

Health Care for Women

What women with Spina Bifida need to know about sexuality, fertility and preventive care.

Sexuality-What if there is bowel or bladder leakage during sex?

In Spina Bifida, bladder function is inseparable from sexual function. Some of the same nerves that control urinary and bowel function are also important in sexual function. Thus, preparing for sex means preparing the bladder and bowels. Emptying the bladder with catheterization and emptying the bowels with an enema or suppository will increase the likelihood for “accident-free” sex. Knowing that a little leakage of urine is harmless to both partners means a small accident is no big deal. Bowel leakage can be quickly cleaned away with a moist towel so it does not get into the vagina. If bowel contents accidentally get into the vagina, this can be cleaned out using a douche. Otherwise, douching is not routinely needed before or after sex. After sexual intercourse, the woman should again empty her bladder to decrease the risk of a urinary tract infection.

For women who do not catheterize, they should also urinate before and after sex. If they still have significant urinary leakage during sex or frequent urinary tract infections, they should talk to a urologist about the possibility of urinary retention. Significant urinary retention is not good for the kidneys and a catheterization program may be warranted.

Is orgasm possible?

The vagina and sex organs can also be affected by Spina Bifida. Sexual arousal may not always induce vaginal lubrication. Thus, it is important to have a lubricant available for the man and the woman to use.

Still other women may have difficulty with intercourse due to physical restrictions from problems with bones, joints and/or muscles that affect movement of hips and legs.

Whether an orgasm is achieved or whether intercourse is physically possible, honesty and open discussion of your sexual experiences as well as your partner's, can enhance your experience and promote a healthy, trusting relationship. Women with Spina Bifida can have happy, healthy sexual relationships, with or without intercourse.

Fertility — Can women with Spina Bifida become pregnant?

Pregnancy is possible for almost all women with Spina Bifida so appropriate contraception is strongly recommended if pregnancy is not currently desired. Because of changes in the pelvic nerves and muscles, pregnancy for women with Spina Bifida is more challenging than in the general population and should be managed by a gynecology team skilled in high-risk deliveries whenever possible. Pregnant women with Spina Bifida should also see their urologist and neurosurgeon in addition to their gynecology team to make sure the pregnancy is not adversely affecting their shunt or kidneys.

- **Contraception** — Women with Spina Bifida have most of the same options for birth control as the general population. Based on all available information, a woman's Spina Bifida level or mobility status does not impact contraception choices, including birth control pills. Of course, age, smoking status, and personal or family history



of blood clots does impact the risk of some birth control choices and should be discussed with the prescribing health care provider.

- **Condoms** — One medical concern is latex condoms. Women with Spina Bifida have the potential for latex allergy so non-latex condoms should be used unless they have tested negative for latex allergy.
- **Folic acid supplementation** — Although not all causes of Spina Bifida are known, women with Spina Bifida are at increased risk of having children with Spina Bifida. Taking folic acid can decrease this risk by up to 70%. Because half of all pregnancies are unplanned, any woman with Spina Bifida who is having sex should take 4 milligrams of folic acid supplementation every day before becoming pregnant, and throughout the first trimester of pregnancy. This is 10 times the recommended dose for women who don't have Spina Bifida, and should be obtained through a prescription from your doctor. You should not take extra prenatal vitamins to get the higher folic acid dose as this would provide too much of the other vitamins.

This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.

Preventive Care — What medical screening is necessary?

- **Breast cancer screening** — Women with Spina Bifida have at least the same risk for developing breast cancer as the general population. Therefore, breast cancer screening should start at age 40 or earlier if there is a family history of breast cancer before age 50 in close relatives. Mammograms may be difficult for those in wheelchairs or with significant spine curvature, but other screening methods are available (including ultrasound and MRI) so all women with Spina Bifida should have some type of screening. Furthermore, self-breast exams should be done every month, and any changes in breast appearance or tissue should be discussed with your doctor.
- **PAP smears** — All women, whether sexually active or not, should have a PAP at age 21, and subsequent tests should occur at two-year intervals until age 30, when the interval can be increased to once every three years for women who have had three consecutive negative tests.
- **Human Papilloma Virus (HPV) vaccine** — Although there are many different types of infections that a woman may be exposed to during sex, HPV is the most common in the US. It is also possible to acquire HPV without having sex. Because HPV infections can increase a woman's risk for developing cervical cancer, all women with SB ages 11–26 are encouraged to receive this vaccine.

Contributing Editor

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More information

More information on both sexuality and sexual function is available in the Health Guide for Adults Living with Spina Bifida available from the Spina BifidaA's Marketplace on our webpage. Also, please read our information sheets on Folic Acid supplementation, Hypertension, Obesity, Type 2 diabetes and Osteoporosis.

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