



ACI NSW Agency
for Clinical
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NSW State Spinal Cord Injury Service

CLINICAL GUIDELINES

Sexuality following spinal cord injury

State Spinal Cord Injury Service



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Abbreviations

ACI	NSW Agency for Clinical Innovation
AD	Autonomic dysreflexia
GTN	Glyceryl trinitrate
LMN	Lower motor neuron
PBS	Pharmaceutical Benefits Scheme
PDE5	Phosphodiesterase type 5
RNSH	Royal North Shore Hospital
SCI	Spinal cord injury
STIs	Sexually transmitted infections
UMN	Upper motor neuron

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Section 1

Introduction

Spinal cord injury (SCI) disrupts motor, sensory and autonomic pathways which, depending on the level and extent of neurological impairment, affect many aspects of the injured person's life, including their sexuality. Sexuality is a complex human phenomenon involving aspects of physiological and psychological functioning. The World Health Organization defines sexuality as a

'... central aspect of being human throughout life that encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. It is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviour, practices, roles and relationships. It is also influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors' (1).

After a spinal cord injury, a person may still have the same desires for sex, being in a sexual relationship and having children as before the injury; their desires may be similar to those of their peers. Although a spinal cord injury most certainly affects the person's sexual and reproductive behaviours, people with spinal cord injury remain sexual beings and can continue to participate in sexual activity. Given that sexuality is an important part of quality of life, and both men and women with spinal cord injury consider sexuality to be a high priority (2), it is important that health professionals actively address sexuality. Many studies have shown that most people with spinal cord injury want to receive information about sexuality, sexual life and fertility, and that education should be provided during rehabilitation and throughout their life. Neglecting this important topic may lead to poor self-esteem and body image, reduced intimacy and relationship difficulties.

Section 2

Psycho-social aspects of sexuality and management

The psychological and social consequences of spinal cord injury are closely related to sexual adjustment and satisfaction after injury. Emotional distress and depression following injury, lowered self-esteem and feelings of being physically unattractive may lead to withdrawal from social and sexual intimacy, deterioration of an existing relationship and/or reluctance to commence a new relationship.

Expression of our sexuality is a very private and personal part of our lives and this should be acknowledged by health professionals providing sexuality education. The broad range of options for sexual expression and pleasure should be discussed in a straightforward and non-judgemental manner. Both the person with spinal cord injury and their partner will need sufficient factual information to enable them to cope with the physical and psychological hurdles.

Individuals with spinal cord injury should be encouraged to widen their sexual repertoire beyond penetrative genital intercourse to increase the opportunity for sexual satisfaction (3). This may include sexual intimacy and pleasure without penetrative genital intercourse; different positions for sexual intimacy; the incorporation of all senses into a sexual interaction, such as pleasurable smells, tastes and auditory stimulation (such as music); the use of fantasy; and the use of sex aids.

As sexuality is discussed, health professionals should note the individual's readiness to learn. While encouragement to experiment and have fun is important, the individual should not be unduly pressured to do so. After all, sexual education and counselling aims to affirm that spinal cord injury need not be associated with a loss of sexuality. An individual's perception of failure due to lack of readiness may only reinforce their belief that he or she is asexual.

Communication is important in any relationship and is paramount for people with spinal cord injury. The importance of positive communication skills and the ability to communicate fears, feelings and desires are important aspects of treatment. People with spinal cord injury (and their partners) may find that honest, open communication, including the willingness to hear a response, enhances their relationship. Open communication can also prevent people making incorrect assumptions or avoiding discussions about sexuality and the impact of spinal cord injury. Health professionals can help people with spinal cord injury to practise what they may want to say through role playing, encouraging them to write it down and/or rehearsing in front of a mirror.

People with spinal cord injury and health professionals hold many myths and misconceptions about sexuality. Being aware of these, and helping people with spinal cord injury to understand the true situation, is a great starting point in facilitating the reconstruction of sexuality. Common myths and misconceptions (4-7) include but are not limited to the following.

- Sexual activity needs to be natural and spontaneous.
- Talking and planning sexual activity takes away the mood.
- Penile–vaginal penetration is the only worthwhile form of sexual expression.
- Maleness and femaleness are linked to sexual competence, attractiveness and roles.
- Urinary incontinence equals genital incompetence.
- Absence of sensation equals absence of feelings.
- People with spinal cord injury are asexual and cannot enjoy sex.
- It is wrong for people to masturbate and/or use sex aids.
- Female sexuality is passive and male sexuality is active.
- It is easier for women with spinal cord injury to adapt to sexual changes than for men with SCI.

One factor that may affect adjustment to changes in sexuality is adherence to traditional masculine and feminine norms. For example, men who adhere to scripts of masculinity that define their self-worth based on their strength, independence, sexual capacity and potency may have greater difficulty adjusting to their injury because the changes in their bodies directly affect those attributes (6, 8). Similarly, women who define their self-worth in relation to body attractiveness may also struggle with adjustment in comparison with women who measure their self-worth on other personal attributes, such as personality, intelligence and/or skills. Understanding the male and female scripts that people with spinal cord injury may be adhering to, and exploring the impact of these, may facilitate positive sexual adjustment following spinal cord injury (8).

Acknowledgement of changes and losses following spinal cord injury is of utmost importance. Encouraging a positive outlook and exploring the impact and consequences of a negative outlook on the person with a spinal cord injury (and their partner), without devaluing the losses, may be useful in facilitating sexual

adjustment. In addition, people with spinal cord injury should be encouraged not to compare their current sexual performance with previous sexual performance (especially that based entirely on penile–vaginal penetration) as this may result in continual disappointment and limit their ability to explore the broader aspect of sexuality and achieve sexual satisfaction.

Peer counselling by individuals with spinal cord injury who have made sexual adjustments may also be effective in facilitating sexual adjustment when provided at an appropriate time during the rehabilitation process (possibly after discharge from the rehabilitation inpatient service).

