Chapter 8: Sexuality and reproductive issues

Managing issues of incontinence inevitably raises issues of sexuality. The complications of spina bifida that affect urinary and bowel function also affect sexual functioning. Routine review requires regular assessment of sexual issues while taking into account any special needs. This chapter highlights some of the common issues general practitioners need to know when treating people with spina bifida.

Key issues for clinicians

- Spina bifida affects sexual function.
- Fertility is often normal in women.
- Vaginal delivery is the preferred method of delivery. A urologist should be present during a caesarean section, especially if there has been past urological surgery.
- There can be problems with erection and ejaculation in males. Ejaculation difficulties are a significant barrier to conception.
- Treatment is available for males with spina bifida.
- Assisted reproductive technologies may be of help in achieving pregnancies.

Clinicians involved in the management of spina bifida need to create an open, nonjudgmental environment that is favourable to the discussion of issues of sexuality. Dealing with issues of incontinence control inevitably raises questions of sexuality and the clinician needs to be prepared to deal with such important issues.

Self esteem issues of spina bifida impact upon sexuality

The issues of body image and self esteem that arise in spina bifida profoundly influence a person's sexuality, but even people with profound disabilities are capable of active sex lives. Creating a safe environment for discussing and dealing with such issues helps to foster a sense of personal wellbeing and to promote healthy sexuality.

Creating an open environment for discussing sexuality

General practitioners can greatly improve the quality of life of their patients with spina bifida by providing a supportive environment for the discussion of sexuality.

Providing permission to discuss sexual concerns helps to normalise sex and helps to overcome fears and isolation that patients may have about sex. This is especially important for young people who are in the process of becoming independent from parents and carers, and who might not otherwise have the opportunity to discuss sexual matters.

Taking the time to listen to sexual concerns validates the fact that the clinician is prepared to help deal with sexual issues. While the GP may not have the expertise or resources to deal with complicated issues of sexual function in spina bifida, demonstrating a commitment to listen enables the GP to detect any concerns early, and then refer the issues to a sexual counselling clinic if necessary.

Providing simple suggestions may be all that is necessary in some cases to assist some sexual problems. As feelings of isolation are common in sexual health

problems, minor concerns can often become major sources of anxiety. Patients may just require simple information about sexuality, such as what menstruation or a nocturnal emission is, to reassure and normalise their sexual concerns.

Many patients will require intensive therapy for specific sexual problems, and this can be arranged through specialist spina bifida clinics for adults or young people.

Privacy concerns and young people

Some young people may not want to discuss sexual health issues when accompanied by their parents. Clinicians may need to indicate to a young person that they are prepared to discuss sexual health problems in the absence of their parents, although considerable diplomacy and tact may be required with the parents when dealing with this sensitive issue.

As long as clinicians are aware that privacy may be an issue, then strategies for achieving this are likely to evolve.

Effect of spina bifida lesions on sexual function

The effect of spina bifida lesions on sexual function varies widely between patients, and often the best way to assess function is through a neurological opinion. This can give a prognosis of the person's anatomical and physiological sexual function, which can provide the basis for developing management strategies during subsequent sexual counselling.

Males may have normal sexual function, but are commonly affected to some degree. Satisfactory erections are often possible, but without ejaculation. Other types of sexual dysfunction are also possible. In some cases, circumcision may be considered appropriate.

In males and females, issues of altered genital sensation can affect arousal patterns and sexual function.

Orthopaedic problems, for example, with lower limbs can affect the ability to use certain sexual positions.

All of these physiological and anatomical issues and others need to be taken into account when counselling on sexuality issues.

Safe sex

Safe sex education needs to take place in the early teen years, as precocious puberty is very common in people with spina bifida.

> The high risk of neural tube defects in pregnancies of women with spina bifida makes safe sex education — in a style and content appropriate to the individual — mandatory prior to the onset of sexual activity.

Safe sex education needs to be adapted to the special physical and cognitive needs of the individual with spina bifida.

For example, the use of some types of contraception, such as condoms, requires good hand–eye coordination. Problems with coordination and manual dexterity need to be taken into account when recommending specific types of interventions.

Similarly, the cognitive effects of spina bifida (see *Chapter 2*) need to be considered when educating about safe sex.

Sexuality, conception and pregnancy issues

Issues for women

Although women with spina bifida often report altered vaginal sensation, normal sexual response is often possible.

Spina bifida generally does not affect fertility in women, and contraception and preconception counselling is therefore paramount to decrease the risk of unplanned pregnancies and neural tube defects.

The course of pregnancy in spina bifida is similar to that in women without spina bifida except for:

- an increased risk of urinary tract infection
- a risk of pressure sores
- an increased rate of lower pelvic pain.

The current recommendation is that pregnant women with spina bifida be encouraged to deliver vaginally as women who have vaginal deliveries have fewer complications, faster recovery times and shorter hospital stays.

