



Actor portrayals

Sickle Cell Disease

Shifting From Acute
Crisis to Proactive
Long-Term Care

Despite advances in care, individuals with sickle cell disease (SCD) continue to experience a markedly **reduced life expectancy**—approximately **20 to 25 years shorter** than that of the general population.^{1,2}



SICKLE CELL DISEASE IS AN INHERITED QUALITATIVE BLOOD DISORDER in which red blood cells (RBCs) can polymerize, sickle, and hemolyze and lead to endovascular inflammation as well as acute and chronic complications and progressive organ damage.^{1,3}

Management of SCD often remains driven by episodic crisis management rooted in the unpredictable and life-threatening nature of the disease's acute complications, including^{1,3,4}:

- Vaso-occlusive crisis (VOC) and/or pain crisis
- Acute chest syndrome (ACS)
- Acute anemia and/or hematologic complications
- Stroke (ischemic and hemorrhagic)

Acute complications of SCD are often severe, potentially life-threatening events that **require prompt recognition and intervention**.

However, even in the absence of acute events, SCD is a **multisystem disease in which morbidity and chronic organ damage are progressive** throughout the patient's life span.^{1,3,5-7}

In SCD, the goal of reducing morbidity and early mortality while improving health-related quality of life requires a comprehensive, proactive approach to⁵⁻⁹:



PRESERVE
red blood
cell health



PREVENT
vaso-occlusive
crisis and fatigue



PROTECT
organ health



Aim to **PRESERVE** red blood cell health

SCD, including its most common homozygous form (HbSS), is characterized by the production of abnormal hemoglobin S (HbS). Deoxygenation in the microvasculature triggers HbS polymerization, distorting normal RBCs into a sickle shape.^{1,3,10}

- Sickled RBCs initiate vaso-occlusion, hemolysis, and vascular dysfunction, leading to key SCD complications such as VOC, ACS, stroke, and organ damage^{1,3,10}

Monitoring hemoglobin, reticulocytes, hemolysis markers (eg, lactate dehydrogenase, bilirubin), and hemoglobin fractions (fetal hemoglobin, HbS percentages) is important to consider in preserving RBC health to improve RBC function, stability, and survival.^{8,11,12}



Normal Red Blood Cell



Sickled Red Blood Cell



Aim to **PREVENT** vaso-occlusive crisis and fatigue

VOCs, acute episodes of ischemic pain caused by microvascular obstruction due to sickled RBCs, are the hallmark clinical manifestation of SCD.^{1,3}

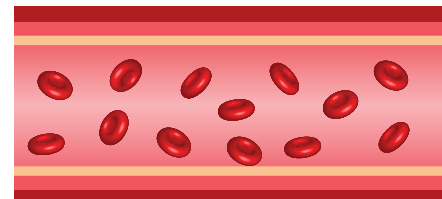
The impact of VOCs may include¹³:

- Poor quality of life
- Frequent emergency department visits
- Hospitalizations
- Life-threatening complications
- Early mortality

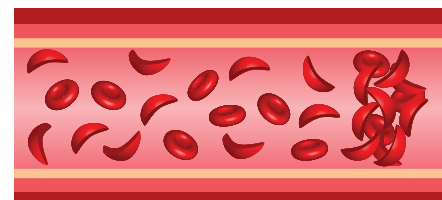
Fatigue is a prevalent and often persistent, debilitating symptom in patients with SCD, with the potential of significantly affecting their daily lives and overall well-being.^{6,14,15}

- Fatigue is multifactorial, with chronic hemolytic anemia, inflammation, and pain contributing to both acute and long-term symptoms^{14,15}

Preventing VOCs and fatigue through proactive, guideline-based management—including infection prevention, trigger avoidance, and recommended therapeutic intervention—is key to improving outcomes and health-related quality of life for patients with SCD.^{1,3,13-15}



Normal Blood Cell Flow



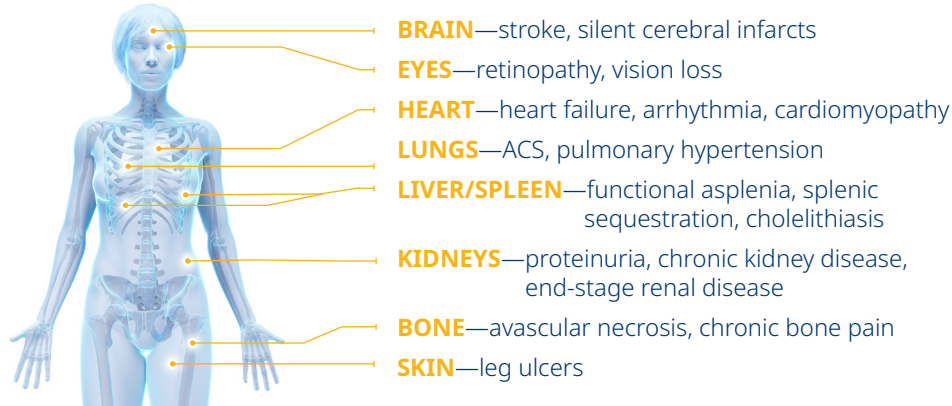
VOC Blood Flow Depiction



Aim to PROTECT organ health

Patients with SCD are at high risk of multiorgan injury, often beginning in childhood and progressing with age.^{1,3,5,16}

Recurrent ischemia, chronic inflammation, vaso-occlusion, hemolysis, and lifelong anemia can lead to widespread damage to nearly every organ system, even in the absence of overt acute crises.^{1,3,5-7,16}



Because organ damage in SCD is progressive and often irreversible, protecting organ health through regular monitoring and timely intervention is critical for reducing morbidity and prolonging survival.^{1,3,5,16}

QR code will take people to an Orphan website to view US25SCD00078 - LiveUnlimited.com/soundofpain

Clinicians may improve health outcomes in SCD by shifting to comprehensive long-term management.

PRESERVE
red blood cell health

PREVENT
vaso-occlusive crisis and fatigue

PROTECT
organ health



Scan QR code to hear "The Sound of Pain: The Realities of Living with Sickle Cell Disease"

By scanning the QR code, we may collect aggregate data for analytics. No personal information will be collected.

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