A child with a spinal cord injury may need to be reassured that they will grow and mature like any other child and will develop all of the secondary characteristics of sexually mature adults. Specialised counselling may be required during puberty because all the normal concerns of adolescents may be exaggerated by the disability.

Section 3

Physical aspects of sexuality and management

All aspects of sexual intimacy and activity should be discussed with people with a spinal cord injury, including planning, foreplay, general pleasuring (including touching), achieving and maintaining an erection, ejaculation, lubrication, orgasm, positioning for loss of mobility or spasm, bladder and bowel management, orogenital sex, self-exploration and stimulation and the potential risk of autonomic dysreflexia in those with lesions above T6 (9).

Healthcare professionals should emphasise to people with spinal cord injury that it is okay to experiment and practise. The emphasis should be on having fun and enjoying intimacy rather than focusing on sexual performance as known prior to the injury.

People with spinal cord injury should be encouraged to explore other areas of the body not commonly associated with sexual pleasure. With time, neuroplasticity occurs in the spinal cord and ascending sensory pathways after injury; areas that were not previously sexually arousing can become arousing when stimulated under sexual circumstances (10, 11). Areas such as the head, hair, face, ears, neck, chest, abdomen, back, arms, underarms, hands, fingers and toes may cause sexual arousal and orgasm with adequate stimulation (12). Stimulation of the skin just below the last area of skin with altered sensation, known as the 'transition zone', may also be a source of sexual pleasure. Individuals should be encouraged to explore this zone and determine the best method for receiving sexual pleasure to this area (13). Experimentation with various sensations, such as soft or firm intimate stroking, licking, kissing, using vibrators, ice cubes and/or different foods (such as chocolate sauce), may be useful. Techniques such as sensate focus exercises, pleasure mapping, self-pleasuring and/or tantra may be useful in providing

some structure for individuals or couples to follow (7, 14). To summarise, self-exploration and cognitive reframing may maximise sexual perceptions and the potential for orgasm through neuroplasticity.

Information on possible sex positions can be conveyed using stick figures, pipe cleaners set up as male and female or demonstration with individuals fully clothed. Pictures such as those outlined in the *The new joy of sex* (15) are also a useful source for conveying information and encouraging experimentation. Aids such as pillows, bolsters, silk sheets, lubricants and the Intimate Rider swing chair (www.intimaterider.com) may also be useful for mobility and positioning during sexual activity, but training in appropriate use is very important. For example, the Intimate Rider will not help with sexual positioning and mobility in individuals who have poor trunk control. Education should also be provided on the impact of impaired sensation and the possibility that joints could be placed in extreme positions that may be detrimental to them (for example, causing hip dislocation) (16).

Spasticity is common in people with spinal cord injury. It can cause thigh adduction or hip and thigh flexion, which can make positioning difficult. Gentle stretching before sexual activity may be helpful, and could be incorporated into foreplay, followed by positioning the legs in a position that causes the least stretch to avoid precipitating spasms. Taking antispasmodics prior to sexual activity may help reduce spasms but may also affect erectile function. Sexual activities in a wheelchair with the arm rests removed could be considered when hip and knee flexion spasms are pronounced, provided there is sufficient truncal strength and balance (17). While wheelchairs do have their advantages for sexual activity for both men and women with spinal cord injury, education about safety measures, such as using anti-tip bars, ensuring the power is off, complying with the manufacturers' weight limits and positioning the chair next to a wall or sturdy piece of furniture, are paramount in avoiding mishaps (16).

3.1. Bladder and bowel management

The nerves S2, S3 and S4 involved in sexual responses (see section 4. Sexual function) are also involved in bladder and bowel emptying. It is therefore possible that the person with spinal cord injury may have a bladder or bowel accident during sexual activity. Understandably, this is a high source of anxiety (18). Education and counselling about the importance of maintaining bowel programs and emptying the bladder before sexual activity should help prevent this. Despite this, people with spinal cord injury need to understand that, no matter how prepared they are, there is a chance of a bladder or bowel accident. Strategies that may be helpful for people with spinal cord injury include discussing with partners their feelings (and their partners' feelings) about this, and developing a management plan in case a bladder or bowel accident should occur. Advanced planning could include having towels close by or protective sheets on the bed. People commencing a new relationship may wonder if, how and when to introduce the subject. While there is no universal right way to do this, behaviour rehearsals where people practise how to raise the topic and prepare for negative as well as positive responses may increase their confidence.

Education about attention to hygiene and the negative impact of urine and faecal smells is important, especially when odours are noticeable.

For people with indwelling urethral catheters, these may be able to be removed before, and reinserted after, sexual activity. Alternatively men can fold the catheter down beside the erect penis and apply a lubricated condom. Females should be educated about their body anatomy, where the catheter is inserted and that vaginal penetration is still possible.

Both urethral and suprapubic catheters should be taped down to prevent tugging or pulling on the catheter during sexual activity. Leg bags may be removed and it may be possible to apply catheter valves or clamps. Alternatively, leg bags that remain attached should be emptied to prevent urine spillage in case the bag breaks during sexual activity.

The impact of catheters and drainage bags on body image should be discussed and suggestions made to help the person feel more sensuous or sexy. Women may like items such as negligees and crutch-less undies, which can hide the catheter and enhance feelings of attractiveness and/or sexiness. For men, wearing a T-shirt or a silk sash around the abdomen may hide suprapubic catheters.

In addition to emptying the bowel before sexual activity and discussing the possibility of a bowel accident to help with minimising the emotional trauma if one should occur, some people with spinal cord injury may be able to use rectal plugs during sexual activity.

