Healthy Living With Sickle Cell Disease

If you have sickle cell disease (SCD), you can live a full life and enjoy the things that most other people do. Follow these tips to support your mental and physical health, manage your condition, and stay as healthy as possible.

See Your Healthcare Team Regularly

Work closely with your healthcare team to develop your unique care plan. Try to establish strong relationships with your hematologist and other specialists, and keep in touch with them as often as needed. Routine checkups can help prevent serious problems. Your healthcare team can offer specific guidance, prescribe medications and treatment options, and address any concerns or questions. Most people with SCD should see their provider every 3 to 12 months. It's also important to get vaccines as directed by your healthcare team, including a flu shot each year, and a COVID-19 vaccine, as recommended.

Manage Your Blood Pressure

People with SCD are at high risk for complications, including stroke and kidney disease. These complications can be worsened by high blood pressure (hypertension), which often adds to the workload of the heart and blood vessels. Ask your healthcare team to check your blood pressure at each visit, and ask what your numbers mean for you — and how to control your blood pressure if it's consistently higher than 130/80 mm Hg.

Take Care of Your Mental Health

Children and adults with SCD may experience pain, anxiety, and depression. Talk to your friends and family about how you are feeling. Your healthcare team can refer you to a mental health professional to develop healthy pain-coping strategies, address negative thoughts, and improve overall well-being. Supportive counseling and, sometimes, antidepressant medicines may help.



Adopt a Healthy Lifestyle

Maintaining a healthy lifestyle is important for overall well-being and managing SCD.

- Be physically active
- Choose heart-healthy foods
- Drink 8–10 glasses of water daily
- Limit alcohol
- Quit smoking or vaping
- Wash hands often to help
 prevent infections
- Take care of your mental health
- Aim for 7–9 hours of sleep each night



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Learn What to Do in a Pain Crisis

When an acute crisis is just starting, drink lots of fluids and take a nonsteroidal anti-inflammatory (NSAID) pain medicine, such as ibuprofen. If you have kidney problems, acetaminophen is often preferred. If you cannot manage the pain at home, go to a day hospital or outpatient unit or an emergency department to receive additional stronger medicines and IV fluids. You may need to be admitted to the hospital to fully control an acute pain crisis.

Know When to Seek Help

Have a plan to get help quickly if there is a problem. Keep a copy of your health records (electronic or print) so you can bring them to a healthcare facility as needed.

Call 9-1-1 or seek emergency room care right away if you have:

- Fever above 101° F
- Difficulty breathing
- Chest pain
- Abdominal (belly) swelling
- Sudden vision problems
- Severe headache

- Sudden weakness or loss of feeling and movement
- Seizure
- Painful erection of the penis that lasts more than 4 hours
- Pain anywhere in the body that will not go away with treatment

By adopting a healthy lifestyle, you can help take control of your well-being. For more information on a healthy lifestyle with SCD, visit <u>sicklecell.nhlbi.nih.gov</u>

"I drink lots of fluids, eat a healthy diet, take my medications, even if I'm feeling good, and make every doctor's appointment," says Yaw Lokko, patient advocate and clinical research trial participant. And to minimize pain triggers, "I try to avoid the heat, avoid the cold. It's not always easy, but it's good to pay attention."



