

# Sickle Cell Care & Support Toolkit

Tools and Knowledge to Support Parents,  
Families, and Communities



# Introduction

Sickle cell disease (SCD) is an inherited blood disorder that affects hemoglobin, the protein in red blood cells that carries oxygen. This toolkit provides simple, practical resources to help you understand, manage, and advocate for better care.

# Key Information

## What it is

SCD makes red blood cells stiff and sickle-shaped, causing blockages, pain, and anemia.

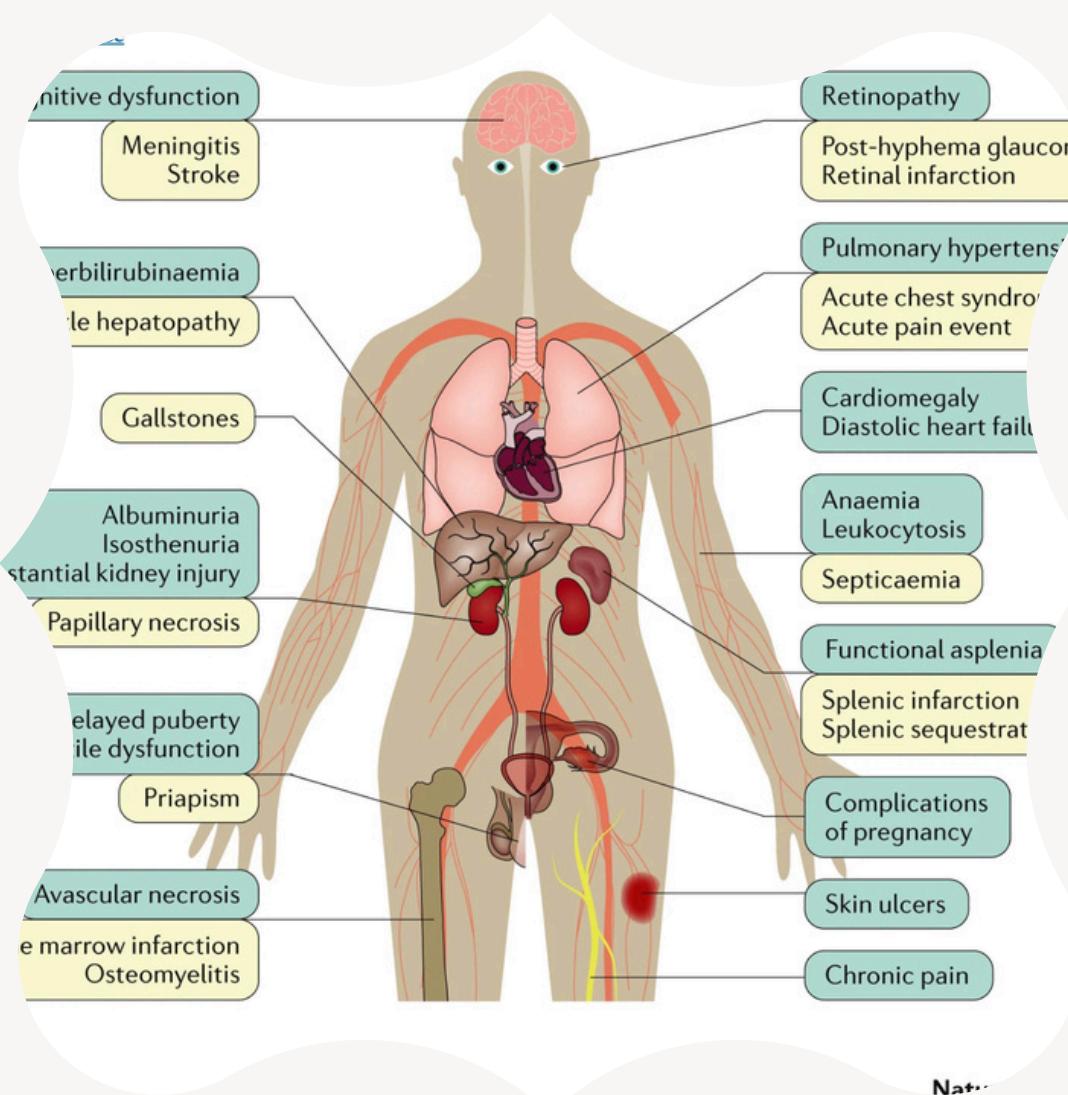
## Types

SS (sickle cell anemia), SC, and trait carriers (AS, AC).



# Common Symptoms

pain episodes, fatigue, swelling, delayed growth, vision problems, frequent infections.



# Complications

stroke, organ damage, pulmonary hypertension, leg ulcers, gallstones.



# Daily Management Tools



## Hydration Checklist

Target 8–10 glasses of water daily; avoid excessive caffeine or sugary drinks.



## Pain Crisis Plan

Keep prescribed pain meds, a heating pad, and emergency contacts accessible. Track triggers and relief strategies.



## Doctor Questions

Are my vaccines up to date? How often should I do lab work, imaging, or screenings?



# Recognize Early Signs of Crisis

Swelling in hands or feet

Complaints of sudden  
pain (especially chest,  
back, arms, legs)

Fever  $> 38^{\circ}\text{C}$  ( $100.4^{\circ}\text{F}$ )

Breathing difficulties or  
wheezing

Sudden headache,  
trouble walking, vision  
changes, or slurred  
speech

KNOW SICKLE CELL.



# When to Go to the Hospital Immediately

1

## Severe Pain

Pain that doesn't improve with usual home care or prescribed medications.

2

## Breathing or Chest Problems

Shortness of breath, chest pain, wheezing, or rapid breathing.

3

## Stroke Warning Signs

Weakness, numbness, slurred speech, sudden headache, loss of balance, vision changes.

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# School Support Checklist

## ✓ Teacher Information Sheet

- Teachers should know your child may need:
  - Frequent water breaks
  - Extra bathroom breaks
  - Rest periods if they look tired or unwell
  - A quick response if your child reports pain

## ✓ School Administration

- Inform the school office that your child has sickle cell disease.
- Provide them with a written care plan if your hospital has given you one.
- Ask the school to allow flexibility with physical education, outdoor activities, and attendance if your child is recovering from illness.
- Keep emergency contact numbers updated at the school.

## ✓ Doctor's Note

- Ask your child's doctor for a note that explains:
  - The need for water and rest breaks
  - Flexibility with physical activity
  - What staff should do if your child becomes unwell
  - Give a copy to the teacher and school office



# Hospital & Emergency Pack

## What to Bring if Admitted:

- Medication list with doses and schedule
- Copies of medical records or care plan
- Emergency contacts
- Health/insurance card
- Comfort items (blanket, toy, headphones, snacks)

## Emergency Info Card (keep wallet-sized):

- Child's name & diagnosis
- Medications & allergies
- Parent/guardian contacts
- Doctor/hematology clinic contact
- Hospital of choice



# Caregiver & Family Support

- Keep a health binder or folder for all labs, hospital notes, and doctor letters.
- Build a support system—family, friends, other parents.
- Care for your own health (rest, eat, and take breaks).

KNOW SICKLE CELL.

# You've Got This!

Caring for a child with sickle cell can feel challenging, but every step you take—big or small—makes a difference in their health, comfort, and happiness. You are not alone, and your care, love, and advocacy help your child thrive every day.

Celebrate your wins, ask for support when needed, and remember: you are capable, strong, and making an incredible impact.

With awareness, support, and action, we can change the story of sickle cell.



images from freepix



# Questions? Clarifications?

We'd love to help!  
[knowsicklecell.org](http://knowsicklecell.org)

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