

SEX AFTER SCI – A GUIDE FOR WOMEN'

FACTSHEET



Introduction

Most women are able to commence or return to a healthy, happy sex life after a spinal cord injury (SCI). While the experience may differ from how it was before, physical pleasure and satisfaction, as well as emotional closeness and intimacy, are all still possible regardless of sexual identity or lifestyle choices.

This factsheet aims to address some of the common concerns and barriers related to sexual activity following a spinal cord injury. It should be helpful for both heterosexual and same sex relationships.

Recommencing sexual activity following spinal cord injury

Many women feel anxious about returning to sexual activity after a spinal cord injury. Not knowing what to expect in terms of sensation or enjoyment, or worrying that a partner may not find you as attractive or enjoy sex as much as before, are all common thoughts and feelings following an injury.

There are various strategies that can help address this “fear of the unknown” and support preparation for what to expect. Having sex after a spinal cord injury can feel like having sex for the first time all over again while you learn about your new body and what is sexually satisfying for it. Being open to experimenting and trying different things can lead to more enjoyment long term as you may discover activities that you had previously dismissed are now more rewarding.

If you were experiencing any difficulties with sexual activity prior to your spinal cord injury (e.g. pain during sex, vaginal tightness, or difficulty achieving orgasm), these may still be present afterwards and may require separate treatment. Support for these issues can be accessed through gynaecology services, via referral from your GP or spinal consultant.

Having a spinal cord injury will also not diminish previous sexual experiences, therefore if you have previously experienced trauma or abuse you may wish to reach out for further support with this either through a GP referral to counselling or by privately accessing services such as psychosexual therapy.

If you have had a prolonged stay in hospital, some of the closeness and intimacy in your relationship may have been affected due to a lack of privacy and opportunity for time alone. After discharge, it can be helpful to spend quality time together as a couple, perhaps doing activities you both enjoy or going on dates to help rekindle your relationship. Try not to put pressure on yourselves to resume sexual activity immediately. Instead, focus on reconnecting through talking, holding hands, kissing, and cuddling, allow intimacy to rebuild so that when you feel ready for sex, you are both relaxed and comfortable.

Partners may also feel anxious about returning to a sexual relationship. Many worry about causing harm to their partner with the spinal cord injury or cauda equina syndrome or being unable to provide pleasure to them in the same way as before. Taking time to discuss each other's anxieties and concerns before becoming sexually active can be very beneficial in providing reassurance and mutual support. If you are feeling particularly anxious it may be helpful to share your thoughts and concerns with someone you trust outside of the relationship, such as a close friend, healthcare professional involved in your care, or a peer support worker from a spinal charity.

Libido/desire

You may find that your libido or desire to be sexually active after your injury has reduced. This can be for many reasons. You will have potentially had a long stay in hospital and will need to give yourself time to settle in back at home. Initially just plan to spend quality time with your partner, if you have one, rather than putting pressure on yourself to launch straight into being sexually active.

There are many psychological reasons why you may not feel ready to engage in sexual activity. You will have potentially experienced changes in your body image reducing your confidence to initiate sex or feel anxious about the ability to please a partner. You may still be coming to terms with your injury or feel low in mood reducing your motivation to want to have sex. These feelings are all valid, should be acknowledged and discussed with your partner, someone you feel able to confide in or with a healthcare professional or counsellor.

Normal hormonal cycles can be disrupted by a catastrophic injury, such as a spinal cord injury. These changes can also have an impact on sexual desire. It can take time after an injury for the menstrual cycle to return and the same is true for libido. Hormonal changes resulting from peri and post menopause can also have an impact on an individual's sex drive. If you are concerned regarding your sex drive it is recommended that you discuss this with your GP.