3.2. Sexual assistive devices (sex toys)

While sex toys are not for everyone, they can be useful for people with motor and sensory impairments. Vibrators can be particularly useful for providing pleasure. There is a wide variety of vibrators, from those that can be worn on a hand or finger to those that go around the waist, and a wide range of varying vibrations. Small silver bullets can be put in gloves and larger vibrators can be attached to hands or legs. There are also many other devices that can assist people with spinal cord injury.

Explaining that the person with spinal cord injury will need more sensory and proprioceptive stimulation that may be able to be delivered through a sex aid can make the topic more acceptable. Sales people in sex shops are often happy to discuss their products and to make suggestions. Other sources of information include the Independent Living Centre NSW (www.ilcnsw.asn.au) and the resource titled *PleasureABLE: sexual device manual for persons with disabilities* (19). Healthcare professionals should emphasise that it is important to follow the manufacturer's instructions for cleaning sex toys and clarify the type of lubricant that may be used.

3.3. Autonomic dysreflexia

Individuals with spinal cord injury above T6 are at risk of autonomic dysreflexia during sexual activity, especially during ejaculation and orgasm. Some individuals with spinal cord injury do not experience any symptoms of autonomic dysreflexia (20) while others experience vasomotor headaches in the absence of significant blood pressure rises (17). Education about autonomic dysreflexia should include how to intervene if it occurs. If the symptoms of autonomic dysreflexia occur during sexual activity, the individual with spinal cord injury should stop what they are doing, sit up to take advantage of the postural drop in blood pressure and follow the steps outlined in the NSW Agency for Clinical Innovation (ACI) *Treatment of autonomic dysreflexia for adults and adolescents with spinal cord injuries* (9) fact sheet. The rise in blood pressure and occurrence of symptoms related to autonomic dysreflexia are usually limited to occasions when the individual is exposed to the stimuli that caused the autonomic dysreflexia.

Therefore, if the cause is related to sexual activity, then the symptoms of autonomic dysreflexia should subside when the activity stops.

The need for prophylactic antihypertensives for autonomic dysreflexia should be considered on an individual basis. A recent systematic review (20) reported nifedipine as the most widely used treatment for autonomic dysreflexia during sexual activity. While recent concerns suggest increased cardiovascular risks with sublingual nifedipine in people without spinal cord injury, negative long-term effects have not been reported in the SCI population. Individuals should discuss their risk of autonomic dysreflexia and the need for prevention with their doctor.

3.4. Safe sex

Sexually transmitted infections (STIs) remain a problem and any discussion about sexual activity should include safe sex. People with a spinal cord injury may not consider safe sex to be important, especially when their self-esteem is low. Healthcare professionals should provide education on the risk of acquiring STIs with multiple sexual partners and unprotected sexual activity, and recommend open discussion with sexual partners about their sexual history.

Section 4

Sexual function

Sexual function is a complex interaction of spinal cord reflexes and supraspinal influences as well as hormonal and psychological factors.

One model for teaching people with spinal cord injury about the human sexual response cycle is that originally described by Masters and Johnson (21) as involving four stages: excitement, plateau, orgasm and resolution. Kaplan (22) refined this model to include sexual desire and arousal. People with spinal cord injury should be taught that these models focus on physiological changes of the genitalia and do not take into account the broader aspects of sexuality. For women especially, but also men, intimacy is an important aspect of sexuality and the meeting of intimacy needs was reported in Anderson et al.'s (2) study as the primary reason for pursuing sexual activity.

Basson's (23) alternative model of sexual response is useful when providing female sexual function education. It recognises that a woman's sexual response more commonly comes from intimacy and 'spin-offs' rather than a biological urge to be sexual for the release of sexual tension.

In men, normal erectile function is a neurovascular event incorporating a complex set of neural and vascular interactions. Erection can begin by two distinct mechanisms, known as reflexogenic and psychogenic erections (24, 25).

Reflexogenic erections result when tactile genital stimulation is conveyed to the sacral spinal cord (S2–S4) via the pudendal nerve. Activation of the sacral parasympathetic outflow via the pelvic nerve leads to vascular and trabecular smooth muscle relaxation in the corpus cavernosum of the penis; this allows filling of the cavernosal spaces so the penis becomes enlarged. The filling of the cavernosal spaces compresses the venules in the penis, decreasing venous outflow. Reflex erections are poorly maintained without constant tactile stimulation.

Psychogenic erections are activated in response to auditory, visual, olfactory and/or imaginary stimuli that are sexually arousing. These arousing messages travel via the thoracolumbar sympathetic nerves (T10–L2) to the sex organs.

Ejaculation (11, 25) involves sperm transport from the epididymis to the urethral meatus, resulting in the expulsion of semen. The two phases of ejaculation are seminal emission and propulsive ejaculation. Closure of the bladder neck at the time of ejaculation prevents semen from entering the bladder and may make urination difficult immediately following ejaculation. Ejaculation usually results in penile detumescence, which is followed by a refractory period.

Orgasm is the brain's interpretation of ejaculatory events, even if ejaculation does not proceed in a normal fashion. Men with penile amputation or loss of their prostate may still experience orgasm even if no erection or ejaculate is present. However, a small amount of testosterone appears to be crucial for attainment of orgasmic release. Orgasm is a cerebral event usually experienced at the time of ejaculation, but can occur in its absence (11).

In women (18), sympathetic and parasympathetic fibres innervate the uterus (T10–12), fallopian tubes, ovaries and vaginal walls. Somatic innervation via the pudendal nerve provides afferent pathways from the clitoris and perineum. The labia and clitoris are also innervated through the autonomic nervous system and the responses are thought to be in the same configuration as in the male, resulting in clitoral erection and vaginal lubrication leading to orgasm (26).

Hence, psychogenic genital arousal results in increased vasocongestion that usually presents as clitoral engorgement, vulvar swelling and vaginal lubrication and occurs from arousal generated by the brain. Reflexogenic genital arousal has the same results but this occurs from arousal generated by tactile genital stimulation.

