

## Sex and Spina Bifida for Women



Sex and Spina Bifida can and do go together and many women with Spina Bifida are happy with their sex lives. Others may have some worries and this information is for them. There's a lot of general information out there for people with a disability on 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. This may not be penetrative sex (penis into vagina). Many people get equal pleasure from oral sex (using your mouth, licking, sucking or kissing to pleasure your partner) or from being touched, stroked or massaged. 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...

Some of you with Spina Bifida may feel unhappy about your body and how you look and worry that no-one will want to have a relationship with you. Lack of privacy or continence issues may have given you fewer chances to explore your own body and you may have missed out on teenage chat about sex.

Sex education at school may not have covered all you needed to know and often it isn't easy to talk to your parents about sex. Your non-disabled friends might think that you're not able to enjoy sex or have children. You might find other disabled people your best source of support and information. Other sources of help might include urology nurse specialists, spinal injury or rehabilitation unit staff, sex therapy services, a friendly gynaecologist or some family planning clinics.

### Some of the main concerns for Women with Spina Bifida

#### Fear of getting into a relationship.... when to tell?

When do I tell my partner that I have continence difficulties or show the parts of my body which might be scarred or unusually shaped? Do I do it straight away and maybe frighten them off? Or do I wait until I feel I can trust them and run the risk of being really hurt if the relationship ends? While we all know that relationships have to be worked at and you don't have to have sex on your first date, we're also aware of all the pressures on people to be sexually active and experiment and this may be difficult for disabled people. There are no magic answers to these questions but it might help for you to think about it a bit in advance and maybe discuss it with disabled friends. You can see around you that

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there are many disabled people whose partners find them sexually attractive but also that personality is often much more important than looking perfect.

### **I don't want a disabled partner.....**

Keep your options open. Try and approach other people the way you'd like them to approach you – without prejudice. Disabled women who have had both disabled and non-disabled partners will tell you that there are advantages and disadvantages both ways. Some disabled women with non-disabled partners don't want their partners to be their carers too as they feel this changes their relationship.

### **Managing bowel and bladder control:**

This is a really important issue for many women with Spina Bifida – not just for sex but in your everyday life and work. Good personal hygiene is vital. You might feel that having to follow the suggestions below will take all the spontaneity out of lovemaking: it's probably true but being wet or soiled isn't very romantic either.

If you have difficulties with bladder control, you might find it helpful to avoid drinks for a few hours before having sex. If you can empty your bladder normally (but maybe without much warning) or you use self-catheterisation, make sure you pass urine before making love. If you have difficulties with bowel control, try to make sure that you have used a washout, suppository, enema or carried out your usual routine. Some people find anal plugs can stop leakage from the bowel.

If you have a urostomy or a colostomy, again, empty your bag and try to make sure it's secure. You may want to experiment with positions for lovemaking – maybe on your side or on top of your partner - to reduce the pressure on the bag. If you don't like the sight of it, you might want to cover it – which would also stop it chafing your partner's skin - or wear sexy underwear. If you have a colostomy, you may want to watch what you eat in the hours before having intercourse: you will know what to avoid.

If you have an indwelling catheter, remember that it is placed in the bladder outlet (the urethra) and not in the vagina so shouldn't affect your ability to have vaginal sex. Again, you might find it helpful to lie on your side. With a female length catheter, you can tape it to one side or cover it if you wish. You might be able to spigot or clamp the end of the catheter and remove the bag. Some people with indwelling catheters learn to take them out temporarily during intercourse.

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### What should I be feeling?

Some people with Spina Bifida will have no feeling in the lower parts of their bodies. For some, it might be patchy. Others will have good feeling. Just because there isn't sensation in some part of your body, don't forget it is there!

Young children explore their bodies from a very early age but this is often more difficult for disabled children who might always have adults around or have to wear pads or nappies. You may have had so many professionals and carers looking at your body, touching it and treating you as if you were not a sexual person that you have switched off from it.

Get to know your body. Make sure you have privacy and can relax; explore the different parts of your body: touch, stroke, squeeze and tickle it. Get to know your genital area but, even if you have no feeling there, there is a good chance you might enjoy being touched or massaged on the breasts, ear-lobes, neck, back, lips or palms of your hands. Maybe you will get excited from using certain words, using different materials such as silk or feathers, dressing in a certain way or fantasising. Talk to each other about what you like and dislike. Only you will know what makes you feel good and, when the time comes, you will be able to show your partner how to give you pleasure and learn what turns your partner on. Some women who do not have good sensation do not want their partners to touch, kiss or bite some areas where they have no feeling or like their partners to tell them when they've reached climax.

Usually, as she becomes sexually aroused, a woman's genitals will become wet. If you have Spina Bifida this might not happen and you may need to use a water-based lubricant such as KY Jelly, Boots Lubricating Jelly, Astroglide, Sensilube, or Ann Summers XY jelly. If you have some sensation, this will probably increase the pleasure you feel. It will also make it easier for you to have penetrative sex or be stimulated by a finger. If you do not have much feeling, it might prevent you being hurt without realising it by enthusiastic sex. If you have limited sensation and use a vibrator, use it with care. You can buy waterproof vibrators if continence is a problem.

### How do I do it – positions for Sex

You will need to experiment to find out what is most comfortable – and possible - for you. Lying face to face, or like spoons (back to front), using pillows to prop up your hips, sitting on your partner or your partner on you may be better than the missionary position (one partner lying on top). "Sex Matters" and "The Ultimate Guide to Sex and Disability" have more detailed information on this area. See our Spina Bifida Resources section for information on where to source these books

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If you have fragile bones, you might want to think about the positions which are safest for you or might not want your partner to move you without warning – this can help to make you feel that you are in control.

### Can I get pregnant?

Work on the basis that you can, though there will always be some women who cannot conceive or bear a child. Some women with Spina Bifida will need to deliver by Caesarean section. If you don't want to be pregnant, see the section below on contraception. If you do, consult with a friendly obstetrician or gynaecologist in a specialist centre will often agree to see you, if you have particular medical concerns, before you try to get pregnant. Taking 5mg of folic acid a day for at least three months before trying to get pregnant should reduce the chances of you having a child with Spina Bifida. You have to get this dosage on prescription.

Contraception: details of the many methods used can be found through your GP or local family planning clinic

Some issues which might affect your choice include: whether you are taking medication such as anti-convulsants (such as Epilim) or anti-coagulant drugs (e.g. Warfarin); whether you are a wheelchair user and therefore might have a higher risk than normal of thrombosis, whether you would have any difficulties remembering to take a pill every day and whether you have good manual dexterity.

If your partner is using a condom, a latex-free one such as Durex Avanti is recommended. 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, you may not recognise it as quickly. Again remember to use latex-free condoms