

Urgent Sickle Cell Disease Warning Signs to Speak Up About with Your Healthcare Provider



While sickle cell disease (SCD) is a lifelong condition, it doesn't have to prevent you from living a full life. You are the expert of your body. If you don't feel well or something is concerning you, speak up. The tips below will help you stay as healthy as possible and offer guidance on sharing your concerns with your healthcare provider.

Tips:

- Bring this conversation guide with you to your healthcare appointments, along with any other questions or concerns you want to talk about.
- Bring your list of medications with you to all your healthcare appointments.
- Tell your healthcare provider what medications you're taking or have taken recently, and about any side effects you're experiencing.
- Speak up about your pain level, including what your pain levels have been since your last visit, and what you do to control your pain.
- Take notes and ask questions about anything that you don't fully understand.

Urgent Warning Signs to Speak Up About

If you're experiencing any of these signs or symptoms, seek out medical care right away:

- Fever (body temperature above 101° F)
- Trouble breathing
- Chest pain
- Swelling of the abdomen (belly)
- Severe headache
- Sudden weakness or loss of feeling or movement
- Seizure
- Painful erection of the penis lasting more than four hours

This list does not cover all possible urgent symptoms.

If something does not feel right, speak up and talk to your healthcare provider.

Use This Guide to Start Your Conversation:

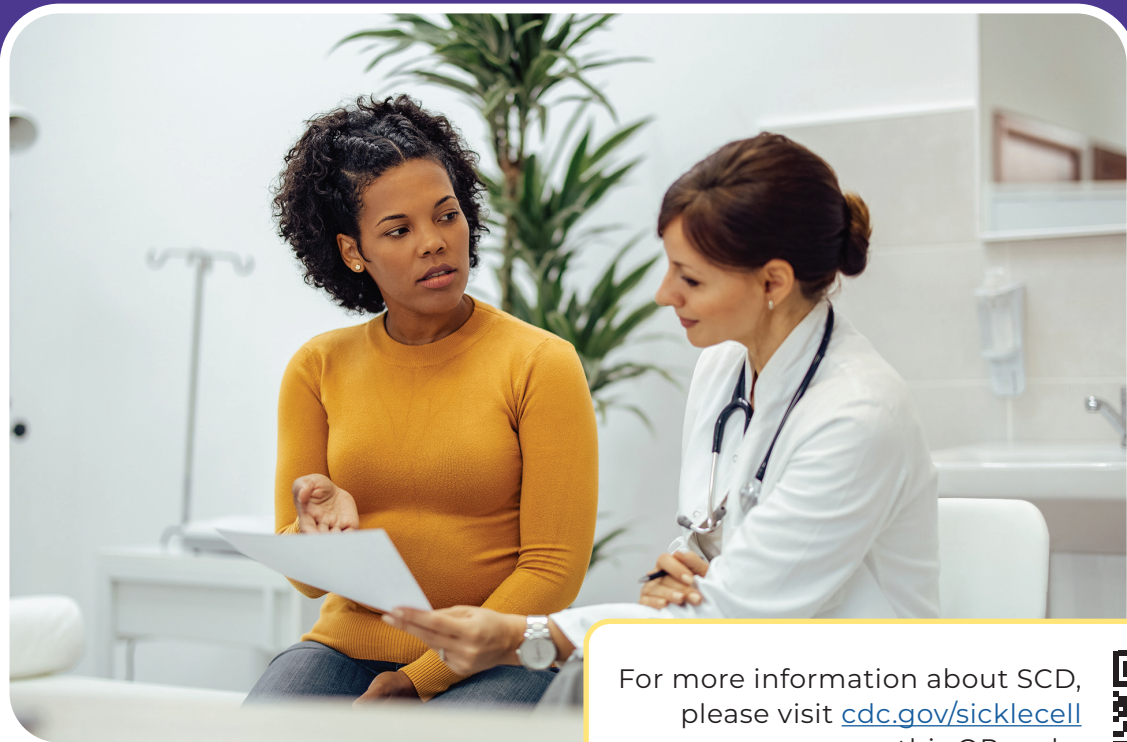
- My SCD symptoms have been worse since my last appointment, and I have serious concerns about my health that I'd like to talk to you about.
- I've been having (list symptoms) that feel like (describe in detail) and have been lasting (number of hours/days).
- I know my body and my symptoms, and this doesn't feel normal.

If you feel like your concerns aren't being heard, politely say that you don't feel like you've been heard or understood.

Clarify your concerns for the provider.

Sample Questions to Ask:

- What could these symptoms mean?
- What tests do you recommend to rule out a serious problem?
- What is the recommended treatment for these symptoms?
- What are the benefits and risks of the treatment?



For more information about SCD, please visit [cdc.gov/sicklecell](https://www.cdc.gov/sicklecell) or scan this QR code:



Tips for Your Health:

- Stay up-to-date with your medical care, including yearly wellcare appointments and vaccines.
- Work with your healthcare provider to develop an action plan to manage your symptoms.
- Know when to call your provider if your pain isn't getting better with treatment at home.
- Know when to seek emergency care/call 911.
- Adopt and maintain a healthy lifestyle to support your health and manage your SCD.
 - ✓ Make physical activity part of your daily routine.
 - ✓ Choose [heart-healthy foods](#) and [manage your blood pressure](#).
 - ✓ Drink eight to ten glasses of water every day.
 - ✓ Limit alcoholic drinks.
 - ✓ Quit smoking or vaping.
 - ✓ To help prevent infection, [wash your hands](#) often.
 - ✓ Try to get seven to nine hours of sleep every night.
 - ✓ Take care of your mental health and speak up about your feelings.



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Español (Spanish): ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1.800.859.9889 (TTY: 711).
Português (Portuguese): ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1.800.859.9889 (TTY: 711).