Changes in sensation following SCI

Following a spinal cord injury or cauda equina syndrome diagnosis you are likely to experience changes in sensation below your level of injury. This is likely to involve both the internal and external genital areas. It is impossible to predict exactly what someone will be able to feel during sexual activity solely by their level and completeness of injury. Some individuals will have no internal or external genital sensation whereas some will find that they can still feel but the sensations are duller or feel numb compared to pre-injury. Others report that their sensation can be patchy, with some areas where they can feel a lot and other areas that are numb or have no sensation. In this situation the positions they adopt during sexual activity can have a large impact on their ability to feel stimulation or penetration. You may also notice that changes in the dosages of certain medications that you are on may have an impact on genital sensation, particularly those for neuropathic pain or spasticity. Noticing these changes is not a reason to come off a medication. Any side effects, such as sensation changes, should be discussed with your spinal consultant or GP if you have particular concerns.

Prior to being sexually active after your injury it is recommended that you take time by yourself to explore your body. If you do not have the hand function to do so you can ask a partner to help you with this. Take time to explore your genitals by touch both internally and externally. This will give you the opportunity to relearn your body and prepare you for what to expect when you are sexually active for the first time after your injury.

Body mapping can be a useful technique to use either by yourself, or with your partner, to help you learn about your body. Using different touch pressures (soft and firm) and different textures/temperatures (eg. feathers, ice) explore your whole body, both above and below the level of injury, to work out what feels enjoyable to you and what might elicit uncomfortable or painful responses. Knowing how your body responds to different stimuli can help you make sexual encounters as fun as possible, as well as giving you empowerment to communicate your needs with a partner. This will then give them the knowledge of how to enhance your experience and what to avoid if you do have any areas of discomfort or hypersensitivity. These types of body exploration exercises can also be used on your partner as a way of learning more about their body and how it reacts to different stimuli and sensations too.

Some women report that they notice changes in their sensation above the levels of their spinal cord injury. For example, they may find that they are more sensitive or get more enjoyment from being touched or kissed in areas such as their neck or ears than they did pre-injury. Being open to exploring the body as a whole can unlock different experiences to enhance pleasure.

Following a spinal cord injury or cauda equina syndrome diagnosis what you previously found enjoyable during sexual activity may have changed. Being open to experimenting and trying different activities and positions can be really beneficial for working out what you get the most enjoyment from.

Orgasm

It is still possible to orgasm after a spinal cord injury or cauda equina diagnosis however it may not be the same experience that you had before your injury. Orgasm can take longer to achieve and many women report that it doesn't feel as intense. Messages from the genitals travel via the vagus nerve to the brain bypassing the spinal cord. Therefore, it is still possible to orgasm from being touched in your genital area even if you can't feel it due to your injury.

The body has many areas that can produce a sexual response when touched. These are called erogenous zones. Being touched, kissed or bitten in these areas can enhance sexual experiences and also help in achieving orgasm.

Orgasm in women is a combination of both physical and psychological factors. The body needs to receive physical stimulation but if the brain is not "in the mood", or thinks an orgasm can't happen, it won't occur.

Many women think that they will be unable to orgasm after spinal cord injury however for most women this is not the case. If someone thinks it's not going to happen though then it definitely won't.

It is very easy to allow the brain to carry out a running commentary of what is happening while in the moment. This voice is known as "spectatoring" and can actually jeopardise the ability to achieve an orgasm. Try to switch off this internal voice, relax and focus on being in the moment, thinking about what you are feeling and/or enjoying rather than fretting about whether an orgasm will happen or not.

Masturbating, prior to returning to sexual activity with a partner, can be a great way to explore both genital sensation and orgasm. Sex toys, such as vibrators or air / suction products can also enhance this experience due to the level of intensity they can provide compared to using touch alone

Positioning

Positioning for sexual activity obviously depends on your level and completeness of spinal cord injury, as well as your flexibility and upper body strength to support yourself to maintain a position. The strength and build of your partner in comparison to yourself may also have an impact, particularly if you are relying on them to help you into a position or to maintain your balance once there.

There are many different positioning aids available on the market, but these are often very expensive particularly if marketed towards people with a disability. Moving chairs, wedges and slings are all available. However, having extra cushions or pillows to hand can be sufficient to help you maintain a position during sex or enable you to relax and be comfortable. Also make use of the equipment you might have available at home. Profiling beds, bed rails, wheelchairs, showerchairs and grab rails could all be used to assist positioning and enhance your experience.

