NATIONAL COMMISSION ON CORRECTIONAL HEALTH CARE

Caring for People With Sickle Cell Disease in Correctional Settings

Position Statement

The National Commission on Correctional Health Care (NCCHC) recognizes the importance of caring for people living with sickle cell disease (SCD) and recommends that jails, juvenile detention facilities, and prisons take the following steps to support people who are incarcerated and have SCD:

1. Screen all people for blood disorders at medical intake in any carceral setting.
2. Establish comprehensive care for people who have SCD.
3. Establish protocols and guidelines for recognizing and managing vaso-occlusive crises.
4. Ensure proper hydration and temperature control, and ensure the patient avoids strenuous activity.
5. Identify and manage acute SCD-related complications, such as medical emergencies requiring hospital transfer.
6. Consistent with NCCHC's position, people with SCD should not be charged fees for services.
7. Support transition to comprehensive SCD care in the community on reentry.

Each of these steps is explained in detail below.

Discussion

Sickle cell disease is a life-threatening, genetic blood disorder that affects more than 100,000 Americans.[1] Complications include higher risk of infection, acute and chronic organ damage, and the painful vaso-occlusive episodes (pain crises) that are the hallmark of SCD.[2] Without proper management, SCD affects all organs and is associated with severe morbidity and decreased quality of life.

People with SCD who are incarcerated often have multiple intersecting marginalized identities that increase their susceptibility to substandard treatment.[3,4] In particular, the overlay of chronic pain,[5] incarceration, and racism leads to undertreatment of patients with SCD.

Jails, juvenile detention facilities, and prisons should offer comprehensive care for individuals with SCD that includes the following:

1. Screen all people for blood disorders at medical intake in any carceral setting.

Individuals should be asked if they have a blood disorder in conjunction with their medical history at the time of medical intake and when acute medical conditions occur. The question "Do you have a blood disorder?" may be unclear, so explicitly asking people if they have sickle cell disease or other blood diseases can improve understanding.

People who report having SCD at medical intake but having no symptoms of a vaso-occlusive episode, SCD-related complication, or other acute symptoms should have the following:

a. Medication reconciliation to align medications taken in the community with medications provided in the facility
b. Communication with an SCD specialist (a provider with SCD expertise) to discuss medication management optimization

c. Documentation of an SCD-focused history, including past complications, hospitalizations, and known triggers in each patient's chart

An SCD specialist may be a hematologist or other pediatric, internal medicine, or family medicine provider with SCD-specific training. At the time of this writing, a formal definition of SCD specialist is forthcoming from the National Alliance of Sickle Cell Centers.

2. Establish comprehensive care for people who have SCD.

People with SCD in any carceral setting for 30 days or longer should receive preventive health care services in accordance with condition-based recommendations from the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices and the National Alliance of Sickle Cell Centers[6] and should have routine access to an SCD specialist. If an individual with SCD already has an SCD specialist, they should continue seeing this provider, when feasible. If the individual does not have an SCD specialist, this care should be established. If barriers prevent patients from seeing specialists in person, telemedicine is a useful option.[7–9]

The NHLBI and the American Society of Hematology (ASH) guidelines recommend use of individualized care plans for SCD management across care settings.[10–12] Individualized care plans include basic information on contacting the patient's SCD provider, as well as SCD- and patient-specific treatment plans (e.g., the initial pain plan for a vaso-occlusive episode). Consistent with national guidelines for care in the community that recommend that an individualized care plan (if available) should be implemented as written, health care staff should adhere to the plan. If there are questions, medical staff at the facility should contact the community SCD specialist. Since each patient has unique needs, it is essential to follow the individualized care plan, ensure access to prescribed medications and therapies, monitor lab results as required, and provide treatments without charge.

