregiver Help Desk to serve the sickle cell disease (SCD) community. Sick Cells and CAN worked with the SCD community, including caregivers, individuals with SCD, and medical professionals, to identify gaps in current resources available to caregivers, and provide training to the Help Desk staff so they can address the needs for the SCD community. The Caregiver Help Desk is a unique, free support center that provides support to caregivers via phone, email or live chat. The output of this project serves as a roadmap of resources with educational tools and referrals to support SCD caregivers. This project was conducted through the support of Novartis' 2021 Solutions to Empower Patients (STEP) program.

Background

ABOUT SCD CAREGIVING: Caregiving is an inherently difficult role, replete with the emotional strains of watching a loved one deteriorate physically and/or mentally while trying to balance work, home responsibilities, personal medical conditions, and often times, other family members. These challenges are inflamed by the anxiety, depression, and stress that caregivers experience. In the case of SCD, the burden of caring for a person with a rare disease that not only suffers from medical comorbidities, but also racial and societal consequences, adds unprecedented burden to this population's caregivers. All of this is exacerbated by the current pandemic which has highlighted existing inequities for the SCD community and underscored the impacts of limited available resources for the population.

ABOUT SICK CELLS: Sick Cells is a national advocacy organization that empowers SCD warriors and caregivers to play an integral role in advocacy. Sick Cells developed the Ambassador Program to activate a network of SCD advocates dedicated to changing the landscape of SCD through policy change and the Faces of SCD Storytelling Program to empower the SCD community to share their stories and eliminate stigma through the power of their narratives. Additionally, Sick Cells conducted the “My Life with Sickle Cell” Survey in February of 2020. Findings from the survey showed that caregivers of a loved one with SCD experience missed work days, troubles maintaining work, and impacts on mental and emotional health.

ABOUT CAN: Caregiver Action Network (CAN) is the nation’s leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer’s disease. CAN (the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

ABOUT THE CAREGIVER HELP DESK: CAN has a designated telephone line for caregivers in need of support, called the Caregiver Help Desk or Help Desk. The Help Desk is a unique, free support center that caregivers can access by phone, email or live chat. Providing multi-channel access to caregiving experts reduces caregiver stress through live conversations with accredited professionals providing tailored guidance on basic and complex caregiving issues. The Caregiver Help Desk began as a pilot program in November 2019 and has served more than 10,000 family caregivers. Since the pandemic, the Help Desk has noted a significant uptick in the volume of calls and have been tracking how many calls are related to COVID-19. There has been a notable increase in calls related to financial distress, personal stress and concerns for a distant loved on.

Methods

Overview

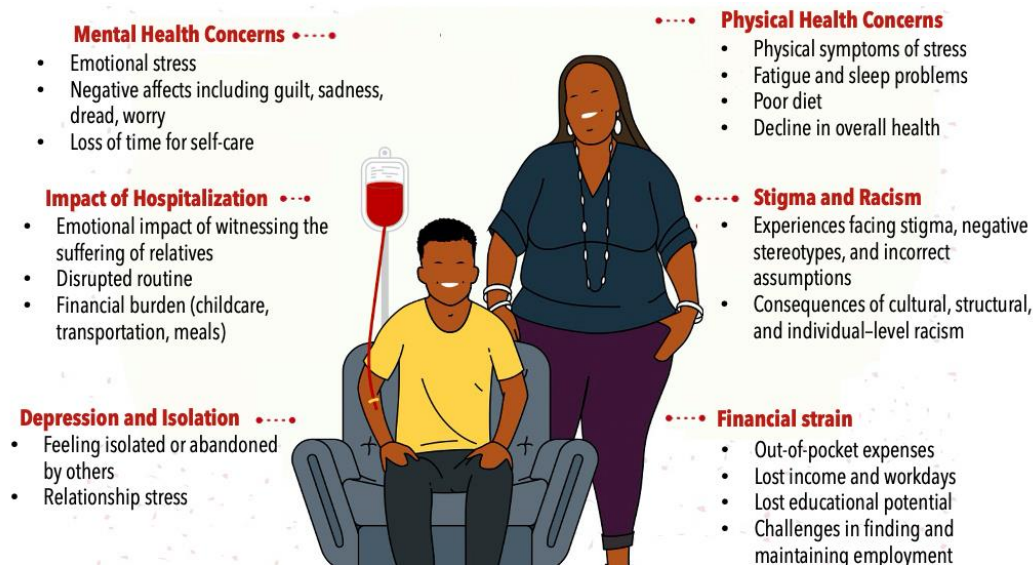
Sick Cells and CAN employed the following steps to identify gaps, align available resources and expand the ability of the Help Desk staff to support caregivers in the SCD community:

- 1) Identify challenge areas for SCD caregivers
- 2) Map the journey of a SCD caregiver
- 3) Host the May 2021 Roundtable on Resources for SCD caregivers
- 4) Develop the Roadmap of Resources

Challenge Areas for SCD Caregivers

In order to identify areas where support was needed, Sick Cells utilized survey results from the “My Life with Sickle Cell” Patient and Caregiver survey conducted in February 2020. With 547 respondents, this survey provided a robust summary of the main challenges faced by SCD warriors and caregivers. Additionally, Sick Cells conducted an environmental scan of available resources for caregivers in the rare disease and SCD communities to locate existing resources and identify potential gaps in available information. The diagram below summarizes key challenges that SCD caregivers face identified through survey results.

Figure 1: Challenge Areas, Identified from Sick Cells “My Life with Sickle Cell” Patient and Caregiver Survey, Feb 2020.



Journey Map of a SCD Caregiver

The **Journey Map of a SCD Caregiver (Appendix A)** is a blueprint of the encounters an individual can go through as a caregiver to a loved one with SCD. This diagram was created by Sick Cells and used during the May 2021 Roundtable on Resources for SCD Caregivers in effort to visualize an individual’s experience and align resources and support. This caregiver journey map is adapted from the HHS Health+ SCD Initiative and supported by data from Sick Cells’ “My Life with Sickle Cell” Patient and Caregiver Survey and roundtable discussion.

The journey map is discussed in 3 phases: (1) caregiver of a child with SCD, (2) caregiver of an adolescent with SCD, and (3) caregiver of an adult with SCD. Each phase highlights eight “pain points” or common areas where caregivers experience challenges or barriers that may require support. Roundtable participants reviewed the journey map and identified resources to bridge the gaps. The final journey map can be viewed in **Appendix A**.

Roundtable on Resources for SCD Caregivers

Sick Cells hosted a roundtable on May 25, 2021. The objective of the discussion was to inform trainings for the Caregiver Help Desk and identify available resources to address the specific needs and challenges of SCD caregivers. The roundtable was attended by 4 SCD caregivers, 4 Help Desk staff members, and 2 SCD clinical providers and moderated by Sick Cells and CAN Staff. The roundtable participants shared personal anecdotes of lived experiences and challenges associated with caregiving. A public summary is available on the [Sick Cells’ website](#).

Roadmap of Resources

Following the roundtable, the Sick Cells and CAN teams gathered established resources and referrals to address areas of need. This centralized collection of resources specifically for caregivers to a loved one with sickle cell disease, summarized in **Appendix B**, are publicly shared through the “Caregiver Resources” page on the Sick Cells’ website. This document also serves as a training guide to equip Help Desk staff to better support SCD caregivers. The Roadmap of Resources will continue to inform trainings for the Caregiver Help Desk in the future.

Results and Evaluation

The SCD Caregiver Help Desk campaign was launched on July 22, 2021, offering free support services to caregivers everywhere and now having the tools to connect caregivers the SCD community with the resources they need. This launch was promoted through social media, email, events, online advertising, community boards, and newsletters. The evaluation period lasted for eight weeks from July 22nd to September 15th, 2021. Key aggregated performance metrics are reported below.

