

START HERE

Questions to Ask Your Doctor

A checklist of things to discuss at your first hematology appointment. Bring this sheet with you, check off what you cover, and jot down notes as you go.

Understanding your diagnosis

- What type of sickle cell disease do I (or my child) have (HbSS, HbSC, HbS beta-thalassemia, etc.), and what does that mean day to day?
- How severe is this likely to be, and how much does that vary between people with the same genotype?
- What blood tests or scans will I need regularly, and how often?
- Are there any organs I should be monitoring more closely (spleen, lungs, heart, kidneys, eyes)?

Managing pain and preventing crises

- What usually triggers a pain crisis, and are there triggers I should watch for specifically?
- What's my personal plan for a mild pain episode at home versus one that needs the ER?
- What pain relief methods, over-the-counter or prescribed, are safe for me to use?
- Would hydroxyurea or another disease-modifying treatment be appropriate for me?
- Should I be doing anything differently around exercise, travel, or altitude?

Emergency planning

- What symptoms mean I should go to the emergency room right away?
- Should I carry a card or letter explaining my diagnosis for emergency staff?
- Which hospital or ER is best equipped to treat my sickle cell disease, and is there a way to alert them in advance?
- What is acute chest syndrome, and how would I recognize it?
- Who do I call after hours if I'm unsure whether something is an emergency?

Medications and prevention

- What medications am I currently prescribed, and what are they each for?
- Are there vaccinations I should get that I might otherwise miss?
- Do I need daily penicillin or another preventive antibiotic (common for young children)?
- Are there over-the-counter medications or supplements I should avoid?
- How should I store and manage my medications while traveling?

Living well day to day

- What does a "typical" good day look like for someone managing this well?
- Are there dietary or hydration guidelines specific to me?
- How might this affect school, work, sports, or pregnancy planning?
- Is genetic counseling available if we're planning to have more children?
- What mental health or peer support resources do you recommend alongside medical care?

Before you leave the appointment

- Do I have a written summary of today's plan and next steps?
- When is my next appointment, and what should I track before then?
- Who is my main point of contact between visits?
- What's the best way to reach the care team with non-urgent questions?

Tip: Take a photo of this sheet once it's filled in, or ask a family member or peer supporter to come with you and take notes so you can focus on the conversation.