THE SICKLE CELL FOUNDATION OF TENNESSEE (SCFT)

Reginald French, CEO

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Practical resilience strategies for caregivers of individuals with sickle cell disease (SCD) from birth through young adults.
The SCDCARE for SCDCARE module is a guide to practical resilience strategies and resources for caregivers of individuals with sickle cell disease (SCD) from birth through young adults. This is an interactive SCD Caregiver Resilience Educational Module.
Resilience is the ability to function effectively in the face of adversity. The effectiveness of resilience strategies has been demonstrated in many disease processes. SCD caregivers develop numerous resilience strategies throughout the years.

This project provides SCD caregivers with resilience strategies. The strategies were obtained from SCD caregivers sharing tools that have helped them successfully care for their child with SCD. A list of caregiver resources was developed along with a caregiver educational module.
Resources … A Way of Life

Chris Bridges (Father of teens with SCD)
Three focus groups were held with parents of children with SCD from 11 months to 20 years old. Caregivers were asked to discuss:

- How having a child with SCD impacted them and their family?
- To talk about the emotional impact of having a child with SCD?
- To share how they established support systems, and to discuss what strategies they used to successfully navigate caring for a child with SCD?
Four Main Themes Emerged from the Focus Group Discussions

- Being Organized
- Establishing A Support System
- Finding Faith and Spirituality
- Recognizing the Impact of Mental Health
“I actually created a binder when we first found out that my son had sickle cell. And it was, it was different things from, what do you do if he has a fever? What do you do if he has a fever? What do you do if he's lethargic? What do you do if he seems a little pale and ... , I also had ... resources in there that I was given, literature resources that I was given from the partners at the hospital. His medical records, I kept records of all of his appointments, anything that he had, his lab work.” Caregiver of Child with SCD
Being Organized – Tips!

• Keep a Journal
• Put appointments in your phone
• Have an emergency hospital bag ready at all times
• Establish a routine
• Have important numbers easily visible
• Schedule “Me” time
• Make To Do Lists
• Remember this is a journey – forgive yourself for any missteps along the way
Establishing a Support System
Ask for HELP!

Don’t be afraid to ask for help
Prepare ahead of time
Make a plan that you can follow during emergencies
Make a list
Be specific with your request
Share responsibility
Ask several people for help
Show appreciation to those that help you
Think outside the box
“I just... believe in God and, ..., they pray along with me, they just started getting ... (on their) knees at night, even though I know they don’t know what to say to God, ... just trusting God.” Caregiver of a child with SCD.
Ways to Use Faith/Spirituality

- Prayer
- Silent Meditation
- Forgive Yourself
- Don’t judge others
- Attend support/prayer groups
- Remain hopeful
- Stay positive
- Perform acts of kindness for others
Recognizing the Impact of Mental Health
MENTAL HEALTH

“You say, how do you, how do you manage your emotions? I mean, your emotions are good as long as they're good, but as many times as they've been in the hospital, I've gone through the guilt trip. I, ... I've been in my highs, and I've been at my lows.” Caregiver of Child with SCD

“I know if they see me stressed or if I lose my head about it, they give up too. They break down and I don’t want them to feel like that, ...” Caregiver of Child with SCD
Mental Health Tips

Get
• Get connected - Join support/caregivers groups

Set
• Set realistic expectations

Ask
• Ask for family/support to relieve you for a couple hours a week

Take
• Take care of your health; make doctor’s appointments; exercise
Knowledge and Understanding Helps Us Move Forward

Nichole Bridges (parent of teens with SCD)
Resources

Resilience Support
Caregivers Need to Care for Themselves as well

Practicing Mindfulness to Relieve Caregiver Stress
https://www.vnsny.org/article/practicing-mindfulness-to-relieve-caregiver-stress/

Caregivers, Let’s Talk About Caring for Yourself
https://www.mindful.org/caregivers-lets-talk-about-caring-for-yourself/

Exercises
• Exercise reorganizes the brain to be more resilient

• Exercising to relax
  https://www.health.harvard.edu/staying-healthy/exercising-to-relax

• Exercise: A healthy stress reliever
Thank You to Novartis and Our SCD Caregivers

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