When in a missionary position, lots of women find placing a pillow under their pelvis helpful as it helps maintain the pelvis in a tilted position for penetration.

Those who experience lower back pain find that the doggy position can be a helpful position to adopt during sex, if they have the physical ability to maintain it, as it prevents pressure on their spine and enables them to control the posture that their lower back adopts.

If you require physical assistance from a partner during sex to move and position your body ensure that you maintain control over how you are positioned. Don't just let a partner move you without you first instructing them to. Ensure you are always verbally in charge of your body as this will ensure you remain empowered rather than feel dominated.

Bladder and bowel management

Most women diagnosed with a spinal cord injury or cauda equina syndrome experience changes in bladder and/or bowel function that require management during sexual activity. Any activity that increases pressure on your abdomen can put you at a greater risk of a bladder or bowel accident.

Bladder management

It is still possible to have penetrative sex with an indwelling urethral catheter. You need to ensure that the tubing is positioned so that it won't get caught. Using tape to secure it out of the way can help reduce the risk of this occurring. If you self-void, use intermittent catheters or use a flip flow tap with no leg bag it is recommended that you empty your bladder prior to having sex to reduce any potential leaking that may occur. This can take away some of the spontaneity of sexual activity but ensuring your bladder is empty will enable you to relax and not worry about having a potential accident while being intimate.

If you have a supra-pubic catheter you need to ensure that the tubing is positioned out of the way so that it doesn't get caught and pulled during sex. Taping it to your lower abdomen can be a good way to ensure this.

Having a catheter bag and tube on show during sexual activity isn't particularly sexy however there are lots of different covers for tubes and leg bags available on the market, from companies such as Amazon or Etsy, that can be used to conceal them if you wish to. Ensure you check that the product is compatible with the size of your catheter bag and tube length prior to purchasing as there is variation between different catheter brands.

If you find you are having to limit your fluid intake in order to be sexually active, please seek support from your GP or spinal centre

Bowel management

The best way to avoid bowel accidents during sexual activity is to know your bowel routine. You will know which days you have a good result and which days you haven't so should have a clear idea of when you might be more at risk of an accident.

If able, you might choose to pop to the toilet to check your bowels are empty prior to sexual activity, either by trying to empty them voluntarily or by performing a digital check. Timing of sex in relation to your bowel routine is also something you might wish to consider, eg. If you have sex first thing in the morning and you have a morning bowel routine you might wish to empty your bowel first to avoid any accidents.

Wind can be difficult to control, particularly if adopting a position that increases pressure on your abdomen. This can lead to embarrassing moments however using humour, if this occurs, can help prevent it from ruining the mood.

Autonomic Dysreflexia (AD)

If you have a spinal cord injury at level T6 or above you may be at risk of experiencing autonomic dysreflexia during sexual activity. If this occurs it is important that you stop whatever activity you are doing at the time, sit yourself upright, remove any tight clothing and find the cause of the issue. It may be as simple as your body telling you that you need to change position, that your catheter is caught or that you require extra lubrication. The intensity of vibration can also be a trigger for some individuals. Experiencing AD does not mean that you have to stop being intimate with your partner each time it happens. Just change the activity and wait for the symptoms to resolve before returning to what you were doing.

If you find that you are regularly having episodes of AD while being sexually active please contact your spinal consultant or GP for advice.



BODY MATTERS



Managing Pain

Many women with a spinal cord injury or cauda equina syndrome diagnosis will also experience chronic pain, both nerve and musculoskeletal in origin. When first returning to sexual activity after your injury it is worth considering your pain levels and scheduling sex to be at a time when you have good coverage from your pain medication(s). This way you can ensure that sex is a positive experience and not linked to making your pain increase. It is not healthy to develop a link between sexual activity and pain as it will start to impact on your libido and motivation to be sexually active. If you find that this is an issue for you, please reach out and seek advice from a healthcare professional, such as your GP or spinal consultant, to ensure that this doesn't become a long-term concern for you.

