

# Reproductive Health Considerations in Sickle Cell Disease: Focus on Menstrual Management, Family Planning, & Pregnancy

## Reproductive Health Goals

Empowering individuals with Sickle Cell Disease (SCD) in defining and achieving their reproductive health goals requires inclusive, patient-centered, and sensitive conversations. The following sections provide questions and discussion topics to help guide providers in addressing each individual's needs and priorities during various reproductive life stages.

## Menstrual Management

Menstrual management is a critical component of comprehensive reproductive healthcare for individuals with SCD. Hormonal therapies, including contraceptive agents, may also support menstrual management and other health needs for individuals with SCD. Selection of therapeutic options should be individualized, incorporating medical comorbidities, treatment history, developmental stage, and patient preferences, within the context of social and cultural factors. These discussions are particularly important during key transition transitions such as puberty, menarche, and the initiation of sexual activity.

## Pregnancy Prevention and Contraception

For individuals not planning for pregnancy now, or who wish to avoid it altogether, contraception becomes a key part of reproductive health planning. Contraception and hormonal therapy may also support menstrual management and other health needs for individuals with SCD. When appropriate, multidisciplinary consultation (e.g., Hematology, Gynecology, Reproductive Endocrinology, Adolescent Medicine, Genetic Counseling, Family Planning, or Maternal-Fetal Medicine (MFM)) is recommended. Framing contraception as a proactive step in reproductive health goal-setting helps normalize the discussion and ensures individuals feel supported in their choices.

### Questions to guide this conversation:

- Are you interested in preventing pregnancy at this time?
- If yes, what options are you interested in or most comfortable trying?

## Preconception Planning

For those considering pregnancy, now or in the future, preconception planning helps ensure informed, personalized care. FWGBD's preconception handout can support this process by guiding discussions between patients and providers. Referrals may include Obstetrics/Gynecology, Hematology, Reproductive Endocrinology and Infertility, Urology, and Genetic Counseling.<sup>15</sup>

When discussing family planning, consider asking:

- Have you considered whether you'd like to have children, and if so, when?
- Would you like to meet with a high-risk obstetrician (MFM) to discuss a future pregnancy?
- Would you like to explore assisted reproductive options, such as egg freezing, sperm preservation, or in vitro fertilization (IVF)?
- Would you like to review your medication(s) in anticipation of a possible pregnancy?
- Are you interested in preconception genetic counseling to understand your potential inheritance risks?

A simple framework to guide discussions is the **Three Ts**:

- **Testing:** Ensure partners are tested for sickle cell trait/disease, and relevant hemoglobinopathies that could put a child at risk of having a sickle cell syndrome
- **Testing for STIs:** Encourage testing for both the individual and partner
- **Talking:** Encourage open conversations with partners about reproductive goals

## Options for Menstrual Management and Contraception

### **Long-acting reversible contraception (LARC):**

- Implantable devices administered by healthcare providers:
  - Copper intrauterine devices (Cu-IUD)
  - Levonorgestrel intrauterine devices (LNG-IUD)
  - Implants (i.e., Etongestrel implant)

### **Non-Hormonal Contraception Options**

- Copper IUD
- Barrier methods: External (male) or internal (female) condoms
- Fertility-based awareness methods
- Withdrawal

### **Progestin-only oral hormonal therapy:**

- Progestin-only pills (POP)

### **Combination hormonal therapy and devices:**

- Estrogen-progesterone combination oral/hormonal contraceptives (COC / CHC)
- Estrogen-progesterone combination hormonal devices (hormonal patches, vaginal rings)

### **Injectable contraceptive method:**

- Medroxyprogesterone acetate (DMPA)

### Key Considerations (see Tables on Page 3)

**Effectiveness:** Overall, LARC methods have the lowest contraception failure rates. For guidance, refer to the [U.S. Medical Eligibility Criteria for Contraceptive Use, 2024 \(U.S. MEC\) | Contraception | CDC](#)<sup>1</sup>

### Risks/Benefits for Sickle Cell Disease:

**Benefit outweighs risk:** POP, Cu-IUD, and LNG-IUD for contraception

**Risk may or may not outweigh benefit:** DMPA depending on risk of thrombosis. The CDC notes that thrombosis risk is higher in DMPA users. However, DMPA can reduce clinical complications of SCD.

