

Sex and Spina Bifida for Men



Sex and Spina Bifida can go together and many men with Spina Bifida are happy with their sex lives. This information is for those who may be having some difficulties. There's a lot of general information out there for disabled people on general topics such as managing continence, positions for sex etc. and we won't duplicate this information – see our Spina Bifida section for useful resources.

Remember....

People in the papers and on TV seem to be having wonderful sex lives but most of us have to work at our relationships and at enjoying our bodies. If you're in a relationship, gay or straight, what matters is what gives you and your partner pleasure and this may not be penetrative sex. Being in a warm and comfortable position, dealing with any continence-linked issues, using sex aids such as vibrators can all help. And a sense of humour... Many of you with Spina Bifida will have had less chance to explore and enjoy your bodies and may have a poor body image. Lack of privacy or continence issues may have given you fewer chances to masturbate and you may have missed out on the playground chat at school:

“My brother always stopped talking about shagging when I came into the room”

Sex education at school may not have covered all you needed to know, parents are often as much in the dark as you are and doctors tend not to tell you unless you ask:

“They don't seem to think I knew or wanted to know about relationships”.

You may find other people with a disability your best source of support and information. Unless you are lucky enough to have a specialist in sexual medicine in your area, your urologist is likely to be the most helpful in dealing with technical questions. Spinal Injuries Unit or Rehabilitation Medicine staff and urology nurse specialists and your SBHI Family Support Worker may also be able to help.

The effects of Spina Bifida

These will vary depending upon the site and extent of the original damage to your spine, which muscles and nerves are affected and the amount of feeling you have. If you have difficulties with your bowel and bladder, you may find some difficulties with sex as well. Effects may include:

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Getting and Keeping an Erection

This may be caused by your Spina Bifida or other conditions such as diabetes but can also be affected by whether you are feeling anxious, self-conscious or tired. Different treatments are available depending on the type of difficulty you're having. Your doctor may want you to have a blood test to check your levels of testosterone, a hormone which can affect your body and feelings in different ways. The effects of some medication, nicotine and drug use can also be important.

Treatments can include:

Injections:

Some treatments are given into the penis by injection. Prostaglandins, such as Alprostadil, have a high success rate with a quick response and few interactions with other medication.

Papaverine has a lower success rate. Such treatments may be given at spinal injury units, urology clinics, or rehabilitation centres. You, or your partner, can learn to give these injections. There may be a risk of scarring, and the penis becoming misshapen (called priapism) or having a prolonged erection. There may be medical reasons why treatment is not suitable in your case.

Alprostadil can also be given without injection, as a pellet in the urethra (Muse) but this has a much lower success rate and can also cause priapism, pain in the penis, and irritation to your partner's vagina/mouth.

Drugs:

Such as Viagra and Cialis are available on prescription in limited amounts for people with Spina Bifida. A doctor who knows you will know whether there are any particular risks (such as a history of heart disease) for you in taking these and it is important for you to have a thorough physical examination in the area of your genitals to check there are no problems before starting to take them. They are available to buy privately on the net but you are advised not to do this – you may not always get the genuine article. There is some evidence that these have also boosted the sexual confidence of men with Spina Bifida using them. You need to take them at least 20-30 minutes before you hope to have intercourse and they will not work on their own: you need to have the usual foreplay to help you become aroused. If they don't seem to work for you, try them out on three separate occasions before giving up and check with your doctor whether a different dose can be tried.

Sex and Spina Bifida for Men



Vacuum devices:

The penis is placed in a tube in which a vacuum is artificially created and blood is drawn into the penis, giving an erection. A constricting band is placed on the base of the penis to hold the blood in the penis and help the erection to last. They give a softer erection but enough for penetrative sex. They can be fiddly to fit and need practice and persistence. Newer models have an electric rather than a manual pump. If you have reduced sensation, you should not leave one on too long and should check your skin and pressure areas around the penis. Some vacuum devices are available on prescription from a GP.

Some men, who can get a partial erection but want to maintain it, use just the ring part of the device and you can buy something similar in sex shops but need to be sure that you have the right size.

Surgical implants:

These are usually a last resort and you would need to be fit for surgery which would be carried out by a urologist. Older models involving a silastic (like flexible plastic) implant into the penis give you a permanent erection allowing penetration but not sensation or ejaculation. Newer models into the groin and penis allow you to press part of the implant in the groin to give an erection when needed and release it afterwards. Again they do not improve sensation or ejaculation.

Premature Ejaculation

This is 'coming' earlier than you'd like. When you're masturbating, this may not matter so much to you but, if it is a problem for you or your partner, you may be helped by learning to understand your body signals or through some counselling or behavioural therapy. Medication may be considered as part of managing the problem. You may be able to find help with this through a local specialist clinic or Spinal Injuries Unit or through your urologist or urology nurse specialist.

Slow Ejaculation

When you're unable to come to orgasm or it takes an age. Again, this may not happen when you're masturbating and it might be caused by Spina Bifida or by how you're feeling or a mixture of both. In some cases it may be caused because the nerve supply is damaged so that you don't get the contractions that lead to orgasm or get the full sensation of orgasm. Again, remember that many people who have difficulty with penetrative sex can still have very good sex lives, finding pleasure in other areas of the body.

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Retrograde Ejaculation

This is when semen goes back into your bladder instead of out through your penis. It doesn't do any harm but can make your urine look cloudy when you next empty your bladder. It might be important for you if you hope to have children, and there are alternative ways of collecting your sperm. (See Fertility below).

Fertility

There are many proud fathers with Spina Bifida but, if you're worried about this, you need to discuss it with your GP, urologist or other specialist who may run some tests to check that all is well with your sperm count. If it's low or if you have difficulties with retrograde ejaculation (above) you may need to ask about referral to a specialist sexual health or fertility clinic or Spinal Injuries Unit.

Contraception

If you are using condoms, remember to get latex-free ones – available from Durex. And finally.....SAFE SEX is important for everyone, straight or gay and whether you're having full intercourse or oral sex. You are as likely as anyone else to pick up a sexually transmitted infection but, if you have reduced feeling, may not recognise it as quickly. Again remember to use latex-free condoms to avoid any possible allergic reaction.