



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

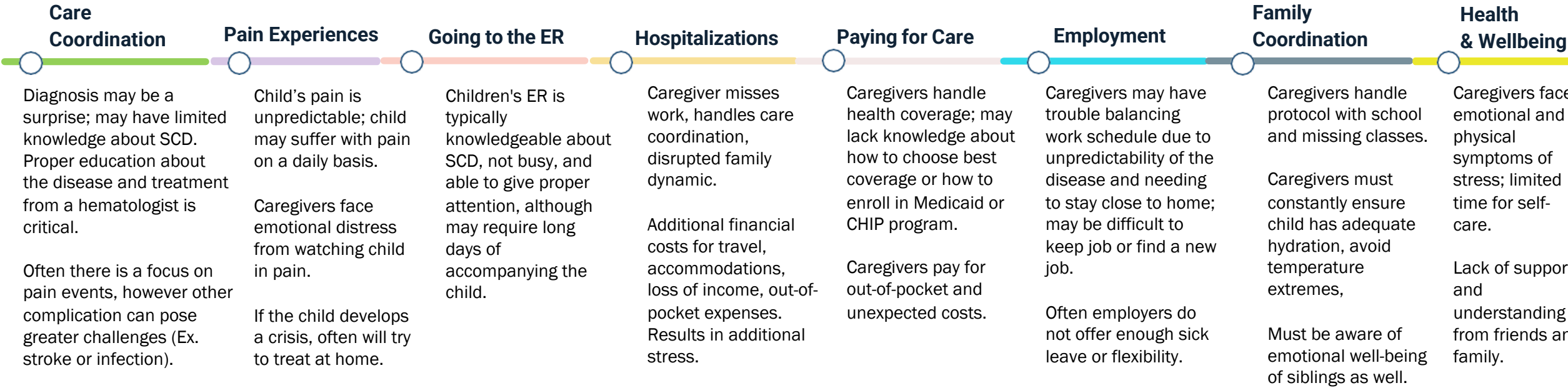
Each phase highlights **eight "pain points"** or common areas where caregivers experience challenges or barriers that may require support:





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.”

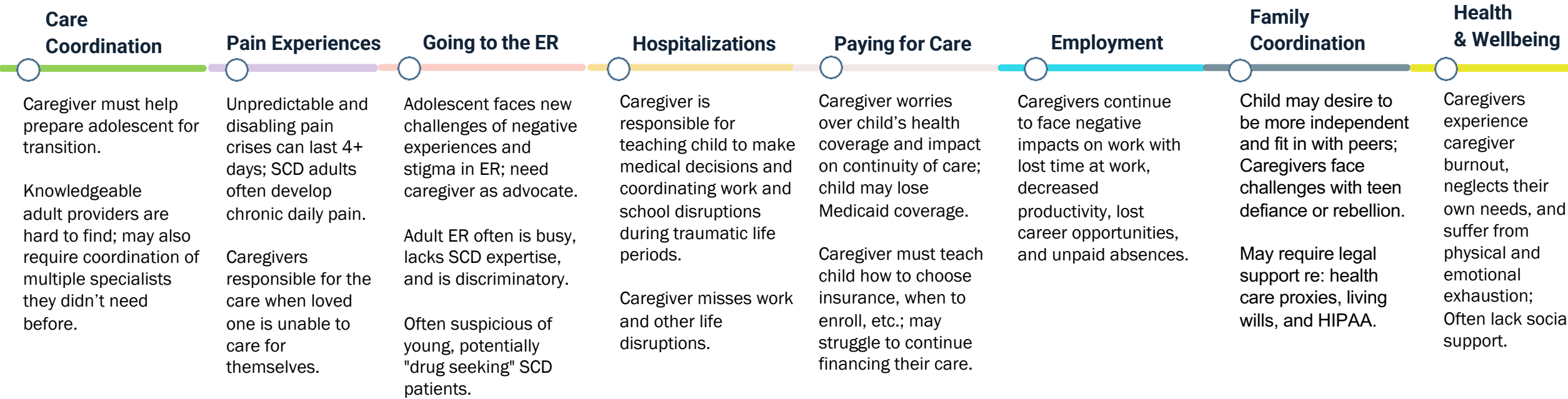
“Caring for a person with SCD makes it difficult to obtain new employment since the need for FMLA is almost inevitable. It will take 12 months before one becomes eligible and one will probably lose job for absenteeism before they hit the 12 month eligibility.”

“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.



“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

Pain Experiences

Going to the ER

Hospitalizations

Paying for Care

Employment

Family Coordination

Health & Wellbeing

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 exacerbations may become more frequent, requiring greater caregiver involvement.

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

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.

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.

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

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.

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.

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.”