**Unacceptable health risk:** CHC (pill, ring, and patch)

### SCD-Specific Issues:


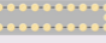
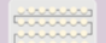



**Venous Thromboembolism (VTE) risk:** Individuals with SCD have higher risk of VTE compared to the general population, which is higher in adult versus pediatric patients.<sup>2-4</sup> Special populations requiring Hematology and Gynecology consultation include those with history of stroke and prior VTE. CHC, and to a lesser extent, DMPA, also increase VTE risk.<sup>2,3,5</sup> POP, IUD and LNG-IUD have not been shown to increase VTE risk, and are preferred. However, given the high-risk nature of unplanned pregnancy in women and girls with SCD, benefits of estrogen-progesterone combination could be considered after careful discussion.<sup>2,3,5</sup>

**Dysmenorrhea and Heavy Menstrual Bleeding (HMB):** Individuals with SCD may experience HMB, dysmenorrhea, shorter and more irregular cycles compared to the general population. Use of most hormonal contraception improves symptoms of dysmenorrhea and HMB.<sup>6-10</sup>

**Vaso-Occlusive Crisis (VOC):** DMPA has been shown to decrease the intensity and frequency of menstrual bleeding, in addition to decreasing episodes of painful crisis and dysmenorrhea. There is limited data to provide guidance regarding the impact of POP, CHC, IUD on VOC.<sup>6,9,11</sup>





**Bone Mineral Density:** DMPA has been shown to have negative effects on bone mineral density in adults and children which may be reversible.<sup>1,12</sup> There is limited data regarding the impact of CHC; however, studies show no effect on BMD with POP, IUD and LNG-IUD.

## Progesterone Only Options for Managing Periods and Preventing Pregnancy in Sickle Cell Disease

Progesterone Only Medication Name	How It Looks	How Often	Decrease in Cramping	Decrease in Period Bleeding	Effectiveness of Pregnancy Prevention	Increase Risk of Blood Clot	Additional Considerations
<b>Norethindrone acetate</b> Aygestin®		1-2 times per day	Possibly	Yes	Not studied	Yes	<ul style="list-style-type: none"> <li>Higher progestin-only dose options</li> <li>Typically used for HMB</li> <li>Not FDA approved for pregnancy prevention</li> </ul>
<b>Norethindrone</b> "Minipill"		Once a day	Possibly	Possibly	93%	No	<ul style="list-style-type: none"> <li>Lowest progestin-only dose option</li> </ul>
<b>Norgestrel</b> Opill®		Once a day	Possibly	Possibly	91%	Unknown	<ul style="list-style-type: none"> <li>Available over the counter</li> </ul>
<b>Drospirinone</b> Slynd®		Once a day	Possibly	Possibly	96%	Unknown	
<b>Emergency Contraception (NOT AN ABORTIVE MEDICATION)</b>							
<b>Levonorgestrel</b> Plan B One-Step®		Once within 3 days or 72 hours	N/A	N/A	89%	N/A	<ul style="list-style-type: none"> <li>Available over the counter</li> <li>Take 1 tablet as soon as possible after unprotected sex</li> <li>May not work as well for weights over 165 lbs</li> </ul>
<b>Ulipristal</b> Ella®		Once within 5 days or 120 hours	N/A	N/A	85%	N/A	<ul style="list-style-type: none"> <li>Take 1 tablet as soon as possible after unprotected sex</li> <li>May not work as well for weights over 195 lbs</li> </ul>

## Non-Pill Options for Managing Periods and Preventing Pregnancy in Sickle Cell Disease

Last longer. Individual does not have to take a pill everyday.