Medications prescribed to people with SCD in the community should be continued without charge or copayment. Hydroxyurea is the gold standard for preventive management of SCD.[13] If the patient is on this medication, it should be continued. When taken daily, hydroxyurea can reduce the occurrence of vaso-occlusive episodes that include acute pain as well as the need for blood transfusions and hospitalizations.[14,15] The Food and Drug Administration (FDA) has approved a number of drugs that reduce both the frequency of vaso-occlusive episodes and SCD-related symptoms.[16,17] Additionally, people with SCD should have access to all future FDA-approved therapies. NSAIDs and opioid-based medications, including oxycodone, morphine, and hydromorphone, are currently critical components of the standard of care when treating vaso-occlusive episodes that result in pain.[11]

Other procedures that aid people with SCD include regular blood transfusions, exchange transfusion, and apheresis.[18,19] These must be continued to prevent further complications.

People incarcerated for over one year should receive an annual comprehensive exam. However, some may be due for their exam before reaching the one-year mark. Therefore, each facility should confirm the date of the patient's last exam to ensure visits are scheduled promptly when needed. Care delivery through a comprehensive SCD care model has been shown to improve health for people with SCD by ensuring they receive evidence-based care.[6,20]

An important aspect of comprehensive SCD care includes mental health counseling.[21] Managing SCD while

incarcerated poses unique challenges to mental health. Since stress can trigger a vaso-occlusive episode, it is crucial that patients have access to mental health counseling at no cost.

3. **Establish protocols and guidelines for recognizing and managing vaso-occlusive crises.**
Vaso-occlusive episodes are rapid in onset and can be life-threatening, which underscores the need to screen all people at intake for SCD. Vaso-occlusive episodes are initially managed with fluids, warmth, and appropriate pain medication.[11] It is common for acute severe pain from a vaso-occlusive episode to produce no objective changes in vital signs or lab results. Changes in vital signs and lab results are often indicative of other vaso-occlusive complications of SCD, including acute chest syndrome, splenic sequestration, infections, stroke, priapism, and an increased risk of death.[2]

Custody and health staff should be trained to immediately respond to people with SCD if they report having a vaso-occlusive episode or pain. All people with SCD should have timely (within 2 hours) evaluation and management of a vaso-occlusive episode.[10,11] Initial treatment should follow the patient's individualized care plan, if available, and will typically involve an opioid-based medication.[12,22,23]

If no individualized care plan is available, initial management for most people with SCD includes fluids (start with increased oral hydration), temperature control, and initial pain control with scheduled oral medications (standard dosing of acetaminophen and ibuprofen if not contraindicated). A health care professional should obtain vital signs including pulse oximetry and a focused assessment, with initial interventions occurring within 2 hours when concern for a vaso-occlusive episode is identified by a patient or medical staff to help differentiate whether this is an uncomplicated episode or an SCD emergency (see below). Patients reporting vaso-occlusive episode pain that does not respond to scheduled oral pain medications within 12 hours or who develop other symptoms should immediately be transported to the hospital for emergent management.

If the individual's pain does not improve after their initial management plan or if symptoms worsen, the patient should be transferred to the hospital for additional care. If in doubt about whether a person with SCD needs further medical attention, get them to see an emergency medicine provider as soon as possible. Early intervention and escalation of care for management of vaso-occlusive episodes is critical.

4. **Ensure proper hydration and temperature control, and ensure the patient avoids strenuous activity.**
Adequate hydration and temperature control are critical to preventing vaso-occlusive episodes.[24] People with SCD should have unlimited access to water and, therefore, also need easy access to a bathroom to facilitate staying hydrated. Facilities need to develop a process (e.g., a medical identification card) for ensuring people have an exemption from daily activities so they can drink water, access the bathroom, and take rest breaks.

There is robust evidence that people with SCD suffer in extremes of temperature. Cold and hot temperatures increase the chance of a vaso-occlusive episode and affect the severity of symptoms. Ensure that all people, especially those with SCD, have access to clothing (e.g., jackets) and implement temperature mitigation systems that minimize exposure to extreme temperatures both indoors and outdoors, such as heaters, blankets, fans, and air-conditioning. See the NCCHC position statement on Climate Control for Extreme Temperatures in Corrections. (ncchc.org/position-statements/climate-control-for-extreme-temperatures-in-corrections-2024/)

Additionally, people with SCD should be exempt from strenuous physical activity as that can provoke a vaso-occlusive episode. Again, an exemption process such as a medical identification card is needed.

