

Sex and spina bifida

Golden rule 1:

Many people with spina bifida have great sex lives. All should.

Golden Rule 2:

Many people with spina bifida get married and have a family of their own.

Sexual performance and spina bifida: The facts

- The nerve damage in spina bifida that affects urinary and bowel functions may also affect sexual functioning.
- Males may have normal sexual function, but this is commonly affected to some degree. Satisfactory erections are often possible, but there is no ejaculation. Other types of sexual dysfunction are also possible.
- Females are generally less affected in their sexual functioning.
- In males and females, altered genital sensation can affect – but does not prevent – arousal patterns and sexual functions.
- Orthopaedic problems, for example with lower limbs, can affect the ability to use some, but not all, sexual positions.
- Most males and females with spina bifida are fertile. Many of the issues surrounding conception in spina bifida are due to mechanical and anatomical difficulties in conceiving rather than a lack of fertility. There is access to assisted reproductive techniques. Consult your clinic about these.
- Since people with spina bifida often have latex allergies, you and your partner may need an alternative form of contraception to condoms. See your doctor for advice about forms of contraception.
- The major obstacles to a happy sex life are:
 - lack of confidence and self esteem
 - not meeting people
 - no car
 - not seeing 'sex' as being possible
 - incontinence
 - gaining independence from your parents.

All people have a right to a full sexual life. Sex and reproduction are increasingly important for young people as they reach adolescence and adulthood.

Sex and spina bifida: Important questions and positive answers

I don't want to discuss sexuality in front of my parents. I'm too embarrassed.

This is a common concern.

A supportive environment is essential.

You should feel free to ask your doctor or continence nurse for any information about your own sexual functioning when consulting them for routine assessment.

Remember, these professionals have a lot of experience in dealing with sexual issues and will understand any concerns you may have.

The best people to speak to about sexuality, relationships and achieving a meaningful sex life are adults with spina bifida who have 'been there and done that'.

When you first start to talk about sex it will be embarrassing, but after a while you will realise that it's good to do so and that it will help you help yourself!

What about the way my body is 'different' from other people's?

The issues of body image and self esteem that arise in spina bifida profoundly influence a person's sexual expression.

Remember, people with profound disabilities are capable of active sex lives.

Be reassured. Stephen Hawking the famous physicist, has overcome a great physical disability. He has fathered children.

Could my baby have spina bifida?

Yes. If you or your partner have spina bifida your risk of having a child so affected is much greater. Did you know that folate (a safe vitamin) taken by women before and during pregnancy significantly protects against spina bifida?

Genetic counselling is very important for both men and women who want to have a child. A genetic counsellor will explain the risks and the ways of protecting your baby from getting spina bifida and what screening tests can be done during the pregnancy. Your doctor can arrange for you and your partner to see a genetic counsellor before you get pregnant.

spina bifida

Passport to success

Sex and spina bifida: Important questions and positive answers for men

Can males with spina bifida father children?

Yes, of course. Many men with spina bifida are fathers.

Less is known about fertility in men with spina bifida than in affected women.

Men typically have problems with sexual function, which can be overcome.

Most men are fertile and can successfully father children.

What difficulties do men with spina bifida have during intercourse?

The major difficulty is achieving erections and ejaculation.

Difficulty in achieving erection is a common problem and is often easily treatable. Drugs, including Viagra, or injections often work. Physical techniques such as vacuum pumps or surgery are available. If you have difficulty with erections, you should not give up the idea of having sex until you have looked at treatment options.

Ejaculation is often impaired in men and achieving ejaculation is more difficult. Did you know that failure to ejaculate will not have any effect on the pleasure you give your partner?

There are safe methods of artificially collecting sperm which can be used to make your baby. This can be explained to you by a specialist.

Many young inexperienced guys worry that leg weakness will impair their sexual performance using the missionary position (on top). There are many other positions which can be used. Did you know that using these positions will not reduce the pleasure you give your partner?

Golden rule:

Men with spina bifida can have great sex lives and can give their partners as much pleasure as guys without disability.

Having a happy sex life: Case study

Rod is a 34 year old male with spina bifida, shunted hydrocephalus and has used a wheelchair since childhood. He has a urinary diversion and a stoma. He is continent. He has never been able to have an erection or to ejaculate. At 32, Rod formed a stable relationship with a nondisabled woman. He was given Caverject injections (an erection producing drug) and received advice about different positions which he could try during sex, as he has weak legs. He and his wife now enjoy a good sex life and are planning to commence a family.

Sex and spina bifida: Important questions and positive answers for women

Do I have a normal sexual response which is the same as for a woman without spina bifida?

Yes. Although women with spina bifida often report different vaginal sensation, this is not an obstacle to normal sexual responsiveness or your capacity to give pleasure to your partner.

Can women with spina bifida bear children?

Yes. Of course. Many women with spina bifida are mothers. Generally, fertility is not affected in women. In fact, it is important to use contraception to avoid an unplanned pregnancy.

Did you know that a study of women with spina bifida in Victoria found that although special intervention is sometimes needed, pregnancy and child birth is not tremendously difficult and does not do damage to, or worsen, mobility, continence, functioning or shunt function.

There are obstetricians (specialists who care for pregnant women and deliver babies) with experience in spina bifida who can advise and care for you. Your doctor can refer you and your partner to a specialist for advice before you become pregnant as well as for the pregnancy.

I am in a stable relationship and would like to have a child. How will spina bifida affect my pregnancy?

As described above, the course of pregnancy for you is similar to women without spina bifida except for:

- an increased risk of urinary tract infection
- the risk of pressure sores – from the extra weight you are carrying
- an increased risk rate of lower pelvic pain.

Should I have a vaginal or caesarean delivery?

The current recommendation is that you should be encouraged to deliver vaginally. It has been noted that women who have vaginal deliveries have fewer complications, faster recovery times and shorter hospital stays.

Women delivered by caesarean have a higher rate of complications, and surgery can be complicated if there is past history of urological surgery. Your specialist will recommend the best course for you to take.

Golden rule:

Women with spina bifida can have great sex lives and can give their partners as much pleasure as women without disability.