Medication Name	How It Looks	How to Use	How Often	Decrease in Cramping	Decrease in Period Bleeding	Effectiveness of Pregnancy Prevention	Increase Risk of Blood Clot	Additional Considerations
<b>Depotmedroxyprogesterone acetate</b> Depo-Provera® "The Shot"		Injected in arm or butt cheek by doctor or nurse	Every 12 weeks	Yes	Yes	96%	Yes	<ul style="list-style-type: none"> <li>May cause lower bone density with prolonged use</li> <li>May cause weight gain</li> <li>Most studied in decreasing vaso-occlusive pain</li> </ul>
<b>Levonorgestrel-Intrauterine device (IUD)</b> Mirena®, LILETTA®, Kyleena®, and Skyla®		In office procedure; placed in uterus	Every 3-8 years	Yes	Yes	99.9%	No	
<b>Etonogestrel implant</b> NEXPLANON®		In office procedure; placed in arm	Every 5 years	Possibly	Possibly	99.9%	No	<ul style="list-style-type: none"> <li>Commonly associated with irregular bleeding</li> </ul>
<b>Copper IUD</b>		In office procedure; placed in uterus	Every 12 years	No	No	99.4%	No	<ul style="list-style-type: none"> <li>Can be used for emergency contraception within 5 days</li> <li>For baseline painful or heavy periods, may increase period bleeding and pain</li> </ul>

**Combined hormonal options NOT recommended due to estrogen content.** Estrogen progesterone combination hormonal medications are not recommended in people with sickle cell disease due to unacceptably high risk of blood clots. Further multidisciplinary care discussions regarding specific patient risk factors should include Gynecology, Hematology, Reproductive Endocrinology, and Genetic Counseling. Shared decision making with the patient and provider team is critical. These estrogen containing options include the patch (Norelgestromin/ethinyl estradiol (Xulane®), Ethinyl estradiol/levonorgestrel transdermal (Twirla®)) and the vaginal ring (Etonogestrel/ethinyl estradiol (NuvaRing®), Segesterone/ethinyl estradiol (Annovera®)).

## Sexually Transmitted Infection (STI) Prevention

For individuals with SCD who are sexually active, especially adolescents and young adults, STI prevention is an essential part of care. Low awareness and limited contraception use may increase risk<sup>13, 14</sup>, making education and open dialogue critical. Providers should create a safe, nonjudgemental space for questions and discussion. Key points to cover:

- Encourage regular STI testing, particularly with every new partner
- Explain the impact of untreated STIs on fertility and long-term reproductive health
- Emphasize safe sex practices including use of condoms, HPV vaccination, reducing the number of sexual partners, or choosing abstinence/monogamy
- Support open discussions with partners about consent, prevention, and shared responsibility

### Questions to guide this conversation:

- Have you had STI testing in the past year? If not, would you like to discuss this at our next clinic visit?
- Do you feel comfortable talking with your partner about safe sex practices? Would resources or strategies help?

## Resources:

- **Sickle Cell Reproductive Health Education Directive (SCRED)** offers tools and guidance for individuals and providers: [www.sicklecellred.org](http://www.sicklecellred.org)
- **How to Prevent STIs:** <https://www.cdc.gov/sti/prevention/index.html>
- **Women with Sickle Cell Disease and Postpartum Care:** <https://www.cdc.gov/sickle-cell/communication-resources/women-with-sickle-cell-disease-and-postpartum-care.html>
- **Women with Sickle Cell Disease and Preconception Care:** <https://www.cdc.gov/sickle-cell/communication-resources/women-with-sickle-cell-disease-and-preconception-care.html>
- **Women with Sickle Cell Disease and Prenatal Care:** <https://www.cdc.gov/sickle-cell/communication-resources/women-with-sickle-cell-disease-and-prenatal-care.html>