Effect of spinal cord injury on sexual function

Spinal cord injury can affect male and female sexual function in many ways. Following spinal cord injury there is:

- decreased or absent sensations
- decreased lubrication
- erectile dysfunction
- decreased clitoral engorgement
- changes in ejaculation
- changes in orgasm.

While both men and women lose the ability to have reflexive sexual responses in the immediate post-injury period, the extent of impaired sexual functioning after this period depends on the level and completeness of the spinal cord injury.

4.1. Sexual function in men with spinal cord injury

The majority of men with spinal cord injury can obtain an erection through the reflexogenic (S2–4) pathways or the psychogenic (T11–S2) pathways. However, these erections are often unreliable, inadequate and poorly sustainable. The following outlines changes in sexual function in men with spinal cord injury (17, 27–29).

Erection

- In men with complete lesions above the S2–4 reflex centre (upper motor neuron, UMN), the sacral reflexes, although isolated, are intact and reflex erections are retained but are often unpredictable.
- Men with complete lesions below or involving the S2–4 reflex centre (lower motor neuron, LMN) lose reflex erections but may be able to achieve psychogenic erections though they are poorly sustained.
- Men with low cord (mixed) lesions between the sympathetic (T11–L2) and parasympathetic (S2–4) spinal centres may retain both types of erections.

Note: Erectile dysfunction is a marker of cardiovascular disease (30), which should be assessed in spinal cord injury.

Ejaculation

Ejaculation is a highly complex process requiring the sequential coordination of the sympathetic, parasympathetic and somatic nervous systems. The

exact alteration in ejaculatory function after spinal cord injury can be unpredictable. In general (11, 27, 29, 31):

- men with complete (UMN) lesions above the emission centre (sympathetic T11–L2) retain only about a 5% chance of achieving reflex ejaculation without intervention
- men with complete (mixed and LMN) lesions below the emission centre (sympathetic T11–L2) may retain the ability to achieve psychogenic seminal emission (often precocious) with associated partial orgasm.

Few men with spinal cord injury achieve true ejaculation. The ejaculation is often retrograde, where the semen is forced into the bladder instead of out of the urethra due to inefficient bladder neck closure.

All men with complete spinal cord injury lack genital sensation, but many experience pleasurable feelings above the level of injury during sexual activity (phantom orgasm). Discussion and counselling regarding the exploration of erogenous zones may be required.

Men with incomplete spinal cord injury, depending on the level, may retain significant but altered sexual functioning.

Managing erectile dysfunction

Treatment for the management of erectile dysfunction in men with spinal cord injury has improved considerably in recent years with the advent of phosphodiesterase type 5 inhibitors (PDE5 inhibitors). Interventions for erectile dysfunction include the following (32).

- **Maximising conditions for good sex**, such as getting adequate sleep, reducing stress and planning.
- **Modifying reversible contributors**, such as smoking, alcohol and medications.
- **Taking oral PDE5 inhibitors**, such as sildenafil (sold as Viagra), vardenafil (Levitra) and tadalafil (Cialis).

In addition to maximising conditions for good sex and modifying reversible contributors, PDE5 inhibitors are the first line of treatment for erectile dysfunction in spinal cord injury. The starting dose is usually small to medium for males with spinal cord injury (for example, 25–50 mg Viagra). Men with preserved reflexogenic function (UMN lesions) will respond better to PDE5 inhibitors.

Education on the use of PDE5 inhibitors should include the following information.

- If a person with spinal cord injury has used Viagra or Levitra in the last 24 hours, or Cialis

within the last 72 hours, and has an episode of autonomic dysreflexia, nitrate-containing medications such as glyceryl trinitrate (GTN) spray and recreational nitrates (poppers) are contraindicated due to the risk of hypotension.

- Sexual stimulation is required for PDE5 inhibitors to work.
- The amount of time it takes to work varies from 20 to 60 minutes for Viagra, Levitra and Cialis. It can take longer if the medication is taken with a heavy meal. Advice should be given to not drink large amounts of alcohol in order to obtain the maximum benefit.
- The effects of Viagra and Levitra last for approximately four to eight hours. Cialis has a longer duration (up to 36 hours), but may require a higher dose to be as effective (33).
- The most common side effects of PDE5 inhibitors are headache, nasal stuffiness and facial flushing. As these symptoms are similar to those of autonomic dysreflexia, the possibility that they are related to autonomic dysreflexia needs to be eliminated (9).
- As PDE5 inhibitors lower blood pressure, there is a risk of dizziness for several hours after administration due to postural hypotension, especially in men with higher level injuries. Care should be taken with transfers due to the risk of falling.
- Cost may be prohibitive as the medications are not yet on the Pharmaceutical Benefits Scheme (PBS). They cost approximately AU\$70 per four tablets.
- **Intra-cavernosal (penile injectable) medications**, for example, alprostadil (sold as Caverject). These are the next line of treatment for erectile dysfunction when PDE5 inhibitors are ineffective. Injection therapy involves the delivery of medication directly into the corpus cavernosum of the penis. The starting dose is 5 µg but it is likely that a higher dose (up to 60 µg will be required; the lowest effective dose should be prescribed.

Education on the use of injection therapy should include the following information.

- While the technique is invasive, most people find doing the injection easy and not painful, especially if there is no penile sensation.