CAN's Published Post Performance Summary:

- Campaign published to Facebook, Twitter, and LinkedIn
- Total Reach (number of unique people to see content): 36,143
- Total Engagement (number of interactions across all platforms): 602
- Engagement Rate per Impression (number of interactions as a percentage of impressions) = 1.7%

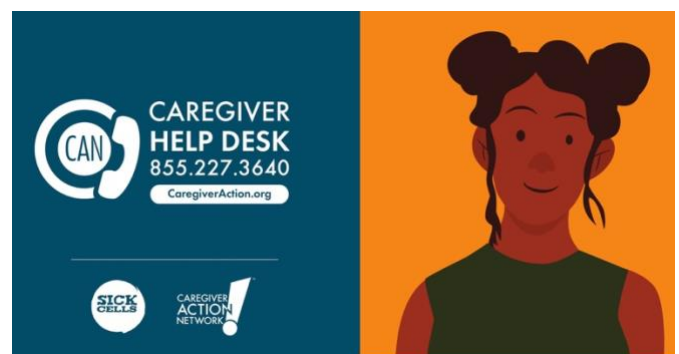
Sick Cells' Published Post Performance Summary:

- Campaign published to Instagram, Facebook, Twitter and LinkedIn
- Total Impressions (number of times a post was viewed) = 17,911
- Engagement Rate per Impression (number of interactions as a percentage of impressions) = 1.2%

Top Performing Social Media Graphics:



Account: Caregiver Action Network Facebook
Total Engagement*: 237



Account: Caregiver Action Network Facebook
Total Engagement*: 86



Account: Sick Cells Facebook
Total Engagement*: 65

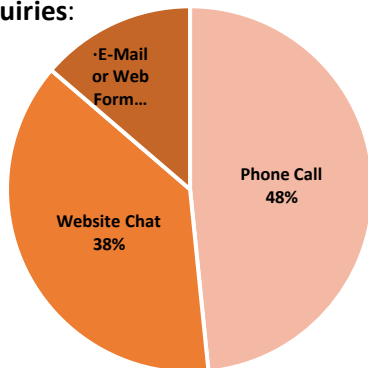


Account: Sick Cells Instagram
Total Engagement*: 48

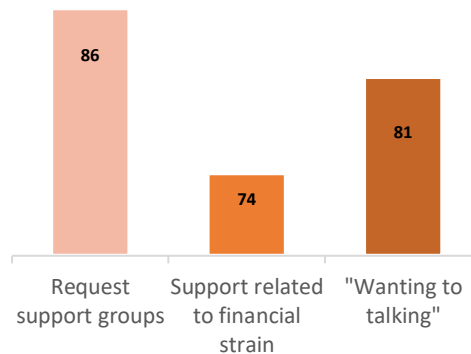
**Total Engagements is the total number of times users liked, commented, and saved the post. This includes organic activity only.*

CAN's Caregiver Help Desk Performance Summary:

- Reporting Period: July 22 to September 15, 2021
- Total number of Help Desk conversations with caregivers: 506
- Number of conversations indicating their loved one has sickle cell disease: 2
- Number of conversations indicating their loved one has a genetic condition: 6
- **Type of Inquiries:**



Reason for Outreach:



Sick Cells' Caregiver Resources Website Page Performance Summary:

- Reporting Period: July 22 to September 15, 2021
- Total unique view: 167
- Average time spent on webpage: 5 min 12 sec

Discussion

While the aim of the project was to equip the Caregiver Help Desk staff with resources to better support the SCD community, our team highlighted several other important take-aways that resulted from this work. The creation of the "Caregiver Resource" page will be a long-standing benefit for the SCD community. Having information and resources centralized addresses many of the challenges caregivers face when looking for support or accurate information. It is also important to highlight the impact this work has had on Help Desk staff. Many caregivers contact the Help Desk in order to have a non-judgmental ear or someone to talk with. By participating in the roundtable and reviewing the Journey Map, the Help Desk Staff was able to gain understanding and sympathy to those unique challenges of the SCD community, which will allow them to establish trust and understanding and facilitate their ability to be a good listener with empathy and compassion. We have included several quotes from Help Desk staff members that speaks to this impact:

*"I learned that **Sickle Cell does not always have conditions that are visible** yet is a very serious medical condition that needs daily attention from both the patient and the caregiver. I also learned that there are resources and ways to educate and support patients and caregivers along their journey."*

*"It was evident that **sickle cell disease is a challenging condition**, and the medical system does not always do a great job of diagnosing and treating it... It was disappointing but not surprising that many of the [caregivers] had to push and push to get their kids to the best providers and to get providers to recognize their children's changing needs over time."*

*"**I did not know about the stigma**, and in many cases, racism that these individuals experience. For me, learning about resources we can give to clients of the helpdesk was very useful. I have used sickcells.org as a reference for information for my own learning as well as referring it to a nurse with sickle cell patients."*

This project had several limitations. During the eight-week reporting period, only two clients of the Help Desk indicated having a loved one with sickle cell disease, which was lower than our targeted outreach. While our team was surprised by this result, we have identified several reasons for this outreach to be lower than anticipated: 1) caregivers may not immediately need to connect with the Help Desk at the time they viewed the promotional materials, and 2) caregivers who did connect with the Help Desk may not have disclosed the condition or disease of their loved one during their conversation with Help Desk Staff. Additionally, there is a lack of available resources to address the specific financial and legal challenges faced by the SCD community.

Future work to provide critical tools for managing medical bills, financial health, and estate documents, is needed to address important gaps. We were unable to identify sufficient resources that provide the information caregiver need to help navigate issues with insurance coverage, minimize the financial burden, and reduce stress. Other areas for future work include more robust psychosocial support including mental health counseling, education, group support, and other services tailored specifically for the sickle cell community, as well as respite care to provide short-term relief for primary caregivers of a loved one with SCD. Targeted outreach to SCD caregivers within the Hispanic community may also be fruitful in order to identify key educational gaps for this subcommunity and create targeted bilingual educational tools to fill those gaps.

Conclusion

The Sickle Cell Disease Caregiver Help Desk Project was able to address challenges several challenges that SCD caregivers face. By providing free support to family caregivers across the country, the Caregiver Help Desk can be important tool for the SCD community. Sick Cells and CAN will continue to disseminate this work and ensure caregivers are informed about this resource. Future efforts are needed to expand this work and create more robust tools to address lingering gaps for SCD caregivers.

Acknowledgements

We are thankful for Novartis for their willingness to support patient advocacy communities and to fund this project through their STEP Program.

We acknowledge the hard work, collaboration, and commitment from the teams at CAN (Chance Browning, Nichole Goble, Lisa Winstel, and Jodi Koehn-Pike) and Sick Cells (Maggie Jalowsky, Emma Andelson, Abby Tainter, and Ashley Valentine), along with our caregiver advisors (TaLana Hughes and Adrienne Sharpiro). We also thank the Carallel's Care Advocates for their dedication to caregivers and their participation in this project.

Lastly, we thank all of the SCD caregivers who participated in efforts related to this project.

Appendix A: The Journey Map of the Sickle Cell Caregiver

[see next page]



The Journey Map of a SCD Caregiver

The **Journey Map of a SCD Caregiver** is a blueprint of the encounters an individual can go through as a caregiver to a loved one with sickle cell disease (SCD). This diagram was created by [Sick Cells](#) and used during the May 2021 **Roundtable on Resources for SCD Caregivers** in effort to visualize an individual's experience and align resources and support. This caregiver journey map is adapted from [the HHS Health+ SCD Initiative](#) and supported by data from Sick Cells' "My Life With Sickle Cell" Patient and Caregiver Survey and roundtable discussion.