## References:

1. Nguyen AT, Curtis KM, Tepper NK, et al. U.S. Medical Eligibility Criteria for Contraceptive Use. *MMWR Recomm Rep*. 2024; 73(No. RR-4):1–126. doi: 10.15586/mmwr.rr7304a1.
2. Kumar R, Stanek J, Creary S, Dunn A, O'Brien SH. Prevalence and risk factors for venous thromboembolism in children with sickle cell disease: an administrative database study. *Blood Adv*. 2018; 2(3):285–291. doi: 10.1182/bloodadvances.2017012336. PMID: 29431623; PMCID: PMC5812330.
3. Abou-Ismaïl MY, Citla Sridhar D, Nayak L. Estrogen and thrombosis: A bench to bedside review. *Thromb Res*. 2020; 192:40–51. doi: 10.1016/j.thromres.2020.05.008. Epub 2020 May 11. PMID: 32450447; PMCID: PMC7341440.
4. Oedingen C, Scholz S, Razum O. Systematic review and meta-analysis of the association of combined oral contraceptives on the risk of venous thromboembolism: The role of the progestogen type and estrogen dose. *Thromb Res*. 2018; 165:68–78. doi: 10.1016/j.thromres.2018.03.005. Epub 2018 Mar 15. PMID: 29573722.
5. Cockrum RH, Soo J, Ham SA, Cohen KS, Snow SG. Association of progestogens and venous thromboembolism among women of reproductive age. *Obstet Gynecol*. 2022; 140(3):477–487. doi: 10.1097/AOG.0000000000004896. Epub 2022 Aug 3. PMID: 35926206; PMCID: PMC9669089.
6. Haddad LB, Curtis KM, Legardy-Williams JK, Cwiak C, Jamieson DJ. Contraception for individuals with sickle cell disease: a systematic review of the literature. *Contraception*. 2012; 85(6):527–537. doi: 10.1016/j.contraception.2011.10.008.
7. Sharma D, Day ME, Stimpson S, et al. Acute vaso-occlusive pain is temporally associated with the onset of menstruation in women with sickle cell disease. *J Womens Health (Larchmt)*. 2019; 28(2):162–169. doi: 10.1089/jwh.2018.7032.
8. Stimpson SJ, Rebele EC, DeBaun MR. Common gynecological challenges in adolescents with sickle cell disease. *Expert Rev Hematol*. 2016; 9(2):187–196. doi: 10.1586/17474086.2016.1126177. Epub 2015 Dec 29. PMID: 26613137.
9. De Sanctis V, Soliman AT, Daar S, et al. Current issues and options for hormonal contraception in adolescents and young adult women with sickle cell disease: an update for health care professionals. *Mediterr J Hematol Infect Dis*. 2020; 12(1):e2020032. doi: 10.4084/MJHID.2020.032. PMID: 32395221; PMCID: PMC7202337.
10. Samuels-Reid J, Scott RB. Characteristics of menstruation in sickle cell disease. *Fertil Steril*. 1985; 43(1):139–141. PMID: 3965308.
11. de Abood M, de Castillo Z, Guerrero F, Espino M, Austin KL. Effect of Depo-Provera or Microgynon on the painful crises of sickle cell anemia patients. *Contraception*. 1997; 56(5):313–316. doi: 10.1016/s0010-7824(97)00156-x. PMID: 9437560.
12. Lopez LM, Grimes DA, Schulz KF, Curtis KM, Chen M. Steroidal contraceptives: effect on bone fractures in women. *Cochrane Database Syst Rev*. 2014; (6):CD006033. doi: 10.1002/14651858.CD006033.pub5. Accessed 25 March 2024.
13. Carrithers B, Klein R, Kanter J. Addressing reproductive education among young adults with sickle cell disease (SCD): Sickle Cell Reproductive Outreach and Education (ROE) Project. *Blood*. 2023; 142(Supplement 1):3903. doi: 10.1182/blood-2023-190927.
14. Pecker LH, Hussain S, Lanzkron S, et al. Women with sickle cell disease report low knowledge and use of long-acting reversible contraception. *J Natl Med Assoc*. 2021; 113(5):552–559. doi: 10.1016/j.jnma.2021.05.005. Epub 2021 Jun 10. PMID: 34119338; PMCID: PMC10206766.
15. Oteng-Ntim E, Shangaris P. Evidence-based management of pregnant women with sickle cell disease in high-income countries. *Hematology Am Soc Hematol Educ Program* 2022; 2022;(1):408–413. doi: 10.1182/hematology.2022000378.