- The injection should be administered into the corpus cavernosum on either side of the penis (see Figure 1). Instruction should be given on the administration technique as outlined on the instruction sheet provided with the medication.
- Full engorgement of the penis occurs approximately 10 minutes after administration.
- The erection lasts 1–1.5 hours.
- No more than one injection should be used every 24 hours.
- Injections can be used up to three times a week, but the person should be counselled on the possible risk of fibrosis.
- There may be side effects such as fainting, painful erection, prolonged erection (lasting more than four hours), priapism (persistent and painful erection lasting more than six hours), testicular pain, bruising, injection site reactions, hypotension and dizziness.
- If the erection is still present after three hours, treat in the first instance by increasing exercise (for example, pushing self in wheelchair) and/or a hot shower to promote peripheral vasodilation. Administer 60 mg oral pseudoephedrine (Sudafed) if erection is still present. Instruct spinal cord injury person to check that Sudafed content contains 60 mg pseudoephedrine. If the erection is still present four hours after administration of medication, seek urgent medical treatment at the emergency department for medical detumescence. If priapism is not treated, penile tissue damage and permanent loss of potency may result.
- As with oral medication, the cost may be prohibitive.

Figure 1. Image of corpus cavernosum on either side of the penis for penile injection therapy

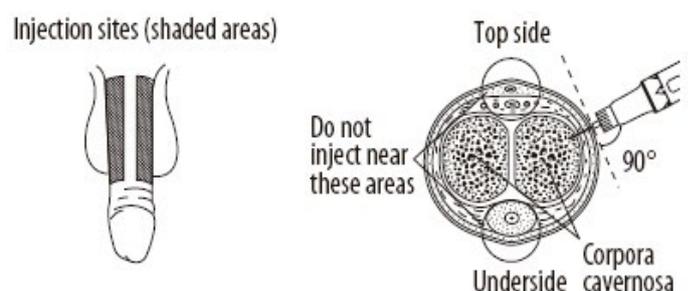


Image from www.caverject.com (Patient instructions for use) with permission from Pfizer.

- **Vacuum constriction device and/or penile tension ring**

Medically sanctioned vacuum constriction devices and penile tension rings such as the Osbon ErecAid Vacuum Therapy System (www.osbon.com.au) are noninvasive techniques for achieving adequate penile rigidity for intercourse. The vacuum device operates by applying continuous negative pressure to the shaft of the penis which draws blood into the corpus cavernosa. The penile ring retains the blood in the corpus cavernosa when applied to the base of the penis. There are many vacuum devices available and there have been a number of studies investigating the effects on men with spinal cord injury. Most have shown that the devices are well tolerated with minimal side effects, and that they improved erectile function and sexual satisfaction (34).

Education should include discussion of:

- using the device according to the manufactures instructions provided
- the 'hinged erection' due to only distal engorgement of the penis
- the penis looking a bluish colour and feeling cold due to trapped blood in the penis
- how to incorporate the device into sexual play
- lubrication of the penile tension ring to assist with application and removal
- the need to remove the penile tension ring within 30 minutes of application due to the risk of circumferential pressure injury.

Note: The penile tension ring may be used without the vacuum device to maintain an erection that is not sustainable.

- **Other management options**

As some men with spinal cord injury have discovered that particular positions assist with maintaining erections, experimenting with positions should be encouraged. In addition, perineal muscle training may help improve penile rigidity in men with some capacity for voluntary pelvic floor contraction (35, 36).

Managing ejaculation

Vibratory stimulation of the penis to obtain ejaculate for reproductive reasons has been performed for many years. This involves the application of high-amplitude vibrators, such as Ferticare and Viberec (Figure 2 & 3), to the head of the penis. While many men have no feeling of pelvic arousal or accompanying orgasm with ejaculation, just seeing the ejaculate, possibly for the first time since their injury, may be important to their manhood and sense of self (11). Men with lesions above T6 may feel unwell before ejaculation due to spasms and autonomic dysreflexia, but new pleasurable sensations at ejaculation may also be felt by some who have not previously experienced the sensations (11). Due to the cost of high-amplitude vibrators and the high risk of autonomic dysreflexia in men with lesions above T6, men should be assessed in a sexuality or fertility clinic prior to trying high-amplitude vibrostimulation.

Please refer to the ACI factsheet *Fertility following spinal cord injury* (37) for further information.

Figure 2. Ferticare high-amplitude vibrator



Figure 3. Viberec high-amplitude vibrator



Figures 2 and 3 provided and used with permission from David Buck, Orion Medical

4.2. Sexual function in women with spinal cord injury

While the research on sexuality following spinal cord injury is dominated by men as participants, this is slowly improving. Women with spinal cord injury have to deal with body image, relationship and sexual dysfunction issues. After spinal cord injury, 59% of women reported at least one sexual dysfunction, and this can interfere with quality of life (38). Compounding this impact is the finding that women are more prone than men to depression and psychological disorders after injury (18). Women with spinal cord injury also tend to believe that they have a passive role during sexual intercourse and this adversely affects their sexual functioning (39). Intervention should therefore actively include sexual rehabilitation, rather than simply focusing on fertility.

Sexual changes in women after spinal cord injury may include:

- altered sexual desire and arousal
- altered genital sensation
- altered vaginal lubrication
- altered vaginal accommodation, satisfaction, pain and orgasm.

As with men, the potential for psychogenic arousal may depend on the degree of preservation of sensory function in T11–L2 dermatomes, and reflex genital arousal and lubrication is thought to depend on an intact reflex arc in the S2–5 spinal segments (17, 18).

When determining the presence of psychogenic and/or reflex genital arousal in women, it is recommended to focus on the woman's awareness of vaginal lubrication rather than clitoral engorgement (40, 41). Women with spinal cord injury lesions down to T5 may retain an orgasm reflex unrelated to the degree of neurological impairment due to a specific path carried by the vagus nerve, which can be activated by deep stimulation of the vagina and cervix (42).

Education and counselling for female sexual satisfaction should include the following information.

- A prolonged period of foreplay may be required to achieve vaginal lubrication.
- Perineal sensation of light touch and vibration should be assessed and women should be encouraged to explore clitoral, vaginal and cervical stimulation to achieve reflex lubrication. Self-exploration also helps the woman learn what sensation is intact and what she finds pleasurable.

This builds self-confidence and increases her chances of being able to communicate what feels good to her partner.