The journey map is discussed in 3 phases:

1. Caregiver of a child with SCD
2. Caregiver of an Adolescent with SCD
3. Caregiver of an Adult with SCD

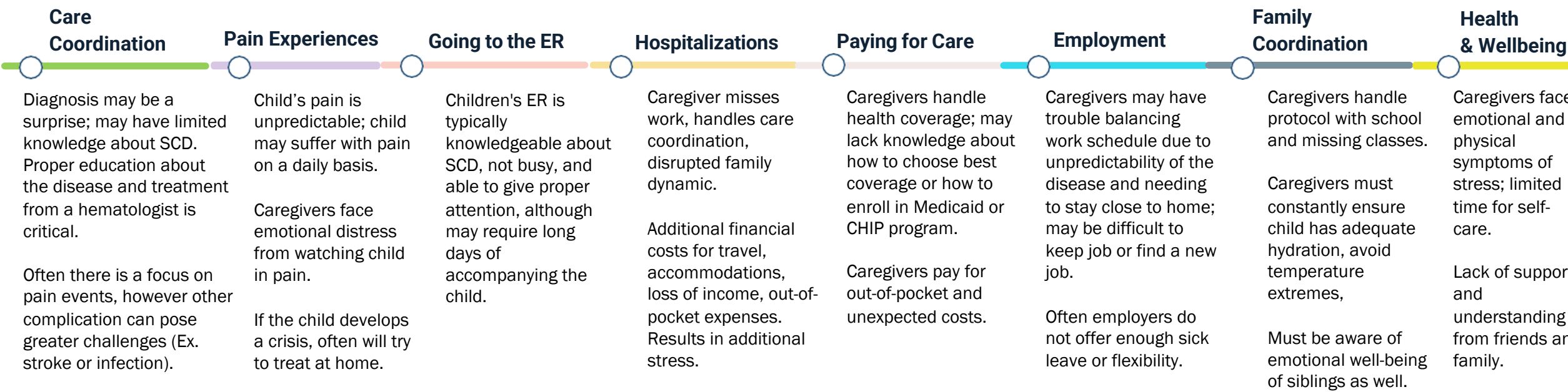
Each phase highlights **eight "pain points"** or common areas where caregivers experience challenges or barriers that may require support:





Caregiving for a Child with SCD

Caregivers bear the responsibility of all care coordination, decisions, life interruptions, and more



“Waking up to your child screaming in agony at 4 o'clock in the morning is a feeling that I wish on no one.”

“She is 4 so we are constantly telling her to stay hydrated, not be too hot or cold and wash her hands. Tough to have a normal childhood with limitations.”

“Our daughter doesn’t get recess during the winter while all her classmates go outside.”

“Caring for a person with SCD makes it difficult to obtain new employment since the need for FMLA is almost inevitable. It will take 12 months before one becomes eligible and one will probably lose job for absenteeism before they hit the 12 month eligibility.”

“You have no control of your life as a caregiver. Your child with sickle cell also has no control. You can try your best to provide for the basic health and nutrition for your child, but you can’t predict and control when a crisis occurs.”



Caregiving for an Adolescent with SCD

With the young adult reaching transition age, there are many new and unfamiliar barriers.

Care Coordination

Caregiver must help prepare adolescent for transition.

Knowledgeable adult providers are hard to find; may also require coordination of multiple specialists they didn't need before.

Pain Experiences

Unpredictable and disabling pain crises can last 4+ days; SCD adults often develop chronic daily pain.

Caregivers responsible for the care when loved one is unable to care for themselves.

Going to the ER

Adolescent faces new challenges of negative experiences and stigma in ER; need caregiver as advocate.

Adult ER often is busy, lacks SCD expertise, and is discriminatory.

Often suspicious of young, potentially "drug seeking" SCD patients.

