

FACTSHEET

This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form.

Relationships and Sexuality

Relationships

Meeting new people and trying new things will create opportunity for you to meet someone special. Remember, the more independent you are the easier it will be to start and maintain a relationship.

Relationships are complex and usually require time to develop. Always remember to keep yourself safe when meeting new people through social networking sites or dating websites.

You may experience additional challenges when becoming sexually active. These include:

- How to manage the bladder and bowel during sexual activity.
- For men, getting and maintaining erections can be difficult as can positioning your body for sexual activity.
- Lack of general knowledge about sexual activity.
- Opportunity to meet others socially may be limited.
- Confidence and self-esteem
- Lack of independence from parents or caregivers.

Finding a partner who you can trust, be comfortable with and explore your sexuality with will enhance not only your sexual experiences but many other aspects of your life.

Some people may not be ready for information about sex or may not want to openly discuss relationships or sexuality with parents or health professionals. There are lots of resources and information available when the time is right. It is important to ask questions to get the information when you are ready.

Contenance and Sexual function

Managing the bladder and bowel is very important for sexual function and good hygiene. Discuss any concerns you have about your continence with your doctor or nurse. Maintaining good continence for sexual function includes:

1. Emptying your bladder and bowel before sexual activity.
2. Have an open discussion with your partner about your concerns. This will help you feel prepared in the case of an accident.

Positioning and Sexual function

Sexual positions that suit your individual needs should be explored. Take care with:

- Stomas and catheters
- Lower limbs
- Skin with decreased sensation.

There are helpful aides which may assist with positioning for satisfaction. You may like to discuss a stretching program with your physiotherapist to improve your flexibility.

Fertility and Sexuality

Fertility and sexuality are two separate issues. Spina Bifida does not impact a woman's ability to fall pregnant. Protection should be used to avoid unplanned pregnancies and sexually transmitted diseases.

Some men with Spina Bifida can produce children without any medical help. Others may require assistance to father children depending on their ability to ejaculate. This can be explored in more detail with your doctor and a referral to a fertility clinic as required.

Further information about sexuality and Spina Bifida is available at:

- The American Spina Bifida Association has a series of useful fact sheets and web based material. Download for free from: www.spinabifidaassociation.org
- Spinal Cord Injury has a variety of resources about sexual function and erectile dysfunction that may be of interest. Fact sheets are available at www.aci.health.nsw.gov.au/networks/spinal-cord-injury/resources.
- ParaQuad NSW has a series of factsheets including sexual function and fertility available online at www.paraquad.org.
- Information about the intimate rider can be found at www.intimaterider.com/sex-aid-for-the-disabled.
- Shine Charity have information about spina bifida and frequently asked questions about sex. You can access them for free at: www.shinecharity.org.uk/spinabifida/information-publications/sex-questions-you-may-ask.
- Spina Bifida Hydrocephalus Ireland have developed good fact sheets called "Sex and spina bifida for men" which are available for free www.sbhi.ie/images/Sex-for-Men.pdf.
- Spina Bifida Hydrocephalus Ireland have developed good fact sheets called "Sex and spina bifida for women" which are available for free www.sbhi.ie/images/Sex-for-Women.pdf.

Video resources include:

- *Untold Desires*, Stephens, Sarah (Director)
- *Sexuality Reborn: Sexuality following Spinal Cord Injury*, Kessler Institute for Rehabilitation. USA. 1993
- *Talking about sexual issues and spinal cord injury: a guide for professional caregivers*, BC Rehab 1990.

Remember:

- There is information available about sexuality.
- Sexual curiosity is normal and sexual health is important.
- Be aware of sexually transmitted diseases (and how to prevent them) and unwanted pregnancy.
- Practice good hygiene.