- Decreased vaginal lubrication strongly and negatively affects sexual function. If reflex lubrication is impaired and/or the woman is post-menopausal, advice should be provided on the use of water-soluble lubricants for sexual activity. Water (or saliva) may be added to water-based lubricants when they become 'tacky', although some lubricants are not palatable.
- Women with spinal cord injury can experiment with manual stimulation or vibratory stimulation of the clitoris using the Feticare vibrator to achieve orgasm. The Lelo vibrator (which has vibration pulsatile options) can be used for vaginal or cervix stimulation to try and achieve orgasm. The Feticare should be initially trialled in a clinic setting as it delivers high-amplitude, high-frequency stimulation, which can cause autonomic dysreflexia. The Lelo (www.lelo.com) is commercially available and can be trialled at home.
- The Eros Therapy Device is a small cup with a pump that fits over the clitoris. When it is turned on, a gentle vacuum is created, increasing blood flow to the genital area. It has been studied in women with female sexual dysfunction with promising results, including improved vaginal lubrication, orgasm, and overall satisfaction (43). It might be worthwhile trialling in women with spinal cord injury. Some centres overseas are combining vibrostimulation with the use of Midodrine, as used with men to increase the rate of orgasm.
- Sexual exploration to find new erogenous zones should be encouraged. The areas of greatest sexual arousal reported by women with spinal cord injury were mouth and lips, followed by neck and shoulder, stomach, clitoris, thigh, feet, ears, breast, and buttocks (44).
- When vaginal spasm causes pain and the inability to accommodate the penis or other sex aids, encourage experimentation to achieve non-penetrative orgasm. There is the possibility that women may be free of spasm for some time post orgasm and, if interested, may be able to achieve penetrative sex. In addition, trialling vaginal dilators in conjunction with anti-spasmodics may be a useful strategy when penetrative sex causes pain due to spasm.

- Medications such as Viagra (sildenafil) have been evaluated for women with sexual dysfunction (45), but there are few studies that recommend them at the time of writing.
- Women who are prone to autonomic dysreflexia should be educated about this and instructed to stop what they are doing if they experience symptoms during sexual activity.
- Women can experiment with positioning and learn to use spasms for sexual positioning. A useful resource for some people with spinal cord injury regarding positioning is this online video: [*Sexual positions for women with paralysis: creativity, adaptability and sense of humour*](#) (46).

CAUTION

Both men and women should be educated about the potential risks associated with purchasing available medications and products without prescription and education. For example, medications sold online may contain unknown or potentially harmful substances and certain sexual aids may be risky without proper education.

Section 5

Quiz

Q1. Which statement is true regarding sexuality and persons with spinal cord injury?

- a. Female sexuality is passive and male sexuality is active
- b. People with spinal cord injury are asexual and cannot enjoy sex
- c. People with spinal cord injury remain sexual beings and can continue to participate in sexual activity
- d. It is wrong for people to use masturbation and/or sex aids

Q2. All the following are strategies for managing psycho-social aspects of sexuality following spinal cord injury EXCEPT:

- a. Discussing the range of options in a non-judgemental manner
- b. Taking note of the person's readiness to learn and not placing undue pressure on the person to experiment
- c. Not acknowledging changes and losses following spinal cord injury
- d. Peer counselling by individuals with spinal cord injury at a time appropriate to the person with SCI

Q3. Which of the following strategies can be used for managing physical aspects of sexuality?

- a. Encouragement to explore other areas of the body not commonly associated with sexual pleasure (including the 'transition zone') using a variety of sensations
- b. Providing information on sexual positioning and aids
- c. Encouraging discussion about feelings and developing a management plan in the case a bladder or bowel 'accident' should occur
- d. Providing suggestions to assist persons feel more sensuous and/or sexy when catheters and urinary drainage bags are used
- e. All of the above

Q4. Regarding autonomic dysreflexia (AD), which statement below is false?

- a. Individual with spinal cord injury above T6 are at risk of AD during sexual activity
- b. If AD occurs during sexual activity, the person with spinal cord injury should stop what they are doing, sit up to take advantage of the postural drop in blood pressure and proceed to follow the steps outlined in the ACI autonomic dysreflexia factsheet (9)
- c. Prophylactic antihypertensives for AD should be considered on an individual basis
- d. Nitrate-containing medications such as GTN spray and recreational poppers can be used at any time when taking oral PDE5 inhibitors for erectile dysfunction

Q5. Penile tension rings used for maintaining erections should be removed after:

- a. 1 hour
- b. 30 minutes
- c. 10 minutes
- d. 2 hours

Q6. Education and counselling for female sexual satisfaction should include:

- a. Informing females that a prolonged period of foreplay may be required
- b. Encouragement to explore clitoral, vaginal and cervical stimulation using light touch and vibration
- c. Advice to use a water-soluble lubricant when lubrication is impaired
- d. Self-exploration to find areas of pleasure, to build self-confidence and increase the chance to communicate what feels good to partner
- e. All of the above

Q7. Is the following statement true or false?

Both men and women with spinal cord injury should be educated about the potential risks associated with purchasing medications and products without prescription and education.

Section 6

Resources

The following resources may be helpful for health professionals and people with spinal cord injury. Some resources may not be available for purchase but may be available for borrowing through libraries.

Organisations

Family Planning NSW – has a specialist library, resources for sale, a talk line and fact sheets.

Spinal Cord Injuries Australia (SCIA) – has an [SCI Resources and Knowledge Library](#) that contains a digital and traditional library collection of materials related to spinal cord injury and disability.

Paraquad NSW – has fact sheets on sexuality and sexual function for male and females.

