Adult Sickle Cell Health Maintenance Recommendations
Duke University School of Nursing

How often should adults with sickle cell see a doctor and what care should occur? Following Duke University School of Nursing's recommendations, "In general, both specialist and PCP visits at least twice a year. All elements of routine health maintenance, including routinely recommended vaccines, in addition to sickle cell specific care. All elements of care could be done by either specialist or PCP with communication of results."

	CARE ELEMENT	SUGGESTED FREQUENCY	GUIDANCE
UTILIZATION	ED Visits and Hospital Admissions (Provider Portal)	■ Each visit	
	Each visit Specialist or other outpatient visits (Provider Portal)	■ Each visit	
PAIN	Acute or chronic pain	■ Each visit	Increasing frequency or severity or chronic pain, See Pain algorithm
	Priapism	■ Each visit	Painful erection or lasting >2 hr, Pain algorithm
	Pain medications used (CSRS, Provider Portal)	■ Each visit	Assess for multiple unexpected fills from multiple providers, Pain algorithm
	Pain Agreement Plan	■ Each visit	Recommended for patients with chronic pain, Pain algorithm
	If long acting pain meds, pain provider?	■ Each visit	One main pain provider preferred, Pain algorithm
HISTORY	Hydroxyurea	■ Each visit	Typically prescribed by specialist. Generally recommended for Hg SS and SBthal0 with 3+ painful crises a year, ACS, severe anemia, etc. Also considered for SC more strongly following the PVIOT trial. CBC every 4-12 weeks if on hydroxyurea.
	Receiving chronic transfusion	■ Each visit	Typically managed by specialists. Marker of severe disease. Risk of liver and heart failure with significant long standing iron overload
	Vision	● Other *(See guidance →)*	Risk of retinal infarction. Refer to ophthalmologist for concerns. *(Also see in Physical section below)*
	Shortness of breath	■ Each visit	Danger of comorbidities of asthma and sickle cell disease. Hypoxia can lead to sickle cell crises. Good asthma control important in sickle cell disease patients
	Depression screen: PHQ-2/PHQ-9	■ Each visit	Manage depression or link to behavioral health specialists in your area
PHYSICAL	Vision	■ Each visit ♦ Annually	Vision screen each visit, Comprehensive eye exam annually, Risk of retinal infarction. Refer to ophthalmologist for concerns
	Spleen	■ Each visit	If palpable and enlarged, consider splenic sequestration, requiring hospitalization and transfusion
	Liver and gall bladder	■ Each visit	If painful or enlarged, consider gall stones which are associated with increased risk of multi-organ failure. Refer to Sickle Cell specialists
	Hip/knee/shoulder pain	■ Each visit	See Pain algorithm
	Leg ulcers	■ Each visit	Possible etiology venous insufficiency, Initial standard therapy (debridement, wet to dry dressings, topical agents), risk of osteomyelitis with chronic recalcitrant deep ulcers, wound culture if infection is suspected or if ulcers deteriorate
	ENT exam, enlarged tonsils with s/sxs of OSA	■ Each visit	OSA associated with nighttime hypoxia, ACS, progression of CNS and peripheral vascular disease. Refer to ENT and Sickle Cell specialist
	Dentition	■ Each visit	Dental caries has risk of chronic seeding and inflammation that can worsen chronic pain and trigger acute pain. Refer to dentist
	EKG to assess QTc if on methadone	♦ Annually	If QTc > 400ms, wean down Methadone
LABS	CBC with retic	♦ Every 6 months ❖ Every 4-12 weeks	Typically done by specialist. Red flag Hg < 2 g/dl or < 6g/dl than baseline. Risk of acute splenic sequestration, aplastic episode, ACS, etc. Refer for emergency care. CBC every 4-12 weeks if on hydroxyurea. To establish baseline, consider doing Hg levels monthly for 3 months.
	Ferritin	♦ Annually	Typically done by specialist. Red flag >1000 ng/m, Ensure sickle cell specialist has results
	T. Bili, LDH	♦ Every 6 months	Typically done by specialist. Red flag significantly elevated above baseline. Ensure specialist has results.
	AST, ALT, Cr	♦ Every 6 months	Typically done by specialist. Red flag elevated above normal. Ensure specialist has results.
	UA. First morning void spot micro-albumin/Cr ratio, if UA+	♦ Annually	Typically done by specialist. Red flag >30mg albumin/g Cr. Ensure specialist has results.
HEALTH MAINTENANCE*	Transition to adult care	■ Each visit	Each visit for patients age 18-22 years, Counseling about school, college, working
	PCN	● Other *(See guidance →)*	If history of surgical splenectomy or pneumococcal sepsis, at least to age 21, consider longer
	Pneumococcal vaccine (PPSV23)	● Other *(See guidance →)*	If confirmed that 2 doses were given during childhood, give another dose after age 65 yrs. If confirmation of earlier doses unavailable, give one dose and then repeat after age 65 years.
	Meningococcal vaccine (MCV4, Menactra)	● Other *(See guidance →)*	Every 5 years

**Consult AAP and ACIP for current vaccination recommendations.*

Source: https://nursing.duke.edu/sites/default/files/documents/SCD-Adult%20Sickle%20Cell%20Health%20Maintenance%20Recommendations%20122014.pdf. Information updated in 2025 in consultation with Duke University School of Nursing to include SC hydroxyurea information and vaccination references. Voices of Winged Warriors (VOWW) does not provide personal medical advice.