QUALITY STANDARD PLACEMAT FOR

Sickle Cell Disease: Care for People of All Ages

Ontario Health

This document is a resource for health care providers and summarizes content from the *Sickle Cell Disease: Care for People of All Ages* quality standard.

Assessment and Care Planning

Quality Statement (QS)* 1: Racism and Anti-Black Racism

- Treat people with sickle cell disease with respect, dignity, and compassion, and work to establish trust with them
- Provide trauma-informed care that is respectful of people's racial/ethnic and cultural backgrounds
- Advocate for people with sickle cell disease who have historically been negatively affected by discrimination and stigma in the health care system

QS 2: Comprehensive Health Assessment and Care Plan

If you work at a dedicated sickle cell disease centre:

- Perform comprehensive health assessments at least annually to develop care plans. For infants and children, perform assessments more often, with timing based on age and health status
- Monitor patient experience and patient-reported outcome measures over time, and share the assessments and care plans with people's circles of care

QS 7: Psychosocial Assessment, Information, and Support

- Ensure that people with sickle cell disease (and their families and caregivers, where appropriate) have psychosocial assessments at least once a year or when there are changes in psychosocial status
- Provide these assessments with respect for the person's culture and racial/ethnic background to identify any psychosocial needs or barriers to accessing care
- Validated psychosocial assessment tools include:
  - PAT and PedsQL (for children)
  - ASCQ-Me and PROMIS (for adults)
- Make referrals to appropriate support services, as needed
- Help people apply and obtain documentation for access to developmental services and financial benefits, as needed

QS 8: Transition From Youth to Adult Health Care Services

- Work with the young person (and their parents and caregivers, where appropriate) to identify a designated health care provider who will coordinate the transition
- This person coordinates care and provides support throughout the transition process; they act as the main link between the young person and other providers and ensure there are no gaps in the transition process
- See also Ontario Health's *Transitions From Youth to Adult Health Care Services* quality standard

*The quality statements are provided in full on page 2.

Acute Complications

QS 3: Vaso-occlusive Acute Pain Episodes

- Treat a vaso-occlusive acute pain episode as an acute medical emergency
- Within 30 minutes of triage or 60 minutes of presentation, assess the pain, assign a Canadian Triage and Acuity Scale (CTAS) score of at least 2, assess clinical signs to determine the cause of the pain, and give appropriate hydration and pharmacological and nonpharmacological treatment
- Throughout a vaso-occlusive acute pain episode, regard the person as an expert on their condition
- Involve the person (and their family and caregivers, where appropriate) in creating a plan to manage their pain at home and for follow-up care, as needed
- Offer translation or interpretation services, as needed
- See also Ontario Health's *Opioid Prescribing for Acute Pain* quality standard

QS 4: Life-Threatening Acute Complications

- Ensure that people presenting with signs and symptoms of a potentially life-threatening acute complication are promptly assessed and treated, even in the absence of vaso-occlusive acute pain
- Severity should be determined by the results of a thorough clinical assessment, rather than based on initial impressions of the person's physical appearance
- Create and document an individualized treatment and monitoring plan, and share it with the person's circle of care
- Most people with sickle cell disease experience chronic anemia; therefore, it is important for the person and their primary care provider to know the person's baseline hemoglobin value to inform ongoing monitoring and management of acute complications

Chronic Complications

QS 5: Chronic Complications

If you are a primary care provider or other local health care team member:

- Monitor for signs and symptoms of chronic complications
- For people with chronic complications, promptly consult with and/or refer them to a specialized centre for assessment and management of their condition, as needed

QS 6: Referral to Health Care Professionals With Expertise in Chronic Pain

- Refer people whose goals for pain control and function are not being met to health care professionals or a chronic pain centre with expertise in treating people with chronic pain related to sickle cell disease
- Help people understand that improvements in functioning and quality of life can be achieved when pain is still present
- See also Ontario Health's *Chronic Pain* quality standard

Sickle Cell Disease: Care for People of All Ages QUALITY STATEMENTS

Quality Statement 1: Racism and Anti-Black Racism
People with sickle cell disease (and their families and caregivers) experience care from health care providers within a health care system that is free from racism and anti-Black racism, discrimination, and stigma. Health care providers promote a culture that is compassionate, trauma informed, and respectful of people's racial/ethnic and cultural backgrounds. They build trust with people with sickle cell disease (and their families and caregivers), work to remove barriers to accessing care, and provide care equitably.