Royal Rehab Sexuality Clinic – offers a range of support options to assist people with acquired disability, and their partners, address sexual health concerns in a confidential environment.
Telephone: (02) 9808 9219

Royal North Shore Hospital (RNSH) Sexuality and Fertility Clinic – outpatient clinic at RNSH with medical and nursing disciplines specifically for people with spinal cord injury. Part of the RNSH [Spinal Cord Injury Clinic](#)

Online

Consortium for Spinal Cord Medicine. [Sexuality and reproductive health in adults with spinal cord injury: what you should know, a guide for people with spinal cord injury](#) (PDF free download)

Dr Mitchell Tepper provides easily accessible sexuality and disability resources, many of them free and others at low cost.

Come As You Are provides information on how to adapt sex toys and provides links to other sexuality and disability sites.

Stanley Ducharme is a clinical psychologist and consultant specialising in the areas of sexual dysfunction, gender, physical disability, addictions, relationship issues and concerns of daily living. He co-authored with Kathleen Gill the book titled *Sexuality after spinal cord injury: answers to your questions*. His website has a number of articles and suggested resources relevant to male and female sexuality following spinal cord injury.

Facing Disability (USA) has personal videos of people answering questions about sex, dating, and maintaining a social life in a wheelchair after spinal cord injury.

Sex, Intimacy and Spinal Cord Injury Forum (NZ) is a collaborative forum of health practitioners, people with spinal cord injuries, their partners and other interested people.

Spinal Cord Injury Rehabilitation Evidence (SCIRE) reviews, evaluates, and translates existing research knowledge into a clear and concise format to inform health professionals and other stakeholders of best rehabilitation practices following spinal cord injury.

Videos/DVDs

Sexuality reborn (1993) 48 min. Kessler Institute for Rehabilitation. [Sexuality reborn order form](#).

Talking about sexual issues and spinal cord injury (1990) 30 min. British Columbia Rehabilitation Society.

Women's sexuality after SCI: understanding the changes and finding ways to respond (2003) 18 minutes. The Miami Project to Cure Paralysis at The Lois Pope LIFE Centre.

Untold desires (1994) 53 min. Fertile Films.

Books

Baer RW. *Is Fred dead?: a manual on sexuality for men with spinal cord injuries*. Pittsburgh, PA: Dorrance Publishing Company; 2003.

Ducharme SH, Gill KM. *Sexuality after spinal cord injury: answers to your questions*. Baltimore, USA: Paul H. Brookes Publishing Co.; 1997.

Harris R. *ACT with love*. Oakland, CA: New Harbinger; 2009.

Kaufman M, Silverberg C, Odette F. *The ultimate guide to sex and disability*. 2nd ed. San Francisco, CA: Cleis Press; 2007.

King R. *Good loving great sex*. Australia: Random House; 1998.

Naphtali K, MacHattie E, Elliott S et al. [*PleasureABLE: sexual device manual for persons' with disabilities*](#). British Columbia, Canada: Disabilities Health Research Network; 2009.

Krol K, Klein EL. *Enabling romance. A guide to love, sex and relationships for the disabled*. New York: Harmony Books; 1992.

Lobley K. *Sex matters: a guide to sexuality for spinal cord injured people*. London: SIA; 2002.

Sandowski CL. *Sexual concerns when illness or disability strikes*. Springfield: Charles C. Thomas Publisher; 1989.

Tepper M. *Regain that feeling: secrets to sexual self-discovery*. North Charlestown, SC: Create Space Independent Publishing Platform; 2015.

Section 7

References

1. World Health Organization. *Defining sexual health: report of a technical consultation on sexual health, 28-31 January 2002*. Geneva, Switzerland: World Health Organization; 2006.
2. Anderson KD, Borisoff JF, Johnson RD et al. The impact of spinal cord injury on sexual function: concerns of the general population. *Spinal cord*. 2006;45(5):328-37.
3. Dahlberg A, Alaranta H, Kautiainen H et al. Sexual activity and satisfaction in men with traumatic spinal cord lesion. *Journal of rehabilitation medicine*. 2007;39(2):152-5.
4. Richards E, Tepper M, Whipple B et al. Women with complete spinal cord injury: a phenomenological study of sexuality and relationship experiences. *Sexuality and disability*. 1997;15(4):271-83.
5. Kaufman M, Silverberg C, Odette F. *The ultimate guide to sex and disability: for all of us who live with disabilities, chronic pain, and illness*. 2nd ed. Berkeley, CA: Cleis Press; 2007.
6. Tepper MS. Letting go of restrictive notions of manhood: male sexuality, disability and chronic illness. *Sexuality and disability*. 1999;17(1):37-52.
7. Lemon M. Sexual counseling and spinal cord injury. *Sexuality and disability*. 1993;11(1):73-97.
8. Burns S, Mahalik J, Hough S et al. Adjustment to Changes in Sexual Functioning Following Spinal Cord Injury: The Contribution of Men's Adherence to Scripts for Sexual Potency. *Sexuality and disability*. 2008;26(4):197-205.
9. Middleton DJ, Ramakrishnan DK, Cameron DI. *Treatment of autonomic dysreflexia for adults and adolescents with spinal cord injuries*. Chatswood: NSW Agency for Clinical Innovation; 2014. Available from: https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0007/155149/Autonomic-Dysreflexia-Treatment.pdf
10. Anderson KD, Borisoff JF, Johnson RD et al. Long-term effects of spinal cord injury on sexual function in men: implications for neuroplasticity. *Spinal Cord*. 2006;45(5):338-48.
11. Elliott S. Ejaculation and orgasm: sexuality in men with SCI. *Topics in spinal cord injury rehabilitation*. 2002;8(1):1-15.
12. Stubbs KR. *The essential tantra: a modern guide to sacred sexuality*. New York: Penguin; 2000.
13. Tepper M, Owens A. Access to pleasure: Onramp to specific information on disability, illness, and other expected changes throughout the lifespan. In: Cooper A, ed. *Sex and the internet: a guidebook for clinicians*. New York: Brunner Routledge; 2002;71-86.
14. Carrellas B. *Urban tantra: sacred sex for the twenty-first century*. New York: Celestial Arts; 2011.
15. Comfort A. *The new joy of sex*. Pocket Books; 1991.
16. Consortium for Spinal Cord Medicine. *Sexuality and reproductive health in adults with spinal cord injury: a clinical practice guideline for health care providers*. Paralyzed Veterans of America; 2010.
17. Hess MJ, Hough S. Impact of spinal cord injury on sexuality: broad-based clinical practice intervention and practical application. *The journal of spinal cord medicine*. 2012;35(4):211-8.
18. Anderson KD, Borisoff JF, Johnson RD et al. Spinal cord injury influences psychogenic as well as physical components of female sexual ability. *Spinal cord*. 2007;45(5):349-59.
19. Naphtali K, MacHattie E, Elliott SL et al. *PleasureABLE: sexual device manual for persons with disabilities*. Disabilities Health Research Network; 2009. Available from: www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf.
20. Courtois F, Rodrigue X, Côté I et al. Sexual function and autonomic dysreflexia in men with spinal cord injuries: how should we treat? *Spinal cord*. 2012;50(12):869-77.
21. Masters WH, Johnson VE. *Human sexual response*. Boston: Little, Brown & Co; 1966.
22. Kaplan HS. *Disorders of sexual desire*. New York: Simon & Schuster; 1979.
23. Basson R. The female sexual response: a different model. *Journal of sex & marital therapy*. 2000;26(1):51-65.