Women delivered by caesarean section have a higher rate of complications, and surgery is often complicated if there has been past urological surgery for spina bifida. The presence of pelvic scarring often makes identification of ureters and other structures difficult.

> A urologist should be present to assist the obstetrician during a caesarean section, especially in the presence of prior urological surgery in women with spina bifida.

Is there an increased rate of birth abnormalities?

Potential parents will want to know about the possibility of birth defects, especially in view of a mother affected with spina bifida. Apart from the increased risk of neural tube defects, the question of whether there is an increased risk of birth defects is unknown.

Newer fertility techniques such as fertility drugs and in vitro fertilisation techniques are sometimes used in

people with spina bifida in conjunction with specialist spina bifida clinics.

Issues for males

Less is known about fertility in men with spina bifida than in women. Undescended testes are more common in men with spina bifida and this can contribute to poor fertility. In addition, repeated catheterisation may result in scarring and past epididymoorchitis infections from repeated urethral instrumentation can also decrease fertility.

However, men with spina bifida can still father children, although they may require the use of assisted reproductive technologies.

The major difficulties associated with conception in men with spina bifida are associated with achieving erection and ejaculation.

Difficulty in achieving an erection is a common problem for men with spina bifida, and while this may be treatable in some men, achieving ejaculation is more difficult.

The lower the level of the lesion, the more likely it is that the male will be able to achieve an erection.

Lack of erections can be treated by using physical techniques, such as vacuum pumps, pharmaceuticals such as sildenafil or prostaglandin injections such as Caverject, and with surgical techniques such as penile prostheses. Issues of cost of treatments become important for patients, especially if they are on a low income or a pension.

Ejaculation in many men with spina bifida does not usually occur during sex. Ejaculation using vibro-ejaculation and electroejaculation techniques often has low sperm counts, resulting in a reduced conception rate.

Case study: male sexual dysfunction in spina bifida.

Rodney, a 34 year old male with spina bifida at L2–3, shunted hydrocephalus and mild intellectual disability has been wheelchair bound all his life. An ileal conduit was constructed when he was a child.

At 34 years of age, Rodney formed a stable relationship with a nondisabled woman. He had never been able to have an erection or to ejaculate. He was prescribed Caverject injections and was counselled on how to optimise pleasure from intercourse, given his severe impairment of mobility. He and his partner enjoy a happy and fulfilling sexual life and are planning to commence a family.

Assisted reproductive technologies

Many of the issues surrounding conception in spina bifida are due to mechanical and anatomical difficulties in conceiving, rather than a lack of fertility. Access to, and use of, assisted reproductive technologies may be of benefit to parents with spina bifida.

Preconception counselling

Preconception genetic counselling to decrease the risk of neural tube abnormalities in offspring (see *Chapter 2*) is generally well accepted by patients and families prior to the young person becoming sexually active.

This can provide a good opportunity for the clinician to demonstrate and emphasise that they are prepared to discuss sexual health issues at any time.

Specialist spina bifida clinics can refer at-risk patients to clinicians experienced in managing pregnancy in women with spina bifida.

Psychological and social issues

Young people with spina bifida and independence

Sexuality is an area where young people with spina bifida often take their first steps toward independence from their parents, family and carers.

Family relationships can be disrupted when a young person begins to become sexually active. Close relationships form between parents, carers and children from many years of intimate contact that is required for the successful management of spina bifida. This relationship is often tested at this time of increasing independence as new boundaries become established.

These issues are further complicated because even when adulthood is achieved, some level of dependence may need to remain. Disharmony, disputes and tense relationships are common, and the GP is in an ideal situation to provide support through this time.

Ending isolation — peer support and finding partners

Young people and adults often feel isolated when affected by spina bifida. Not only do they feel personally isolated due to their disability, but they may have real issues of physical isolation due to difficulty in independent transport which prevents meeting others and prospective friends and partners.

The increasing move towards incorporating disability care into mainstream organisations has increased this isolation for many. In the past, when people with spina

bifida may have been educated together, mutual support and sharing of coping strategies was common.

Peer support — spina bifida associations

Many people with spina bifida find that peer support organisations — such as spina bifida associations — are one of the best ways of overcoming this isolation. These organisations facilitate contact between members through regular newsletters and events, thereby providing opportunities for socialising.

Spina bifida associations are more than just social groups — they create a forum where affected people can offer each other mutual support, identify important common issues which then become the basis for community education and political movements. Some patients become very active in these organisations and find participation a very fulfilling part of their lives.

General practitioners can assist young people and adults with spina bifida deal with issues of social and personal isolation by encouraging them to join their local spina bifida association (see *Chapter 9 Organisations and further resources*).

Further resources

Specialist spina bifida clinics can refer to appropriate sexual counselling clinics if the need arises.

Family planning clinics manage contraception issues for people with disabilities, and are often located close to families.

Reference

1. Bolt J. Meeting life's changes. Sexuality and reproduction in males with spina bifida. Royal Children's Hospital: Melbourne. 2001