Some women with an incomplete spinal cord injury or cauda equina syndrome can experience areas of hypersensitivity, including in their genital areas, as a result of their injury. Depending on where the hypersensitivity is there may be therapeutic options you can trial with the aim of reducing the negative sensations you feel. You may also find that, with stimulation overtime, the hypersensitivity will dampen down and feel less painful. If hypersensitivity occurs, please reach out for support from your spinal consultant or GP as there may be options available to you to help with this.

Many women report that they experience less pain after being sexually active as the release of hormones and endorphins during sexual activity can be a natural pain killer.

Managing Fatigue

Fatigue can be a challenge for anyone with a spinal cord injury or cauda equina syndrome diagnosis. When you feel tired often the last thing you want to do is have sex. When pacing and prioritising your energy it is important that you remember to consider allocating time for you to spend with your partner. These activities don't have to necessarily always be sexual in nature. Ensuring that you have quality time to spend together as a couple, dating, or just enjoying each other's company, can be just as important to a relationship intimacy as sexual activities.

Spasms and spasticity

Getting to know your spasms and spasticity can help you manage them during sexual activity. If there are areas of your body where touch causes spasms, communicating this with your partner can be helpful so they can try to avoid these locations and reduce the likelihood of triggering spasms.

You may also find that certain positions can elicit spasms. For example, many full-time wheelchair users find that returning to bed and lying flat can initially increase spasms as the hips and abdomen are stretched out. In this situation, carrying out some stretches or spending time lying prone, if you can, before sexual activity may help to reduce spasms. These stretches can also be incorporated into foreplay, for example, through a back massage from your partner.

Lubrication

There are many reasons that someone can experience vaginal dryness after a spinal cord injury or cauda equina syndrome diagnosis. It could be due to side effects linked to medication, delays in arousal, stress or hormonal causes, such as peri-menopause or menopause. Attempting sex without sufficient lubrication may lead to pain, or even autonomic dysreflexia for high level injuries, therefore it is important to use lubrication, if required.

There are many different lubricants on the market that you can choose from but not all are the best choice for maintaining a healthy vaginal pH (acidity), a healthy natural bacterial presence and avoiding infections. It is advised that you look for lubricants with low glycerine, paraben and glycol contents as these can increase the risk of vaginal irritation or thrush when using a lubricant regularly. It is also recommended that you steer clear of ones with additional additives such as fragrances, tastes or cooling/tingling effects as these can sometimes cause irritation. Products, such as the YES brand (www.yesyesyes.org) and SUTIL (www.sutilvibes.com), are recommended and available from most high street chemists or sexual product retailers.

It is advised that you try a skin test on your vulval area prior to using a new brand of lubricant during sexual activity. If you do experience any discomfort, pain or itchiness when using a lubricant wash it off immediately and stop using that product.

Water-based lubricants are safe to use with condoms and wash off easily after use without leaving a residue. They are also good for natural moisturising of the vagina which can have additional benefits in peri- and post-menopausal women. Oil based lubricants can last longer during sex but have a tendency to linger after use and will damage latex condoms leaving you at risk of pregnancy (if engaging in heterosexual sex) or sexually transmitted infections. Silicone based lubricants also last for a longer time and work well in water but are not compatible with silicone sex toys as they can damage the surface of them leaving them feeling sticky and difficult to clean.

Never use massage oil as a lubricant as it can cause vaginal irritation and infections. It can also cause a latex condom to break down and become porous, putting you at a higher risk of pregnancy (if engaging in heterosexual sex) and sexually transmitted diseases.

Enhancing pleasure

Having a spinal cord injury will not diminish any memories you have of sexual experiences prior to your spinal cord injury or cauda equina syndrome diagnosis. It is therefore possible to use these experiences to enhance what you feel and experience during sexual activity post injury. You will still be able to remember how something felt or how it made you feel positively to embellish experiences after injury. Using fantasies can also help enhance your experiences. Remember you have five senses. Not all stimulation has to come through touch. Activities such as listening to music, telling your partner what you want to do to them or how they make you feel, using food during foreplay or watching pornography can all increase libido and sexual desire and therefore can be used to enhance a healthy sexual relationship.