5. Identify and manage acute SCD-related complications, such as medical emergencies requiring hospital transfer.

Correctional health professionals must be aware of the clinical signs of common SCD emergencies to ensure timely hospital transfer for evaluation and management. Common potentially life-threatening SCD-related complications include acute chest syndrome, splenic sequestration, infection, stroke, and priapism.[2] Patients presenting with severe abdominal pain, chest pain, cough, difficulty breathing, fever, or neurological symptoms such as confusion or weakness should be treated as experiencing a potential SCD emergency, warranting immediate hospital transfer.[11,18,25,26] Pain is often the first sign of an SCD emergency and should be taken seriously. People with SCD who have pain should be evaluated by a health care professional based on facility SCD protocols within 2 hours. People with SCD who have a fever (temperature 101.3F/38.5C or higher) need to be evaluated by a health care professional within 1 hour.[25,27] There should be a low threshold for escalation to emergency level care/evaluation for an individual with SCD with pain, fever, or other new symptoms. Facilities should have protocols and processes in place to facilitate hospital transport**.**

6. Consistent with NCCHC's position, people with SCD should not be charged fees for services.

Due to the severity of SCD and the medical care required to reduce its morbidity, people with SCD utilize health care resources in carceral settings more frequently than other incarcerated patients. These resources include more frequent clinic visits for acute and chronic issues, pharmacy visits for essential medications, routine bloodwork, and preventive care. As with other chronic conditions, individuals with sickle cell disease should be exempt from incurring fees for health care services. See the NCCHC position statement on Eliminating Financial Assessments for Health Care Services During Incarceration. (https://ncchc.org/position-statements/eliminating-financial-assessments-for-health-care-services-during-incarceration-2/)

7. Support transition to comprehensive SCD care in the community on reentry.

Upon release from custody, it is important to ensure the individual with SCD is connected with comprehensive SCD care and that care is coordinated with their community providers. This care coordination includes, but is not limited to, scheduling a follow-up appointment within 30 days with their SCD specialist and therapies to last until that appointment (e.g., a 30-day supply) at no charge**.**

Adopted by the National Commission on Correctional Health Care Governance Board July 23, 2025

References

1. Piel, F. B., Patil, A. P., Howes, R. E., Nyangiri, O. A., Gething, P. W., Williams, T. N., Weatherall, D. J., & Hay, S. I. (2010). Global distribution of the sickle cell gene and geographical confirmation of the malaria hypothesis. *Nature Communications, 1,* Article 104. https://doi.org/10.1038/ncomms1104
2. Shah, N, Bhor, M, Xie, L, Paulose, J, & Yuce, H. (2019). Sickle cell disease complications: Prevalence and resource utilization. *PLoS One*, *14*(7), 0214355. https://doi.org/10.1371/journal.pone.0214355
3. Smith, W. R., Valrie, C., & Sisler, I. (2022). Structural racism and impact on sickle cell disease: Sickle cell lives matter. *Hematology/Oncology Clinics of North America*, *36*(6), 1063–1076. https://doi.org/10.1016/j.hoc.2022.08.008
4. Power-Hays, A., & McGann, P. T. (2020). When actions speak louder than words—Racism and sickle cell disease. *New England Journal of Medicine, 383*(20), 1902–1903. https://doi.org/10.1056/NEJMp2022125

