

Do you use the ED for care of Sickle Cell Disease?

What to know before you go



Children and adults with sickle cell disease (SCD) often require care in the emergency department (ED) of hospitals or clinics for health issues related to SCD. The ED may be your only option for health care when symptoms, such as pain crises, cannot be managed at home or when you do not have access to a healthcare provider who specializes in treating SCD.

The Sickle Cell Data Collection (SCDC) program found that in California, people with SCD seek care in the ED an average of three times a year from their late teens to their late 50s. Excruciating pain, known as a sickle cell crisis, is the most common reason for these ED visits.

Emergency Department (ED) Visits Among People with Sickle Cell in California, 2013-2023

0-16 years old



<1 avg. visits
per year

17-39 years old



3 avg. visits
per year

40-59 years old



3 avg. visits
per year

60-80 years old



1 avg. visits
per year

Tips for receiving better care in the ED

Before you get sick or have a pain crisis, work with your regular doctor to:

- ✓ Make sure that information in your electronic medical record (EMR) is updated, including your medical history and current pain medicines.
- ✓ Create a pain management plan and make sure it is entered into your EMR. Keep with you a printed copy of the plan and a list of all your medications.

When you go to the ED:

- ✓ Tell the ED staff right away that you have SCD.
- ✓ Share openly with your ED nurse and doctor:
 - Your medical history, including a list of your medications
 - Your pain management plan. Ask the ED nurse or doctor to look up your plan in your EMR or share a printed copy.
 - Your regular doctor's contact information. If the ED nurse or doctor has concerns about your pain management, ask the ED staff to call your regular doctor.

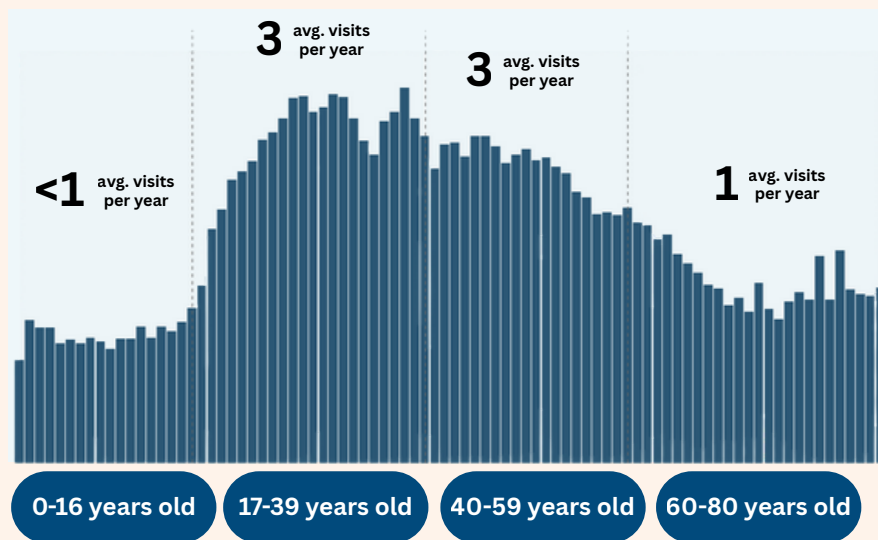
3 Tips about Sickle Cell Disease (SCD)

EVERY EMERGENCY PROVIDER NEEDS TO KNOW



Children and adults with sickle cell disease (SCD) often require care in the emergency department (ED) of hospitals or clinics for health issues related to SCD. The ED may be a patient's only option for health care when symptoms, such as pain crises, cannot be managed at home or when a patient does not have access to a healthcare provider who specializes in treating SCD. The Sickle Cell Data Collection (SCDC) program found that in California, people with SCD seek care in the ED an average of three times a year from their late teens to their late 50s.

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Tips for ED Health Providers

- Take complaints of pain from patients with SCD seriously and treat promptly with appropriate fluids and pain medication.
- Work with the SCD team at your hospital or clinic to develop individualized care plans for patients with SCD, especially those with frequent ED use. When possible, make these plans available in the electronic medical record.

- Refer to the National Heart, Lung, and Blood Institute guidelines for the management of SCD by scanning the QR code to the right.



Primary Health Complaint: Extreme Pain

Pain crises, which can be excruciating, are the most common reason for ED visits among patients with SCD. Patients may not always appear to be in pain because they have often developed a high pain tolerance due to a lifetime of chronic pain.

Patients with SCD require prompt pain treatment. The medical evaluation of patients includes determining the cause of pain and assessing recent medication use. For mild or moderate pain, begin treatment with nonsteroidal anti-inflammatory drugs. For severe pain, treatment with opioids may be needed. If the patient is already on opioid therapy, calculate opioid dose based on current opioid dose. Reassess pain and provide additional opioid administration, if necessary, for continued severe pain. For greater effectiveness, medication can be combined with nonpharmacologic approaches, such as heat application and distraction.