

# Module 6: Sexual Health

## Contents

- Puberty and Sickle Cell Disease
- Menstrual Cycle (Period)
- Birth Control and Sickle Cell Disease
- Depot medroxyprogesterone acetate (DMPA)
- Intrauterine Device (IUD)
- Emergency Birth Control
- Pregnancy and Sickle Cell Disease
- Pregnancy and Health
- What are the Chances my Child will have Sickle Cell?
- What Should I Do if There is a Chance My Child Could Have Sickle Cell Disease?
- More Information About Pregnancy and Sickle Cell
- Priapism
- Masturbation and Fathering Children

## Module 6: Sexual Health

### **DISCLAIMER**

The content in this module should be viewed under adult supervision.

This module was developed for participants 18 years and older. If you are under the age of 18, you need to consult with your parents/caregivers before participating in this module.

## Puberty and Sickle Cell Disease

Puberty is the physical changes that occur as a child's body becomes an adult body capable of reproduction (having babies). Read more about puberty on [kidshealth.org](https://kidshealth.org)

How does having Sickle Cell Disease affect puberty?

Having Sickle Cell Disease can mean that you may experience puberty a little later than average. You will still experience all stages of puberty and the age in which puberty starts is similar to others in your family but having SCD can mean that it happens at an older age.

It can be tough not being as tall or as developed as others your age but remember that many people (not just people with sickle cell) go through puberty at an older age. You should not feel bad about yourself because your body is changing more slowly than others. It is normal to feel awkward about your body at times, but you should not constantly worry about it. If you are concerned about your pubertal development, talk to your doctor.



## Menstrual Cycle (Period)

Remember that there are different types of Sickle Cell Disease and that it is important to know which type you have so that you can take steps to better take care of yourself in all stages in life. In the stage of puberty, women will experience their menstrual cycle, or period. In the U.S., the average girl has her first period around 12.5 years of age.

Depending on the type of sickle cell disease you have, you may get your period at the same time as other girls your age or later than your peers. On average, a girl with SS type sickle cell can almost be the same as girls without sickle cell with good nutrition and healthcare. These ages are averages, and many girls have their first period over a year before or after these averages and are still completely normal.

To get more information about periods, visit [http://kidshealth.org/teen/sexual\\_health/girls/menstruation.html](http://kidshealth.org/teen/sexual_health/girls/menstruation.html).



## Birth Control and Sickle Cell Disease

- What is birth control? Birth control (also called contraception) is a medicine, device, or practice that reduces the chance of pregnancy. Birth control medicine contains one or two hormones that affect the normal menstrual cycle to prevent pregnancy.
- What form of birth control should I use? It is important to discuss with your doctor which options are best for you. If you find that you do not want to get pregnant yet, it is very important that you use condoms. Not only do condoms protect from pregnancy, they are the only method of birth control that also protect against sexually transmitted diseases (STDs) and sexually transmitted infections (STIs). Even though condoms are effective when used properly, all women who do not want to get pregnant should still use another birth control method since there is a possibility that condoms can fail.

Many forms of birth control are available. Most contain estrogen, which is not the first choice for women with sickle cell because of the risks of blood clotting.



## Depot medroxyprogesterone acetate (DMPA)

Depot medroxyprogesterone acetate (DMPA), also called "the shot," is the best studied form of birth control for women with sickle cell disease. DepoProvera, the brand name, is an injection containing only one hormone, a type of progesterone (no estrogen), that you receive every three months at your doctor's office. In addition to preventing pregnancy, DepoProvera seems to have additional benefits just for women with sickle cell. Women with sickle cell disease who took DepoProvera had less pain crisis episodes than women who did not take DepoProvera.

Even though most women with sickle cell disease can safely use most forms of birth control, some methods, including most oral contraceptive pills, contain the hormone estrogen, which can increase the risk of blood clots and stroke.

