Women with Sickle Cell Disease and Preconception Care: What to Know Before Getting Pregnant

Whether you are planning to get pregnant or just thinking about it, it’s never too early to start preparing for a pregnancy. Preconception care focuses on taking steps before getting pregnant to increase the chances of having a healthy pregnancy and a healthy baby. Women with sickle cell disease (SCD) are at greater risk for developing complications (health problems) during pregnancy than women without SCD. For some women with SCD, pregnancy can make their disease more severe, and treatments may need to be changed to help manage complications. This makes preconception care especially important. Learn what steps you can take now to stay healthy during a future pregnancy.

Find providers you trust who have experience caring for people with SCD. Ideally, your healthcare team should include a SCD care provider and an obstetrician/gynecologist or other reproductive healthcare provider, and might also include specialists.

Consider your future reproductive goals and if and when you want to have children. Discuss with your providers how best to achieve these goals.

Discuss and develop a support plan with your partner, family, and employer on issues that may need to be considered when you become pregnant since you will have many medical appointments. Topics can include the following:

- Caring for other children or family members
- Managing household chores
- Managing work schedules with your employer

Ask your care team about testing for you and your partner to learn about the chance of having a child with SCD. Talk to a genetic counselor about the results to understand the chance of having a baby born with SCD and to help you think about your options for starting a family.

Talk with your obstetrician/gynecologist or other reproductive healthcare provider if you have been trying to get pregnant and have had unprotected sex for more than 6 months and are not pregnant. Many people experience fertility challenges, so talk with your provider to learn what options may be best for you.
Visit your obstetrician/gynecologist or other reproductive healthcare provider and your SCD provider for a pre-pregnancy checkup to examine your overall health and to talk about the steps you can take now to help prevent potential health issues that can affect your pregnancy. Your reproductive healthcare provider may refer you to a maternal-fetal medicine specialist (an obstetrician/gynecologist specializing in complicated or high-risk pregnancies). If you live far from where this care is available, try to travel to a medical center for a checkup and coordinate your care with your local care team as well. You might also ask whether a telehealth visit for an initial consultation is a possibility. During your checkups with various reproductive healthcare providers, be sure to do the following:

- Be sure your care provider examines the health of your eyes, lungs, heart, kidneys, liver, and hips to check for any complications that can worsen during pregnancy. Talk to your care team about managing your blood counts, such as your hemoglobin level, and develop a pain management plan.

- Share a list of medicines that you take and ask if you need to stop, change, or reduce your dose before you start trying to get pregnant. You should discuss both prescription medicines (such as non-steroidal anti-inflammatory drugs, chelators, hydroxyurea, voxelotor, L-glutamine, crizanlizumab, anticoagulants, and opioids) and all over-the-counter medicines (including vitamin supplements) that you take regularly or on occasion, whether they are taken for your SCD or another reason.

- Review your current vaccination record with your care team to make sure you are up to date on vaccines (shots) even before becoming pregnant. Talk with your doctor about varicella and rubella screening to see if you need these vaccines before getting pregnant as these are live vaccines and are not recommended during pregnancy. Vaccines are safe for people with SCD. Additional vaccines are recommended for people with SCD to help prevent harmful infections.

- Discuss and develop with your care team a SCD treatment plan and a pain management plan to have them in place if or when you become pregnant and to inform management during and after pregnancy.

- Discuss when to start taking prenatal vitamins and what kind to take.
  - Some women with SCD may have high amounts of iron in their blood from blood transfusions and may need to take a prenatal vitamin without iron.
  - Folic acid is a B vitamin that is important to have both before and during pregnancy. Folic acid is used by the body to make new cells. This includes the cells that will form the baby's brain and spine. Thus, it is particularly important to talk with your provider to ensure you are getting enough folic acid.
Linked Resources

https://www.cdc.gov/preconception/index.html
https://www.cdc.gov/ncbddd/sicklecell/facts.html
https://www.cdc.gov/reproductivehealth/contraception/qfp.htm
https://www.smfm.org/members/search
https://telehealth.hhs.gov/patients/
https://www.cdc.gov/pregnancy/meds/treatingfortwo/index.html
https://www.cdc.gov/vaccines/pregnancy/vacc-before.html
https://www.cdc.gov/ncbddd/sicklecell/healthyliving-prevent-infection.html
https://www.cdc.gov/ncbddd/folicacid/index.html

Additional Resources

Sickle Cell Red: Planning for Pregnancy with SCD:
https://sicklecellred.org/learners/

10 Tips for Preventing Infections Before and During Pregnancy:
https://www.cdc.gov/pregnancy/infections.html

U.S. Department of Health & Human Services Office on Women’s Health:
https://www.womenshealth.gov/a-z-topics/sickle-cell-disease

Women with Sickle Cell Disease and Prenatal Care: What To Know During Pregnancy:

Women with Sickle Cell Disease and Postpartum Care: What to Know After Delivering Your Baby: