

Talking to Patients about Sexual and Reproductive Health After a Spinal Cord Injury

Sexual Health

The World Health Organization (WHO) endorses that: Sexual health is fundamental to the overall health and well-being of individuals, couples and families. They also state that: The ability of people to achieve sexual health and well-being depends on their access to comprehensive, good-quality information about sex and sexuality and ability to access sexual health care.

Sexuality and sexual well-being are important aspects of an individual's identity following a spinal cord injury (SCI) but talking about sexuality can be challenging for both clinicians and patients.

Individuals with SCI will have complex sexual health care needs, but many professionals caring for persons with SCI are uncomfortable providing information about sexuality within the context of SCI rehabilitation. Some health care providers report the lack of educational resources as a barrier to speaking with their patients about sexual health.

Purpose of this Resource:

The purpose of this document is to provide front-line health care providers with guidance to be able to respond in an appropriate manner and offer educational resources to assist and support individuals concerning sexual and reproductive health after a spinal cord injury.

Key Messages:

- Sex and sexuality are essential and healthy parts of being human. Sexuality includes all the ways that persons may experience and express themselves sexually.
- People with SCI are still able to have and enjoy sexual activities and sexual relationships.
- Individuals with acute SCI should receive information about sexual health prior to discharge from inpatient rehabilitation.
- Health care providers may not know the answers to all questions but can assist in finding someone that will be able to answer patient and partners questions and concerns.
- SCI can disrupt sexual sensation and function, necessitating exploration of new methods to achieve sexual pleasure and intimacy.
- Biological parenthood may still be possible.
- Ejaculation may be affected after injury, but sperm is still being made and there are procedures available to assist with fertility.
- After an SCI, most penises can still become erect, but it may be more difficult to maintain an erection.
- Sometimes reflex erections may happen in non-sexual situations (e.g., while inserting a catheter, during peri-care or assistance with dressing). This can make both the patient and the provider uncomfortable. Reassure the patient that this is normal.

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- People who were able to get pregnant prior to SCI are generally still able to get pregnant following SCI. Their choice of contraception may change due to increased risk of thrombosis or blood clots.
- SCI may or may not lead to reduced vulvar response and arousal (such as reduced vaginal lubrication).
- Connecting with peers (people with lived experience) who are in similar stages of their lives can help improve an individual's outlook and provide hope, including around sexual health.

Introduction

An SCI is a life-altering event that often leaves patients and families in shock, denial, and disbelief. SCI causes significant disruption to many areas of a person's life, including sexual health. The stress of recovering from their injury and learning about the changes in their body can be overwhelming and grief provoking.

Although there will be changes, and many physical and sensory aspects may not be the same as before the injury, people with SCI continue to be sexual beings and can still have satisfying sexual and intimate lives after injury.

Sexual health, a basic human right and an important aspect of holistic care, is often not addressed by health care providers. Several studies have highlighted the priority and importance of sexual health among individuals with SCI.

Sexuality describes who people are as sexual beings. It includes all the ways that persons may experience and express themselves sexually, including gender identity, orientation, physical features, how they relate to others, roles in relationships and society, sexual thoughts, values, beliefs and behaviors.

Sexual health is a deeply personal and sensitive topic, requiring a respectful and empathetic approach during discussions. Individuals vary significantly in openness, influenced by unique moral frameworks, values, attitudes, attractions, and feelings.

Health care providers can feel uncomfortable or ill-prepared to respond to questions or concerns. Those caring for individuals with SCI need to have an understanding of their sexual values, biases, and limitations, and communicate in a professional and respectful manner.

Clinical practice guidelines recommend assuring the individual as soon as feasible (preferably during early acute care) that basic information about sexuality will be provided and that more extensive information will be available throughout care, when they are ready to access it and want to learn more. It is very individual, and people will want or be ready for more information at different points during their recovery and rehabilitation.

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In acute care and inpatient rehabilitation, patients are often fatigued, overwhelmed and focused on the task of just getting home. Individuals will frequently have more questions and insight into their own needs when they begin returning to their homes and communities and begin settling into their “new normal”.

Sometimes language or behavior that might be perceived as sexually inappropriate may be the patient’s (or even family member’s) way of seeking information and reassurance about sexual health. If this occurs, ask if they have questions or concerns about sexual health, acknowledge that many people have questions about sexual health, and ask if they would like to speak to someone with expertise in this area. Reassure them that there are several resources with information about sexual and reproductive health.

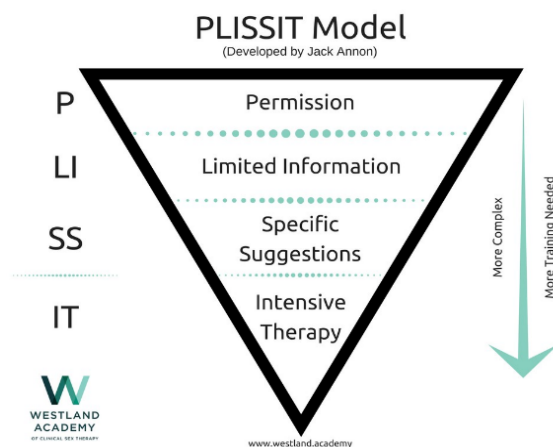
An [overview of Sexual Function and Changes After SCI](#) is covered later in this document.

Sexual Health Rehabilitation Framework

PLISSIT is well known and accepted model for sexual health rehabilitation. PLISSIT is an acronym for four levels of intervention: permission, limited information, specific suggestions, and intensive therapy.

- **Permission** as the initial level refers to creating an environment where discussions about sex are welcomed and valued without implying formal approval or authorization. It involves a reciprocal understanding that individuals also have the autonomy to grant permission, ensuring they will not be pressured into such conversations until they feel ready.
- **Limited Information** relates to an individual’s readiness to receive information regarding the impact of their specific condition on sexual expression. An individual’s readiness to hear and discuss issues of sexuality will vary from one individual to another. Some people may want health-care providers to do nothing more than dispel myths or clear up misconceptions; others may be ready to listen to more detailed information about their sexual function.
- **Specific Suggestions** are particular ideas aimed at helping to solve an individual’s specific sexual health hurdles. This level requires advanced knowledge and clinical skill on the part of the health-care provider.
- **Intensive Therapy** is the highest level and requires formal training and documented competence in sex therapy, sexuality counseling, or psychotherapy.

Figure 1. PLISSIT model for sexual health rehabilitation (fair-use reproduction from Westland Academy website)



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[Sexual Health After Spinal Cord Injury: The PLISSIT Model \(4 min video\)](#) – as it applies to supporting patients with SCI.

All health care providers should allow patients **Permission**. They may not have answers to the questions, but they should acknowledge the individual's concerns and reassure them. They should be able to provide online resources for the patient, their partners and family, and make a referral to an appropriate provider.

Common Questions and Concerns for Individuals after SCI

1. Will I be able to have sex?
 - Sexual drive/interest/desire
 - Sexual function (i.e. orgasm, ejaculation, erection, vaginal lubrication)
 - Motor and sensory function (i.e. sexual positions, sexual aids, erogenous zones, sensory changes, spasticity)
2. Will I be able to have a family? (i.e., fertility and contraception)
3. Will my people find me attractive? (i.e., self-image, self-esteem)
4. Communication (i.e., How do I talk about sex with a partner?)
5. Will I still be able to have an orgasm? (i.e., Will sex still be pleasurable?)
6. Am I just a passive partner now?
7. Will required bladder and bowel routines interfere with having sexual relations?
8. What do I do if I have a bladder / bowel accident during sex?
9. Impact of secondary difficulties (e.g. autonomic dysreflexia, spasms, potential for skin breakdown, fatigue, depression) and medications for management

Examples of Responses to Questions / Concerns

1. That is a great question. I am not comfortable (or knowledgeable) about that, but I will find someone that is.
2. Many individuals with SCI have questions about sexual health after their injury. I know there are some excellent online resources for this topic. Would you like me to give you these online resources?
3. It is often helpful to talk to someone who has experience or expertise in that area. I would be happy to contact the sexual health clinic for you if you like.
4. Many persons with SCI have satisfying and active sex lives. I am not the best person to talk to about lived experience, but I can make a referral to the peer support program if you would like.
5. I've never heard of that. I will find out for you.
6. Re: Am I still able to have children?
Biological parenthood is still a possibility after SCI. In general people who were able to get pregnant prior to SCI, are usually still able to get pregnant following SCI. Ejaculation may be affected after injury, but sperm is still being made and there are procedures available to

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assist with fertility. Many people with SCI become parents. I would be happy to connect you to someone with that lived experience if you would like.

7. Re: Will anyone want to date me? Will people still think I'm attractive?
Relationships are more than physical ability and physical attraction. Intimacy can be defined and explored in many ways.
8. Re: Will my partner leave me?
The continuation of a relationship will likely depend on how well it was doing before the SCI and how well you and your partner cope and communicate during stressful times.
9. Re: I haven't even thought about sex. I'm too (sick, tired, worried, busy, single). I just want to get home.
That's completely normal. Is it ok if I bring this up again before you go home? You might find you have questions and concerns then. In the meantime, please let me know if you have any questions or would like to speak to someone about sexual health.
10. Re: I'm just not interested in sex at all right now. I love my partner, but will I ever want sex again?
Desire is complicated and impacted by internal and external factors. Stress, fatigue, financial and relationship stressors all can impact desire. If you aren't interested in sex, don't put pressure on yourself. It is normal for sexual desire to be affected during times like this.

Assure the patient and family that sexual health will be addressed in their rehabilitation program. Create awareness of the supports and information available in your facility and online.

Peer and Community Support

- Peer support volunteers are individuals living with SCI who share their stories and the knowledge they have acquired over time, in efforts to help others as they begin their journey living with a spinal cord injury.
- Many people with lived experience have shared that speaking with someone who has transitioned to living well with an SCI is motivating and can provide hope; this is different from hearing the same information from someone without shared experience.
- There are several peer support persons that are comfortable speaking about sex and sexuality.

Spinal Cord Injury Alberta

Spinal Cord Injury Alberta can assist patients and their families in providing a connection to peer support both in-hospital and in-patient rehabilitation, and in the community.

[Peer Support Program – SCI Alberta \(sci-ab.ca\)](http://sci-ab.ca)

Resources for Patients and Families:

Please note: These resources may use binary and heteronormative language, so if someone is a member of the 2SLGBTQI+ community, they may not see themselves represented as often.

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Health care providers should be willing to help translate that information to a patient's individual experience as needed.

Printable Pamphlets

1. [Spinal Cord Essentials – Introduction to Sexual Health](#) (4 page – short)
Located under: general health handouts
2. [SCIRE Community Sexual Health After Spinal Cord Injury](#) (13 page – comprehensive)

Canadian Websites

Providing comprehensive information about sexuality, sex, and reproduction:

1. [Living with SCI: Sexual Health](#) hosted by SCI-BC
2. [SCIRE Community Sexual Health After Spinal Cord Injury](#)
3. [SCI&U: Sexuality](#) hosted by SCI-Canda

Videos

[Sex and Social Life After Spinal Cord Injury - facingdisability.com](#): interviews of patients' personal experiences

Webinars

1. [SCI-AB SCILS Webinar-Sexuality After SCI](#) (1.5-hour): includes individuals living with SCI, as well as health care professionals discussing sexual health after a SCI.
2. [Sexual Health After SCI: 3 Medicine Principles](#) (1.5 mins): Dr. Stacy Elliott summarizes 3 important principles for persons with SCI.

Sex stores

There are sex stores that cater to individuals with disabilities. The sexual health clinics should be able to assist with current suggestions.

Sexual Health Clinics

Sexual health clinics provide:

- Education and information to individuals, families, partners, caregivers and professionals
- Assessment and treatment of sexual health concerns
- Referral to a wheelchair accessible clinic for: gynecological health concerns, erectile dysfunction and management of complex fertility concerns

Individuals may be seen by one or more interdisciplinary team members.

1. [Sexual Health Service, Glenrose Rehabilitation Hospital](#)
 - a. Clinic has interdisciplinary team: nurses, physicians, occupational therapists and persons with lived experience.
 - b. Referral can be made by any member of the health care team

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- c. Glenrose patients can self-refer.
- d. External referrals can be made by any Physician or Nurse Practitioner.
- e. For more information and to access referral form: www.ahs.ca/grhsexualhealth

2. Foothills Medical Centre, Spinal Cord Injury Sexual Health Clinic

- a. Confidential service that provides education and treatment of sexual health concerns to people impacted by a SCI.
- b. Services are available to anyone living with SCI of any age, sexual orientation or relationship status.
- c. Patients can self-refer or be referred by a member of their treatment team.
- d. External referrals can be made by any physician or nurse practitioner.
Phone: 403-944-4226. Leave a message and a clinician will return your call.

Sexual Function After an SCI

After an SCI it is still possible for people to have and enjoy sex. People with SCI may experience changes to sexual desire, sensation, arousal, and orgasm because of the injury. Other changes related to the injury, such as changes to bladder and bowel control, movement, self-image, and life roles may also affect sexual health after SCI. The degree of sexual dysfunction varies significantly among people with SCI and depends on the level and the severity of injury.

People with lesions at T6 and above must be aware that sexual stimulation, especially orgasm and ejaculation, as well as childbirth increases the risk of developing Autonomic Dysreflexia (AD).

What Changes After a SCI

(This section is adapted from the [SCIRE Community sexual health website.](#))

In very simple terms: when the spinal cord is injured, some or all of the nerve signals that would normally allow the brain and sex organs to communicate with one another are damaged and cannot get through. This can affect sexual responses in many different ways.

Changes to sensation

Most people will have some loss of feeling in the genitals and nearby skin after injury. Some people experience sensations that are less intense and others may not be able to feel their genitals at all. In some cases, pain or other unusual sensations may be felt in response to touch which was previously pleasurable. While there is typically reduced feeling below the injury, some people notice that areas at or above the level of injury may be more sensitive to sexual touch after injury. People often find they have new erogenous zones where their sensation changes from full to altered (e.g., ears, neck, nipples, chest) and can often incorporate this into their sexual activities.

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Potential changes to sexual desire

Many people experience changes to sexual desire after an SCI. This can happen for several reasons, related to both physical changes from the injury and other life changes. For example, hormonal changes, emotional distress, and reduced sexual sensation may affect sexual desire.

Potential changes to self-image

Self-image may affect how sexually attractive a person feels and their confidence in becoming sexual after an injury. For some people, it takes time to adjust to the physical and life changes after an SCI and become comfortable with their abilities. Some individuals find that assistance from mental health providers or peers can help them regain their self-confidence to be in intimate relationships.

Potential changes to relationships

SCI affects all aspects of life and this can cause changes to relationships as well. (e.g., partners may take on greater caregiving responsibilities, there may be changes in working and family roles within the partnership). While every couple is different, most people do experience some changes to their relationships which can have an impact on their sexual health.

Changes to erection

Erections are rarely the same as they were before the injury. After SCI, most penises can still become erect, but it may be more difficult to maintain an erection. There will likely be some degree of erectile dysfunction. The type of erectile dysfunction that a person has depends on where the injury is on the spinal cord. (For more information, refer to [SCIRE sexual health website.](#)) There are many different options for treating erectile dysfunction after SCI.

Note: Sometimes reflex erections may happen in non-sexual situations (e.g., while inserting a catheter, providing peri-care or during assistance with dressing).