Hospitalizations

Caregiver is responsible for teaching child to make medical decisions and coordinating work and school disruptions during traumatic life periods.

Caregiver misses work and other life disruptions.

Paying for Care

Caregiver worries over child's health coverage and impact on continuity of care; child may lose Medicaid coverage.

Caregiver must teach child how to choose insurance, when to enroll, etc.; may struggle to continue financing their care.

Employment

Caregivers continue to face negative impacts on work with lost time at work, decreased productivity, lost career opportunities, and unpaid absences.

Family Coordination

Child may desire to be more independent and fit in with peers; Caregivers face challenges with teen defiance or rebellion.

May require legal support re: health care proxies, living wills, and HIPAA.

Health & Wellbeing

Caregivers experience caregiver burnout, neglects their own needs, and suffer from physical and emotional exhaustion; Often lack social support.

"Regular ER doctors sometimes dismiss their pain. They don't give them enough pain medicine to help the pain [...] Sometimes doctors/nurses treat sickle cell patients bad."

"Caring for a child with SCD is a constant mental burden whether the child is in crisis or not. There are also many comorbidities with SCD that we have faced: AVN, asthma, loss of hearing, retinal bleed. SCD is way more than pain."

"I worry alot about my child."

"SCD is very unpredictable. Everything you do is in the context of SCD. Where do you go for college? What's the weather?"

"You have no control of your life as a caregiver. Your child with sickle cell also has no control. You can try your best to provide for the basic health and nutrition for your child, but you can't predict and control when a crisis occurs."

"I have missed so many job opportunities, class withdrawals, and work hours. I have stop counting."



Caregiving for an Adult with SCD

Caregivers continue to experience many challenges when providing “informal care” or support for their spouse, adult child, or loved one with SCD.

Care Coordination

With disease progression, patients may have complications in multiple organ systems; may affect functions and lead to impairments that require more involvement from a caregiver.

Lack of specialized care, advance care planning, and longstanding racism in health care create challenges.

Pain Experiences

Pain exacerbations may become more frequent, requiring greater caregiver involvement.

Stigma can be compounded by racism and can pose significant barriers to pain management.

Going to the ER

Patients face bias, excessive wait times, insufficient pain medication, and emotional distress of not being believed. Caregivers are needed to advocate for patient while in ER or file complaints after ER visit.

Hospitalizations

Often patients may be discharged while possible still sick and in pain; Caregivers are needed to assist with recovery.

Emotional trauma of the hospitalization can linger for caregivers.

Paying for Care

Financial burden worsens with age; caregivers often are needed to help mitigate health care costs for patients.

Employment

Caregivers may need assistance to reentering the work force after many years of unemployment.

Unpredictability of onset of unforeseen complications may continue to limit employment opportunities.

Family Coordination

New challenges may arise if patients have children and require childcare; may rely on the help and support of friends and other family members to step in.

Health & Wellbeing

Effects of prolonged stress and post-traumatic stress disorder impact caregivers; struggle to find the time and the energy to take care of their own health.

“It pains me to see the mistreatments that they endure while being in the hospital, the judgments that are passed. The lack of understanding and urgency to their needs bothers me. It’s so much trouble [for] my wife to receive her pain medications.”

“Daily health maintenance without a paid caregiver for serious complications such as seizures, memory impairments, heart failure, renal failure, acute chest and bone death make it nearly impossible to hold down a full time job even with a FMLA in place.”

“As a caregiver I am unable to work and make my place in the world due to negligent hospital care. Instead I spend my life fighting against a racist system.”

“I find that, as a caregiver, I downplay my own health issues so as not to worry my daughter as they seem insignificant in comparison. I also feel that I am judged unfairly by others if I don’t rush to her side when both she and I know this is a “minor” crisis. Yet folks also judge if I am gone too long once she’s released from the hospital. And I don’t get time to recuperate from the time spent caring for her either (and feel guilty for wanting it). Mental health care is very important for all involved.”



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](#)