24. Benevento BT, Sipski ML. Neurogenic bladder, neurogenic bowel, and sexual dysfunction in people with spinal cord injury. *Physical therapy*. 2002;82(6):601-12.
25. Rees PM, Fowler CJ, Maas CP. Sexual function in men and women with neurological disorders. *The lancet*. 2007;369(9560):512-25.
26. Burns AS, Rivas DA, Ditunno JF. The management of neurogenic bladder and sexual dysfunction after spinal cord injury. *Spine*. 2001;26(24S):S129-S36.
27. Alexander CJ, Sipski ML, Findley TW. Sexual activities, desire, and satisfaction in males pre-and post-spinal cord injury. *Archives of sexual behavior*. 1993;22(3):217-28.
28. Elliott SL. Problems of sexual function after spinal cord injury. *Progress in brain research*. 2006;152:387-99.
29. Courtois FJ, Charvier KF, Leriche A et al. Sexual function in spinal cord injury men. I. Assessing sexual capability. *Paraplegia*. 1993;31(12):771-84.
30. Shamloul R, Ghanem H. Erectile dysfunction. *The lancet*. 2013;381:153-65.
31. Courtois F, Charvier K, Leriche A et al. Perceived physiological and orgasmic sensations at ejaculation in spinal cord injured men. *The journal of sexual medicine*. 2008;5(10):2419-30.
32. Elliott S, McBride K. Sexual and reproductive health following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC et al, editors. *Spinal cord injury rehabilitation evidence*. Vancouver; 2014.
33. Soler JM, Previnaire JG, Denys P et al. Phosphodiesterase inhibitors in the treatment of erectile dysfunction in spinal cord-injured men. *Spinal cord*. 2006;45(2):169-73.
34. Brison D, Seftel A, Sadeghi-Nejad H. The resurgence of the vacuum erection device (VED) for treatment of erectile dysfunction. *The journal of sexual medicine*. 2013;10(4):1124-35.
35. Courtois FJ, Mathieu C, Charvier KF et al. Sexual rehabilitation for men with spinal cord injury: preliminary report on a behavioral strategy. *Sexuality and disability*. 2001;19(2):149-57.
36. Elliott S, editor. *Sexual dysfunction and infertility in men with spinal cord disorders*. New York: Demos Medical Publishing; 2003.
37. Leong G. *Fertility following spinal cord injury*. Sydney: NSW Agency for Clinical Innovation; 2014. Available from: https://www.aci.health.nsw.gov.au/data/assets/pdf_file/0016/155203/sex_and_fertility.pdf
38. Lombardi G, Del Popolo G, Macchiarella A et al. Sexual rehabilitation in women with spinal cord injury: a critical review of the literature. *Spinal cord*. 2010;48(12):842-9.
39. Forsythe E, Horsewell JE. Sexual rehabilitation of women with a spinal cord injury. *Spinal cord*. 2005;44(4):234-41.
40. Alexander M, Rosen RC. Spinal cord injuries and orgasm: a review. *Journal of sex & marital therapy*. 2008;34(4):308-24.
41. Sipski ML, Alexander CJ, Gomez-Marin O et al. Effects of vibratory stimulation on sexual response in women with spinal cord injury. *The journal of rehabilitation research and development*. 2005;42(5):609.
42. Mona L, Cameron R, Goldwaser G et al. Prescription for pleasure: exploring sex-positive approaches in women with spinal cord injury. *Topics in spinal cord injury rehabilitation*. 2009;15(1):15-28.
43. Wilson S, Delk J, Billups K. Treating symptoms of female sexual arousal disorder with the Eros-Clitoral Therapy Device. *The journal of gender-specific medicine*. 2000;4(2):54-8.
44. Sipski ML, Alexander CJ. Sexual activities, response and satisfaction in women pre- and post-spinal cord injury. *Archives of physical medicine and rehabilitation*. 1993;74:1025-.
45. Sipski ML, Rosen RC, Alexander CJ et al. Sildenafil effects on sexual and cardiovascular responses in women with spinal cord injury. *Urology*. 2000;55:812-15.
46. Tepper M. *Sexual positions for women with paralysis: creativity, adaptability and sense of humor*. [video] Vimeo: 2015. Available from: <http://mitchelltepper.com/sexual-positions-for-women-with-paralysis-creativity-adaptability-and-sense-of-humor>



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