5. Kanjee, Z., Achebe, M. O., Smith, W. R., & Burns, R. B. (2022). How would you treat this patient with acute and chronic pain from sickle cell disease?: Grand rounds discussion from Beth Israel Deaconess Medical Center. *Annals of Internal Medicine*, *175*(4), 566–573. https://doi.org/10.7326/M22-0038
6. Kanter, J., Smith, W. R., Desai, P. C., Treadwell, M., Andemariam, B., Little, J., Nugent, D., Claster, S., Manwani, D. G., Baker, J., Strouse, J. J., Osunkwo, I., Stewart, R. W., King, A., Shook, L. M., Roberts, J. D., & Lanzkron, S. (2020). Building access to care in adult sickle cell disease: Defining models of care, essential components, and economic aspects. *Blood Advances*, *4*(16), 3804–3813. https://doi.org/10.1182/bloodadvances.2020001743
7. Jacob, S. A., Carroll, A. E., & Bennett, W. E. (2021). A feasibility study of telemedicine for paediatric sickle cell patients living in a rural medically underserved area. *Journal of Telemedicine and Telecare*, *27*(7), 431–435. https://doi.org/10.1177/1357633X19883558
8. Weiss, S., Yang, S., Zhang, S., David, M., Lanzkron, S. M., & Eakin, M. (2021). The telemedicine experience for individuals with sickle cell disease. *Blood*, *138*(Suppl. 1), 1893. https://doi.org/10.1182/blood-2021-152870
9. Pecker, L. H., Ruvalcaba, E., Lanzkron, S., & Eakin, M. N. (2024). "The patient should have a choice": Adults with sickle cell disease advise integration of telemedicine into the comprehensive sickle cell disease care model. *Journal of Racial and Ethnic Health Disparities*, *11,* 3249–3259. https://doi.org/10.1007/s40615-023-01780-6
10. National Heart, Lung, and Blood Institute Expert Panel. (2014). *Evidence-based management of sickle cell disease: Expert panel report 2014*. National Institutes of Health. https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease
11. Brandow, A. M., Carroll, C. P., Creary, S., Edwards-Elliott, R., Glassberg, J., Hurley, R. W., Kutlar, A., Seisa, M., Stinson, J., Strouse, J. J., Yusuf, F., Zempsky, W., & Lang, E. (2020). American Society of Hematology 2020 guidelines for sickle cell disease: Management of acute and chronic pain. *Blood Advances, 4*(12), 2656–2701. https://doi.org/10.1182/bloodadvances.2020001851
12. Tanabe, P., Silva, S., Bosworth, H. B., Crawford, R., Paice, J. A., Richardson, L. D., Miller, C. N., & Glassberg, J. (2018). A randomized controlled trial comparing two vaso-occlusive episode (VOE) protocols in sickle cell disease (SCD). *American Journal of Hematology*, *93*(2), 159–168. https://doi.org/10.1002/ajh.24948
13. Rankine-Mullings, A. E., & Nevitt, S. J. (2022). Hydroxyurea (hydroxycarbamide) for sickle cell disease. *Cochrane Database of Systematic Reviews*, Article CD0022029. https://doi.org/10.1002/14651858.cd002202.pub3
14. Charache, S., Terrin, M. L., Moore, R. D., Dover, G. J., Barton, F. B., Eckert, S. V., McMahon, R. P., Bonds, D. R., and the Investigators of the Multicenter Study of Hydroxyurea in Sickle Cell Anemia. (1995). Effect of hydroxyurea on the frequency of painful crises in sickle cell anemia. *New England Journal of Medicine, 322*(20), 1317–1322. https://doi.org/10.1056/NEJM199505183322001
15. Heitzer, A. M., Longoria, J., Okhomina, V., Wang, W. C., Raches, D., Potter, B., Jacola, L. M., Porter, J., Schreiber, J. E., King, A. A., Kang, G., & Hankins, J. S. (2021). Hydroxyurea treatment and neurocognitive functioning in sickle cell disease from school age to young adulthood. *British Journal of Haematology*, *195*(2), 256–266. https://doi.org/10.1111/bjh.17687
16. Adams-Graves, P., & Bronte-Jordan, L. (2016). Recent treatment guidelines for managing adult patients with sickle cell disease: Challenges in access to care, social issues, and adherence. *Expert Review of Hematology, 9*(6), 541–552. https://doi.org/10.1080/17474086.2016.1180242
17. Newman, T. V., Yang, J., Suh, K., Jonassaint, C. R., Kane-Gill, S. L., & Novelli, E. M. (2023). Use of disease-modifying treatments in patients with sickle cell disease. *JAMA Network Open*, *6*(11), e2344546. https://doi.org/10.1001/jamanetworkopen.2023.44546
18. Chou, S. T., Alsawas, M., Fasano, R. M., Field, J. J., Hendrickson, J. E., Howard, J., Kameka, M., Kwiatkowski, J.