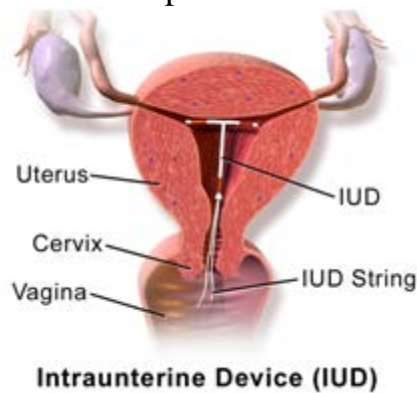
You should talk more to your doctor about which birth control method is right for you.



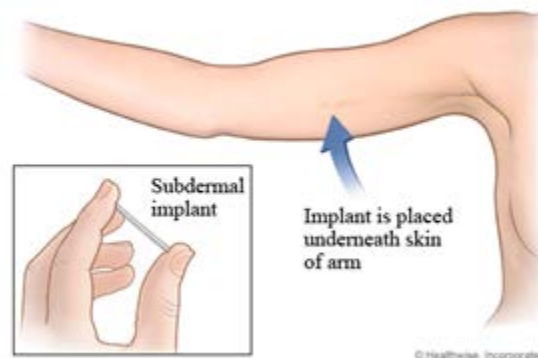
## Intrauterine Device (IUD)

Another form of birth control is a progestin-releasing intrauterine device (Merena™). This is a small plastic device shaped like the letter “T”, about 1 ½ inches long, with a string attached. A healthcare provider inserts the device through the cervix into the uterus, and it releases a progestin hormone. It takes about 7 days for the hormonal IUD to start working to prevent pregnancy, and it is able continue working for 5 to 7 years.

Progestin hormone can also be given as an implant under the skin. A hollow rubber rod (the size of a matchstick) with synthetic progestin is placed under the skin on the inside of the upper or lower arm. The implant can be effective for up to 5 years.



Many other forms of birth control are available. Most of them contain estrogen, which is not the first choice for women with sickle cell because of the risks of blood clotting.



## Emergency Birth Control

I am not on birth control and had sex yesterday without a condom. Is there anything I can do to prevent getting pregnant?

Yes. Emergency contraception (also called Plan B) is a progesterone-only hormone pill that a woman can take after unprotected sex to decrease the chance that she will get pregnant. Women must take the emergency contraception pill within 72 hours after unprotected sex to prevent pregnancy (the sooner you can take it, the better). Women with sickle cell can safely take emergency contraception.

Read more about Plan B:

[Plan B® One-Step](#)

[Planned Parenthood® Federation of America Inc.](#)





## Pregnancy and Sickle Cell Disease

As you get older, you may start wondering how your disease can affect your future. You may start to wonder if you can do everything someone who does not have SCD can do. One question in particular that you may have thought about is whether or not you can start a family while having Sickle Cell Disease. Below are a few common questions that many people with SCD have found themselves asking.

Can I get pregnant if I have sickle cell disease?

Yes, women with sickle cell disease can become pregnant. It is important for all women to get medical care during pregnancy, called prenatal care, but it is especially important for pregnant women with sickle cell disease to be followed closely by a high-risk OB/GYN doctor and sickle cell hematologist because some pregnant women with sickle cell experience more problems.



What should I do if I am planning to have a baby?

You and your partner should get tested for SCT if you are planning to have a baby. Testing is available at most hospitals or medical centers, from SCD community-based organizations, or at local health departments. If a woman or her partner has SCT, a genetic counselor can provide additional information and further discuss the risks to their children.

## Pregnancy and Health

Can I still have a healthy pregnancy?

Yes, with early prenatal care and careful monitoring throughout the pregnancy, a woman with SCD can have a healthy pregnancy. However, women with SCD are more likely to have problems during pregnancy that can affect their health and that of their unborn baby. Therefore, you should be seen often by your obstetrician, hematologist, or primary care provider.

- During pregnancy, SCD can become more severe and pain episodes can occur more frequently.
- A pregnant woman with SCD is at a higher risk of preterm labor and of having a low birth weight baby.
- If you have Sick Cell Trait (SCT) you can have a healthy pregnancy.
- Pregnant women with SCT also should be monitored by their obstetrician or primary care provider for the same health complications as for all pregnant women.

Can I have healthy children if I have sickle cell disease?