Quality Statement 2: Comprehensive Health Assessment and Care Plan
People with sickle cell disease have a comprehensive health assessment at least annually from an interprofessional care team at a dedicated sickle cell disease centre to develop an individualized, person-centred care plan. The assessment and care plan are documented and shared with the person's circle of care.

Quality Statement 3: Vaso-occlusive Acute Pain Episodes
People with sickle cell disease who present to an emergency department or hospital with a vaso-occlusive acute pain episode receive a timely pain assessment and clinical assessment. Their treatment begins within 30 minutes of triage or 60 minutes of presentation. Before discharge, they are involved in the development of a plan for continuing to manage their acute pain episode at home. This plan includes symptom management strategies and information on how to access follow-up care and support from health care providers, as needed.

Quality Statement 4: Life-Threatening Acute Complications
People who present to an emergency department or hospital with a potentially life-threatening acute complication of sickle cell disease have their condition and its severity identified through a prompt clinical assessment. Their condition is managed appropriately with an individualized treatment and monitoring plan.

Quality Statement 5: Chronic Complications
People with sickle cell disease are monitored by their local health care team for signs and symptoms of chronic complications of sickle cell disease. People with chronic complications are promptly referred to a dedicated sickle cell disease or other specialized centre for consultation and/or assessment and management of their condition, as needed.

Quality Statement 6: Referral to Health Care Professionals With Expertise in Chronic Pain
People whose quality of life is significantly impacted by chronic pain caused by sickle cell disease are referred to individual health care professionals or a chronic pain centre with expertise in chronic pain related to sickle cell disease and the ability to offer pharmacological and nonpharmacological interventions.

Quality Statement 7: Psychosocial Assessment, Information, and Support
People with sickle cell disease (and their families and caregivers, where appropriate) have regular psychosocial assessments to identify any psychosocial needs or barriers to accessing care. Those with unmet psychosocial needs are offered information and support to address these needs.

Quality Statement 8: Transition From Youth to Adult Health Care Services
Young people with sickle cell disease have a designated health care provider for the transition from youth to adult health care services. This provider works with the young person (and their parents and caregivers, where appropriate) to coordinate their care and provide support throughout the transition process. The provider continues to provide support until the young person (and their parents and caregivers, where appropriate) confirms that the transition is complete.

Resources

- Sickle Cell Disease Quality Standard and Patient Guide bit.ly/3j0UI9G
- The Provincial Council for Maternal and Child Health and the Ontario Ministry of Health's *Clinical Handbook for Sickle Cell Disease Vaso-occlusive Crisis* bit.ly/3j4taA5
- The Hospital for Sick Children's Clinical Practice Guidelines (see Sickle Cell section) bit.ly/3Yi7HnL
- The American Society of Hematology's ASH Pocket Guides (see Sickle Cell Disease section) bit.ly/3PtLVJv
- The American College of Physicians' High Value Care Pediatric-to-Adult-Care Transition Toolkit: Sickle Cell Disease Transition Readiness Assessment and Clinical Summary bit.ly/3j7xxL6
- Paediatric Project ECHO's training session on sickle cell pain bit.ly/3hrybm4
- The Sickle Cell Awareness Group of Ontario's educational modules and resources for health care providers bit.ly/400f3w0, bit.ly/3FquHbr
- Additional tools and resources are on Quorum bit.ly/3UZNRdM

Note: This resource can be used to support health care providers in the provision of care. It does not override the responsibility of health care providers to make decisions with patients, after considering each patient's unique circumstances. Grouping/directionality of statements may not be applicable for every patient, and clinical judgment should be used.

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