SPINA BIFIDA ASSOCIATION

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1-800-621-3141
Hablamos español

Sexual and Preventive Health for Women with Spina Bifida

January 2024

What women with Spina Bifida need to know about their bodies, sex, and staying healthy.

Statement on Language

In this sheet, we use the word **"woman"** to mean a person born with female body parts or a vagina. We understand that not everyone born with female body parts identifies as a woman, and not all women have the same bodies.

Anatomy

Most women with Spina Bifida (SB) have bodies that are shaped like other women's bodies. Some women may have differences in how their uterus is shaped. These differences usually do not cause problems but should be checked by a doctor.

Women with SB are more likely to have **pelvic organ prolapse**. This happens when muscles that hold organs in place become weak, and organs push into the vagina or anus. This can happen at any age. If you notice changes, talk to your doctor. You may be sent to a specialist called a **urogynecologist**.

Puberty

Girls with SB often start puberty earlier than other girls. Puberty includes changes like breast growth and hair growing under the arms and in the groin. Families and doctors should talk about puberty early and watch for signs that it is starting.

Sexual Feelings and Sexual Activity

People with SB can enjoy sex and have happy relationships. Feeling and movement can be different depending on where the spinal cord is affected.

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Not all pleasure comes from the genitals. Other areas of the body, called **erogenous zones**, can feel good when touched. These include the lips, ears, arms, and neck. Some people also feel pleasure in areas where feelings change from strong to weak.

It is okay to explore your body in safe ways to learn what feels good to you.

Some women with SB do not make enough natural vaginal wetness during sex. This can cause discomfort. **Water-based lubricants** can help protect the skin and make sex more comfortable.

Some women may not be able to have an orgasm. This does not mean sex cannot still feel good or be meaningful.

Positioning during sex is important. Tight muscles or stiff joints can make some positions hard. Pillows, wedges, or special supports can help. Some positions may not be safe because of bone weakness or breathing problems. Physical or occupational therapists can help find safe and comfortable positions.

Talking openly with your partner about what feels good and what is difficult can help build trust and closeness. Women with SB can have loving relationships, with or without sex.

Bowel and Bladder Care

The nerves that control the bladder and bowels also affect sexual function. It helps to empty your bladder and bowels before sexual activity.

This may mean using a catheter for the bladder or an enema or suppository for the bowels. This lowers the chance of leaks.

Leaks of urine or stool can still happen, and that is okay. Urine is not harmful. Stool can be wiped away with a moist towel. Try to keep stool out of the vagina because it can cause infection.

If stool gets into the vagina, it can be gently cleaned. Douching should not be done often because it can irritate the vagina.

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After sex, empty your bladder again to lower the risk of a urinary tract infection (UTI). If you have frequent leaks or UTIs, talk to your doctor or urologist.

Fertility, Pregnancy, and Safe Sex

Most women with SB can get pregnant and have children. If you do not want to get pregnant, it is important to use birth control.

Birth Control

Women with SB usually have the same birth control choices as other women. Your doctor can help choose the best option based on your health, movement, medicines, and personal needs.

Condoms

Condoms help prevent pregnancy and sexually transmitted infections (STIs). Some people with SB are allergic to latex. If you are unsure, use **non-latex condoms**.

Sexually Transmitted Infections (STIs)

STIs are infections spread through oral, vaginal, or anal sex. Women with SB can get and spread STIs just like anyone else.

Condoms lower the risk of STIs. Vaccines can protect against some STIs, like **hepatitis B** and **HPV**. Medicines like **PrEP** can help prevent HIV.

If you have an STI, your doctor will talk to you about treatment. Your partner may also need treatment.

Pregnancy

Pregnancy can be harder for women with SB and should be cared for by a **high-risk pregnancy doctor**. Seeing doctors before getting pregnant is helpful.

Important things to know:

- Women with brain shunts should watch for signs of shunt problems, like headaches, nausea, or vomiting.

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- Women with curved spines may need breathing tests.
- Kidney health should be checked before and during pregnancy.
- Constipation may get worse during pregnancy. Drinking water, eating fiber, and using safe medicines can help.
- Women with SB have a higher chance of early birth.
- Some women may need help walking or may use a wheelchair during pregnancy.
- Past bladder or bowel surgeries may be affected as the belly grows.
- Women with spinal injuries at or above T6 are at risk for **autonomic dysreflexia**, which is serious and needs special care.
- Women with limited movement may have a higher risk of blood clots.

Folic Acid

Women with SB have a higher chance of having a baby with SB. Taking **folic acid** lowers this risk.

Any woman with SB who is having sex should take **4 mg of folic acid every day**, starting at least 1–3 months before pregnancy and during early pregnancy. This dose needs a prescription. Do not take extra prenatal vitamins to get more folic acid, as too many vitamins can be harmful.

Delivery and Breastfeeding

A birth plan should be made with your doctors. Women with SB can breastfeed but should check that their medicines are safe for breastfeeding.

Preventive Care

Women with SB should get the same health screenings as other women.

Breast Cancer Screening

Women with SB have the same risk of breast cancer as others. Screening is usually done every two years between ages 50 and 74. Other tests like ultrasound or MRI may be used if mammograms are hard to do.

Pap Tests

Women ages 21–65 should get Pap tests every 3–5 years to check for cervical cancer.

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Human Papillomavirus (HPV) Vaccine

HPV is very common. The vaccine is recommended for people ages 11–26. Some people up to age 45 may also benefit.

Sexually Transmitted Infection (STI) Testing

People who are sexually active should talk to their doctors about regular STI testing.

More Information

More information about sex and health is available in the Spina Bifida Association's YouTube channel:

- Adults with Spina Bifida
- Sexual Function and Pregnancy

Updated 1/18/2024 by Amanda Appel, MD University of Colorado School of Medicine

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