Using sex toys

There are lots of different stimulation aids and toys available on the general market that can be beneficial and enjoyable for women with a spinal cord injury. If you have limited hand function shop around for different size and shape options as the market is now saturated with different size and shape sex toys.

Vibrators and suction vibrators can provide intense stimulation to the clitoris to help achieve orgasm, either alone or with a partner. They can also be used on other body parts, such as the nipples, too. Ensure, if using the sex toy in your vaginal area, that you consider how lubricated you are before use to avoid any skin damage or friction issues. Also ensure you clean them well after use to avoid the risk of potential infections developing when next using them.



Kink

Sex and sexual expression is not necessarily always related to penetrative sex. It is still possible to have erotic, sensual and satisfying experiences, such as by engaging in kink practices, following spinal cord injury or cauda equina syndrome. Role play and dressing up can provide playful experiences that can be fun and sexually enjoyable.

Extra care will need to be taken if using forms of bondage or BDSM (Bondage and Discipline, Dominance and Submission, Sadism and Masochism) below your level of injury. Sensation would have previously been a protective factor for you and if you can no longer feel how tight knots are or if you are experiencing friction you may develop blisters or skin damage without being aware at the time. Ensure you are careful with this practice and ensure you check your skin well after use to prevent any skin injuries from developing into pressure ulcers.

Depending on your level of injury you may have a reduction in respiratory function therefore breath play is not recommended. It can be risky and potentially life threatening for anyone regardless of disability, with some secondary complications that can occur days later. Therefore, if you chose to pursue this option please seek support from a sex therapist to establish that you are taking all necessary precautions to ensure it is as safe as possible.

Dating

Dating can be full of trials and tribulations at the best of times without having to also consider a disability. Sadly, there are people on internet dating sites that will target individuals with disabilities. This doesn't mean that you should avoid these forums, just be aware that these individuals exist and be extra vigilant. If someone is more interested in learning about your disability, or the equipment you use, rather than getting to know you as an individual then this may potentially be a red flag.

There is no right or wrong as to how much information about your spinal cord injury or cauda equina syndrome diagnosis that you share with a new partner and when. Those who are in a relationship at the time of their injury will often find that their partner knows more about their bladder and bowel management than they ever thought possible due to their involvement in goal planning meetings and discharge planning.

Other individuals who meet their partner at a later date will have to make a decision as to how much information they opt to share and when. Some women will choose to share everything so that their partner is fully informed at an early stage to avoid potential heartbreak in the future. Others will decide to keep certain details more private, particularly when it comes to information such as how they manage their bladder and bowel. The thought of sharing such personal details can feel very daunting and anxiety provoking due to the uncertainty of how someone will react to such information. Speaking to other people who have been through similar experiences can be beneficial. This could be fellow patients from your inpatient rehabilitation, peer support mentors through charities such as Spinal Injuries Association (SIA) and BackUp or through different support groups on social media sites, such as Facebook.



Care

Impact of carers

Starting or maintaining an intimate relationship when you have a full-time carer or care package can feel embarrassing or awkward however this shouldn't be a barrier to engaging in sexual activity. You need to set clear boundaries with carers around personal space and "alone time" with your partner. Those with high level injuries and respiratory care needs may opt to have their partner trained to be able to manage certain situations, such as suctioning or providing an assisted cough, to increase their privacy.

Although carers will not be directly involved in helping you access sexual activity, they can complete tasks to help facilitate this. For example, they should be prepared to hoist you back into bed or into a shower chair so you can then spend time, or take a shower, with your partner.

Carer vs partner role

It is important to consider the role you are happy for a partner to take in your personal care. Some individuals will be happy for their partner to support them with all of their care needs whereas others will have very clear boundaries as to what is acceptable/not acceptable for them to be involved with, particularly when it comes to bladder and bowel management. These boundaries should be discussed with a partner since their desire to want to help and support may clash with what you are happy for them to do. Having clear communication and boundaries can prevent any confusion and difficult situations in the future.