L., Pirenne, F., Shi, P. A., Stowell, S. R., Thein, S. L., Westhoff, C. M., Wong, T. E., & Akl, E. A. (2020). American Society of Hematology 2020 guidelines for sickle cell disease: Transfusion support. *Blood Advances*, *4*(2), 327–355. https://doi.org/10.1182/bloodadvances.2019001143

19. Han, H., Hensch, L., & Tubman, V. N. (2021). Indications for transfusion in the management of sickle cell disease. *Hematology*, *2021*(1), 696–703. https://doi.org/10.1182/hematology.2021000307
20. Kanter, J., Meier, E. R., Hankins, J. S., Paulukonis, S. T., & Snyder, A. B. (2021). Improving outcomes for patients with sickle cell disease in the United States: Making the case for more resources, surveillance, and longitudinal data. *JAMA Health Forum*, *2*(10), e213467. https://doi.org/10.1001/jamahealthforum.2021.3467
21. Harris, K. M., Preiss, L., Varughese, T., Bauer, A., Calhoun, C. L., Treadwell, M., Masese, R., Hankins, J. S., Hussain, F. A., Glassberg, J., Melvin, C. L., Gibson, R., & King, A. A., for the Sickle Cell Disease Implementation Consortium. (2023). Examining mental health, education, employment, and pain in sickle cell disease. *JAMA Network Open*, *6*(5), e2314070. https://doi.org/10.1001/jamanetworkopen.2023.14070
22. Siewny, L., King, A., Melvin, C. L., Carpenter, C. R., Hankins, J. S., Colla, J. S., Preiss, L., Luo, L., Cox, L., Treadwell, M., Davila, N., Masese, R. V., McCuskee, S., Gollan, S. S., & Tanabe, P., for the Sickle Cell Disease Implementation Consortium. (2024). Impact of an individualized pain plan to treat sickle cell disease vaso-occlusive episodes in the emergency department. *Blood Advances*, *8*(20), 5330–5338. https://doi.org/10.1182/bloodadvances.2023012439
23. Baumann, A. A., Hankins, J. S., Hsu, L. L., Gibson, R. W., Richardson, L. D., Treadwell, M., Glassberg, J. A., Bourne, S., Luo, L., Masese, R. V., Demartino, T., Nocek, J., Taaffe, E., Gollan, S., Ruiz, O.-O., Nwosu, C., Qashou, N., James, A. S., Tanabe, P., & King, A. A. (2023). "The project did not come to us with a solution": Perspectives of research teams on implementing a study about electronic health record-embedded individualized pain plans for emergency department treatment of vaso-occlusive episodes in adults with sickle cell disease. *BMC Health Services Research, 23*, Article 1245. https://doi.org/10.1186/s12913-023-10255-7
24. Centers for Disease Control and Prevention. (2024). *Prevention and treatment of SCD complications.* https://www.cdc.gov/sickle-cell/about/prevention-and-treatment.html
25. Liem, R. I., Lanzkron, S., Coates, T. D., DeCastro, L., Desai, A. A., Ataga, K. I., Cohen, R. T., Haynes, J., Osunkwo, I., Lebensburger, J. D., Lash, J. P., Wun, T., Verhovsek, M., Ontala, E., Blaylark, R., Alahdab, F., Katabi, A., & Mustafa, R. A. (2019). American Society of Hematology 2019 guidelines for sickle cell disease: Cardiopulmonary and kidney disease. *Blood Advances*, *3*(23), 3867–3897. https://doi.org/10.1182/bloodadvances.2019000916
26. DeBaun, M. R., Jordan, L. C., King, A. A., Schatz, J., Vichinsky, E., Fox, C. K., McKinstry, R. C., Telfer, P., Kraut, M. A., Daraz, L., Kirkham, F. J., & Murad, M. H. (2020). American Society of Hematology 2020 guidelines for sickle cell disease: Prevention, diagnosis, and treatment of cerebrovascular disease in children and adults. *Blood Advances, 4*(8), 1554–1588. https://doi.org/10.1182/bloodadvances.2019001142
27. Farooq, S., Abu Omar, M., & Salzman, G. A. (2018). Acute chest syndrome in sickle cell disease. *Hospital Practice, 46*(3), 144–151. https://doi.org/10.1080/21548331.2018.1464363