Yes. Even though there is a chance that women with sickle cell disease are more likely to have premature babies that weigh less than average, most children are healthy. In addition to being born early or weighing less, your child could also have sickle cell disease. Remember, SCD is inherited and can be passed down from parents to their children.

To learn more about genetics and how diseases are inherited, there are a few websites to explore:

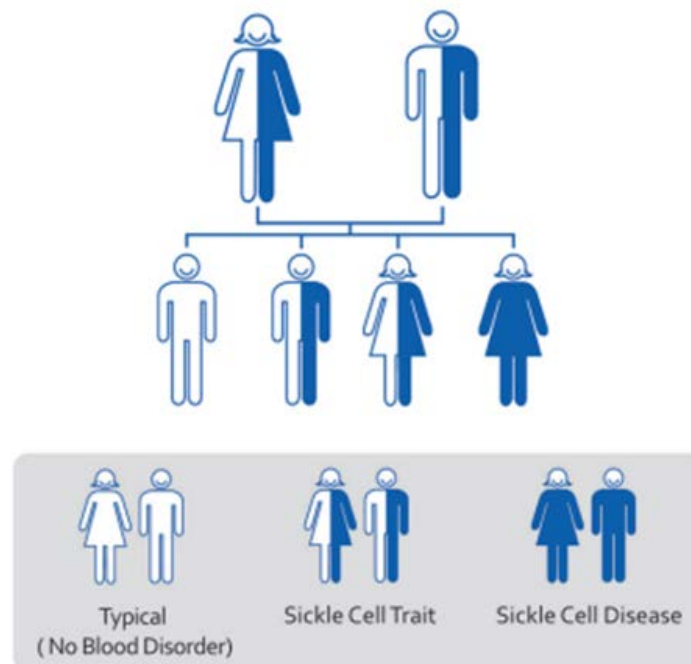
- The US Department of Health and Human Services has an article that shares information about understanding your family history. [Click here](#) to learn more.
- The National Human Genome Project has a website focused on understanding genetics. [Click here](#) to check out the glossary.

## What are the Chances my Child will have Sickle Cell?

If I have a child what are the chances that my child will also have sickle cell disease? When determining if parenthood is right for you, you may have several questions about how your Sickle Cell Disease can affect your child or children. You may wonder what the chances of your child inheriting Sickle Cell Disease are and it is best to consult with a genetic counselor or doctor so that they can explain your specific chances of having a child with SCD. They will look at the type of SCD you have and your partner's hemoglobin genes and give you a better understanding of whether or not your child will inherit Sickle Cell Disease.

In general, Sickle cell disease (SCD) is a genetic condition that is present at birth. It is inherited when a child receives two sickle cell genes—one from each parent. A person with SCD can pass the disease on to his or her children. Sickle cell trait (SCT) is not a disease but means that a person has inherited the sickle cell gene from one of his or her parents. People with SCT usually do not have any of the symptoms of SCD and live a normal life, but they can pass the sickle cell gene on to their children.

- When both parents have SCT, they have a 25% chance of having a child with SCD with every pregnancy.
- When both parents have SCT, they have a 50% chance of having a child with SCT with every pregnancy.



## What Should I Do if There is a Chance My Child Could Have Sickle Cell Disease?

It can be a scary thought knowing that your child could be born with Sickle Cell Disease and that they can face the pain and complications that you have. If you seek advice from people who do not understand the disease, some may tell you not to have children and others may tell you to have children with someone who does not have sickle cell trait to reduce your chances of passing SCD down to your children. But what if you fall in love with someone who does have sickle trait? There are many important features that you look for in a partner, and whether or not they have sickle trait may not rank high on your list, and it certainly doesn't have to. These are tough questions and issues, and there is no right answer. You need to think about the chances and discuss it with your partner before you have children.

Aside from considering whether or not your child may end up with Sickle Cell Disease, there are a few other factors that should be considered. You should choose to have children with someone who loves you, understands you, and plans to be with you for a lifetime. Having children is a huge responsibility, and you want to make sure that you and your partner are in a position to provide for your children's needs, which includes having a stable and loving home. It is also important to be prepared for the possibility that your child may have SCD. They require even more care and attention and it is crucial that you are ready to provide them the proper tools that will help them live a life that is as healthy as possible.