Sexual activity can start to blur these boundaries however as some sexual tasks have a close parallel to those performed by a carer eg. undressing. Stripping a partner in order to be intimate with them has very different aims and intentions compared to getting undressed as part of personal care so you may find that your boundaries for tasks shift according to the situation. Try to be open and discuss this with your partner so you can both understand the differences, reach compromises and ensure that everyone feels comfortable so there are no situations that spoil the moment for either of you.

Other tips for a healthy sex life

- Having a spinal cord injury or cauda equina syndrome diagnosis doesn't change your ability to pick up a sexually transmitted infection. It is therefore important that you practice safe sex, for example using a condom, to protect yourself
- Maintaining good diet and nutritional levels will have a secondary benefit to you sexually. Having a healthy body can help with self-confidence and feeling good about yourself which in turn can help with self-esteem and confidence in sexual situations.
- Continue to follow any exercises or stretches given to you during rehabilitation or from physiotherapy sessions. Maintaining your range of movement and/or exercise stamina can all have a positive impact on your sex life.
- Remember to keep up to date with health checks, such as routine cervical screening and mammograms to ensure that any issues are picked up and dealt with in a timely manner.
- Maintain good personal hygiene standards in your genital area. This will have benefits when sexually active but also reduce the risk of problems such as urinary tract infections.

Where to seek support

Spinal cord injury centres can be a great source of information and advice regarding sexuality after spinal cord injury or cauda equina syndrome diagnosis. There is often a healthcare professional who has a specialist interest in this area within each unit who may be able to advise or support you.

Spinal charities, such as the Spinal Injuries Association (SIA), BackUp and the Cauda Equina Champions Charity, offer support through peer mentoring and counselling. Exploring these services can be beneficial as they often supply a lived experience and provide a safe and supported environment to chat with someone who understands life with a spinal cord injury.

There are lots of support options within private services. Many individuals, and couples, can find accessing psychosexual therapy particularly beneficial when navigating the change an injury can have on their relationship. This can sometimes be accessed through a GP but on the whole is likely to be a private investment. The College of Sexual and Relationship Therapists (COSRT) has a directory of registered therapists that you can search by location.

Social media sites, such as Instagram, TikTok and YouTube, have various disabled influencers who use these platforms to talk openly about topics such as dating, sex and relationships so may be a great source of information. There are also various groups you can join on Facebook that provide a supportive environment, for women with a spinal cord injury or cauda equina diagnosis.

Links

Backup - Offer peer support and mentoring on life after SCI
<https://www.backuptrust.org.uk/support-for-you/mentoring>

Cauda Equina Champions Charity - Provide psychosexual support for individuals with a cauda equina syndrome diagnosis that you can self-refer for.
<https://www.championscharity.org.uk/our-services/psychosexual-therapy/>

College of Sexual and Relationship Therapists (COSRT) - Have a directory of psychosexual therapists by location.
<https://www.cosrt.org.uk/>

Enhance the UK - Provide information and support on dating, relationships, intimacy, sex and disability
<https://enhancetheuk.org/>

Sex and the Spine (Youtube) - Video resources on various topics related to sexuality and spinal cord injury for both males and females.
<https://www.youtube.com/@sexandthespine3447>

Spinal Injuries Association (SIA) - Offer Support Network Coordinators and a Knowledge Hub and psychosexual counselling
<https://www.spinal.co.uk>

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About SIA

Spinal Injuries Association (SIA) is the UK's leading charity for everyone affected by spinal cord injury. We provide free, specialist support to help you navigate the mental and physical challenges you may face now and throughout your life.

Our nationwide team can connect you with our trusted network of experts and partners, offering guidance on legal matters, care, housing, finance, mental health and more. You can reach our support line on **0800 980 0501**.

We are the voice of people with spinal cord injury. Through our expertise we can connect you to the services and organisations you need through our network for all. Join the SIA community for free at www.spinal.co.uk

Tell us what you think

If you have any comments about our publications, you can email academy@spinal.co.uk

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