Changes to ejaculation

Penile ejaculation is frequently affected by SCI. There may be an inability to ejaculate during sex, unpredictable ejaculation, or a condition called retrograde ejaculation. (This is when semen travels back towards and into the bladder instead of emerging out through the penis during orgasm.) Many people with SCI require medical assistance to obtain sperm to have biological children. For some people with injuries above T6, ejaculation can also trigger autonomic dysreflexia.

Changes to vulvar arousal and vaginal muscles

SCI may lead to reduced arousal responses (such as reduced vaginal lubrication). These changes depend on where the injury is on the spinal cord. (For more information, refer to [SCIRE sexual health website.](#)) In addition, people with SCI may also experience spasticity and spasms of the vaginal muscles that may interfere with their sexual health.

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Changes to vaginal or clitoral orgasm

Vaginal and clitoral orgasms may also be affected by SCI. It may become more difficult to have an orgasm, and the orgasms may feel different.

Reproductive Health

Biological parenthood is still a possibility after SCI.

The fertility of people who can get pregnant is typically not affected by an SCI. If an individual was able to get pregnant and give birth prior to their SCI, they likely will be able to do so with an SCI. However, there is an increased frequency of complications during pregnancy, labour and delivery; including AD, bladder problems, spasticity, pressure sores, and problems with mobility.

Amenorrhea may occur immediately following injury, lasting 4-5 months on average, but fertility is generally not affected once regular menstrual cycle resumes. Because there is an increased risk for thrombosis or blood clots after SCI, their choice of contraception may need to change.

Menopause may also be impacted by SCI. This is an area that requires more research. It is thought that people with SCI transitioning through menopause may experience greater bothersome somatic symptoms (e.g., hot flashes), bladder infections, and diminished sexual arousal compared to persons without SCI. While it is not clear if menopause is different for people with SCI, people with SCI do experience menopause symptoms, and these symptoms can sometimes contribute to SCI complications (e.g., autonomic dysreflexia, urinary tract infections).

As mentioned above, ejaculation can be difficult for some people after SCI. Additionally, the number and motility of the sperm tend to decrease or change after SCI. As a result, medical interventions may be required to obtain sperm for reproduction. In these cases, there are several supports that people can access.

SCISexualHealth.ca outlines fertility treatment options for patients.

Practicing safe sex and being informed about contraception options is as important after SCI as it was before an SCI.

Resources for Staff

Note: These resources may use binary or heteronormative language. Staff are encouraged to use gender neutral language (e.g., people with penises, people with vulvas, people who can get pregnant, assigned female at birth, etc.) to ensure that everyone feels included and supported.

Most staff will find the [Patient and Family Resources](#) above very informative.

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The following resources are specifically for health care staff:

1. [SCIRE Professional Sexual and Reproductive Health webpage](#)
2. SCIRE brief education videos for Health Care Professionals:
 - a. [Sexual Health after Spinal Cord Injury: Five Guidelines for Health Care Professionals](#) (3 mins) -introduces important concepts re: speaking to patients about sexual health
 - b. [Sexual Health After Spinal Cord Injury: An Introduction](#) (3 mins) -highlights importance of sex and sexuality
 - c. [Sexual Health and SCI: The PLISSIT model](#) (4 mins) -sexual rehab model as it relates to patients with SCI
3. [Sexuality after SCI](#) educational videos for physicians, occupational therapists, physical therapists, recreation therapists, psychologists, nurses, and social workers. (Mount Sinai Hospital-2017 conference).
4. [Sexuality After a Spinal Cord Injury](#) (7 min video) presented by 3 health care professionals from Mount Sinai summarizes some physiological changes impacting sex after SCI. Intended audience is both persons living with SCI and healthcare professionals.

Contact:

For more information regarding Sexual Health after SCI or to refer your patient (and or partner), contact one of the [Sexual Health Clinics listed above](#).

1. Sexual Health Service, Glenrose Rehabilitation Hospital
2. Spinal Cord Injury Sexual Health Clinic, Foothills Medical Centre

[AHS Diversity and Inclusion](#) is also available to support staff in providing care to sexuality and gender diverse patients.

Acknowledgement

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