Once you are ready, you should meet with a genetic counselor or doctor. He or she can provide more information about your specific chance of having a child with sickle cell disease and the options you have to deal with that chance. There is no one correct choice; the answer is different for each couple, and each couple makes decisions for different reasons. It is important that you take the time to consider the options and make the choice that is right for you and your partner.

## More Information About Pregnancy and Sickle Cell

- Should I See A Genetic Counselor?

The best way to find out if and how SCD runs in someone's family is for that person to see a genetic counselor. These professionals have experience with genetic blood disorders. They also specialize in prenatal genetic counseling. The genetic counselor will look at the person's family history and discuss with him or her what is known about SCD in the person's family. It is best for a person with SCD or SCT to learn all he or she can about SCD before deciding to have children. [Click here](#) to learn more about genetic testing and what you can expect.

- Do my medications for sickle cell disease affect my pregnancy?

This answer will also be different for everyone. Doctors strongly advise that hydroxyurea should not be taken during pregnancy. Medicines for pain require a detailed discussion with your obstetrician (doctor who specializes in pregnancy) and your hematologist. Folic acid is fine.

- When is the best time for me to get pregnant if I have sickle cell disease?

There is no right answer for this question because this answer will be different for everyone. The best time will depend on many things including your age, your personal health, your goals in life, and your support system. It is best to carefully plan when you want to try to get pregnant after talking with your family and doctor. Unexpected or surprise pregnancies can be difficult for anyone but especially for someone with sickle cell disease. If you are having sex, it is strongly recommended that you use some form of [birth control](#) until you are ready to have a baby.

## Priapism

Even though there are a lot of symptoms of Sickle Cell Disease specific to women, it is important to know that men are affected as well. Men experience several unwanted symptoms in their bodies, and one such symptom is priapism.

What is priapism?

Priapism is an unwanted, prolonged erection of the penis. It can last for hours and often causes pain. Priapism does not occur because of sexual feelings or desires but rather it occurs when red blood cells sickle, causing a blockage of normal blood flow draining from the penis.

Why should I care about priapism?

The reason that priapism is a cause for concern is because an erection lasting too long can cause permanent damage to the penis. If untreated, priapism can cause impotence, which means that a man is unable to have an erection for sex.

What should I do if I have an erection that won't go down?

If you have a persistent erection, you should:

- Try to urinate.
- Drink plenty of fluids.
- Do some light exercise, such as walking up and down stairs
- Put a cool towel on the penis or soak in a warm bath
- Take pain medicine.

If the erection lasts longer than one hour then you need to immediately go to the emergency room.

Even though priapism can be something uncomfortable for you to see a doctor about, it is very important to go to the hospital. Do not ignore it or try to just deal with it at home. If you have priapism and wait too long to go to the ED, you could cause irreversible and severe damage to your penis. Priapism is serious and not your fault; do not feel embarrassed to get help for it.

Does priapism follow a pattern?

Priapism often occurs as a severe long episode requiring hospitalization and multiple shorter episodes follow, called “stuttering.” Episodes most often come from infection or normal night-time erections. Onset in the early morning, awakening the patient, is common.

## Masturbation and Fathering Children

Is it safe for me to masturbate?

You may be wondering if there are any sexual restrictions that can be caused by priapism. Generally, priapism is not related to sexual activity; rather, it often occurs during sleep. However, priapism can sometimes occur after sex. Despite this fact, masturbation is safe and usually does not cause priapism. If you have any concerns about having sex or masturbation, talk to your doctor.

Will I be able to father children?

Even though fertility is an option, men with sickle cell disease are more likely to have problems with it. Men with sickle cell disease may have a difficult time getting a woman pregnant because sickle cell disease can affect sperm. However, men with sickle cell can get a woman pregnant and father children. If you have concerns about your ability to father a child, talk to your doctor.

Great job! You're another step closer to finishing the CHECK Sickle Cell Online Program. Hopefully you now know more about sexual health and sickle cell.

Now you can move on to the next topic, which talks about how you transition from your parent taking care of everything to having your own health insurance and seeing an adult doctor.

