

Sexuality and Reproductive Health in Adults with Spinal Cord Injury: What You Should Know

**A Guide for People
with Spinal Cord Injury**

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**A Guide for People
with Spinal Cord Injury**

**Consortium for Spinal Cord Medicine
and Paralyzed Veterans of America**

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Foreword

The Consortium for Spinal Cord Medicine is pleased to provide this consumer guide, *Sexuality and Reproductive Health for Adults with Spinal Cord Injury*. In developing this guide, we have maintained the belief that all people who want to be sexually active after spinal cord injury (SCI) should have the knowledge they need to make that decision and be comfortable with their sex life whatever their level of injury. In addition, we believe that a person who has experienced spinal cord injury has the right to receive the most up-to-date information about how SCI affects sexuality and sexual function. Providing that information to people with SCI and their partners has been our goal in writing this consumer guide.

Although this guide discusses many of the physical aspects of sexuality after injury, we also realize that emotional, psychological, and relationship issues are just as important. Such issues as body image, communication, and self-esteem play a pivotal role in how we express our sexuality. Feeling sad, stressful, and alone after an injury is understandable. For some individuals, the emotional issues after SCI are short-lived; for others these feelings can last for many years and can be emotionally painful and hamper relationships or satisfying sexual experiences. It is important to recognize these feelings to begin to work through them and seek support if needed.

Becoming sexually active and enjoying sex after SCI may take time and practice. For many people, regaining courage and confidence is the first step to becoming involved in a relationship that may lead to physical and emotional intimacy. This means feeling like a person who is important, worthwhile, and has something to offer to another person. For all people, feeling good about yourself is the foundation for a positive and healthy sexual experience. It is important to remember, however, that a satisfying sexual experience is the goal and may take time and practice after injury.

Throughout this guide, you will often read how important it is to be open to new experiences after an injury and to try new ways of receiving and giving sexual pleasure. To accomplish this, it is important to understand how your body works after

injury. In a relationship, it is also important to be able to share your feelings and yourself with someone that you care about. It is our hope that this guide will answer some of your questions about sexuality after SCI. Ultimately, what you do with this knowledge and whether you chose to be sexually active is your decision.

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*Clinical Practice Guideline on Sexuality and Reproductive Health
for Adults with Spinal Cord Injury*

Introduction

THE IMPORTANCE OF SEXUALITY AND REPRODUCTIVE HEALTH

After someone has experienced spinal cord injury (SCI) one of the first thoughts is often, “will I be able to have sex?” Unfortunately, it can be difficult to ask this question. Talking about sex can be difficult. Fortunately, in recent years, health-care professionals and people with SCI have come to realize that it is extremely important to talk, listen, and learn about sexuality and reproductive health after SCI. Furthermore, clinicians and researchers have found that sexual satisfaction remains an important part of life for people with an SCI.

Sexuality affects how we feel about ourselves and our relationships. “Sexuality” can mean different things to different people, but almost everyone agrees it is more than just the act of having sex. Sexuality affects how we see ourselves as individuals; how we see ourselves in our families and communities; the relationships we have with others; and our moral, spiritual, and cultural beliefs. Sexuality can be expressed in many different ways—as part of a romantic relationship, in friendships, in our appearance, and even when we are alone with our own thoughts, feelings, and fantasies.

Unfortunately, in modern society “sexiness” is often equated with having a particular body type, for both men and women. Almost everyone has to work against the urge to compare themselves to the so-called “perfect” images on TV, in movies, and in magazines—these images are nearly impossible for anyone to duplicate in real life. At the same time, if we really consider the characteristics that make someone seem “sexy,” we find a mix of a million things: someone’s ability to be affectionate, funny, kind, loving, physically unusual in some way, quirky, or unique in appearance, style, or dress, etc. In other words, in the real world being attractive is something intangible, and feeling attractive is something that everyone has to work on by enhancing the things we love about ourselves and accepting the things that we cannot change.

BODY IMAGE AND SEXUALITY

“Body image” refers to the way we see or perceive our own appearance. It can have an impact on sexual function and desire. After a serious injury, it is natural that your feelings about your body are in a state of confusion and conflict. It may take some time to feel good about yourself and about your body after an injury like SCI.

Even if you had positive feelings about your body before your injury, there will probably be an adjustment period afterward, during which you will need to spend time becoming accustomed to your changed body and learning to love and take care of it. Focus on the things you love about yourself, your own unique talents and personality. Some steps you can take may include:

- Spending time with other people with SCI who can share experiences and ideas about how to achieve a positive body image;
- Finding role models in the media (sports, TV, politics, writers, artists, etc.) with SCI or other challenges;
- Selecting comfortable clothing that works well with your needs and expresses your individuality;
- Discovering ways to express your individual style with hair styles or colors, jewelry, body art, or other style choices;
- Choosing assistive equipment that can be modified to express your style; e.g., wheelchairs in your favorite color or that can be decorated with decals or other artwork;
- Enjoying any activities that indulge your body and relax your mind, such as manicures, facials, pedicures, hair styling, and massage;
- In general, be creative in your own particular way—enjoying the music you love, looking at your favorite artwork, going to movies, concerts, plays, participating in artistic activities, etc.

The list is endless. Participating in activities that you love, whether they are related to how you look (e.g., fashion or exercise) or how you feel and express yourself (e.g., music, art, literature) will make you feel good about yourself, and feeling good about who you are leads to a better body image and comfort with your sexuality.

REPRODUCTIVE HEALTH AND SEXUALITY

Reproductive health is also a big component of sexuality. For many people, having a family and children is a key part of their life plan, and many individuals with SCI become biological mothers or fathers. Even for people who don't want to have children, want to adopt, or who already have children at the time of their injury—maintaining reproductive health is extremely important to overall quality of life and well-being.

Just as there are many ways to express sexuality after SCI, there are also many solutions to any changes that people may face. This consumer guide is aimed at making sure you and the other people in your life understand all the options and possibilities available to enhance sexuality and maintain reproductive health after SCI.

SEX AFTER SCI

Sexual function is more than just the physical ability to have sex. It is also about feeling like a sexual being and, if you choose, to share your sexuality with another person. No injury, no matter how serious, can take away your ability to have a relationship, experience love, and experience the attraction between two people.

If you have a spouse or partner, it is important to begin experimenting with him or her after your injury in order to find out how sex may have changed and how the two of you can share sexual pleasure. If you do not have a spouse or partner, or if you would prefer to learn about the changes in your body on your own, you may want to use your own touch to find out how you respond sexually after injury. Because sensation and functioning may change over time, the sexual feelings you experience immediately after injury may change over time as well.

Try to start talking about sexuality and sexual function as early as possible in the rehabilitation process. Ask your doctor, nurse, therapist, or counselor direct and honest questions, and bear in mind if your provider isn't giving you the information you need, you can always find a health-care provider who

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is helpful and knowledgeable about this topic. If you don't feel comfortable talking with your health-care provider about these issues, find a provider with whom you feel more comfortable discussing these questions.

MAINTAINING SEXUAL WELL-BEING

In order to achieve a feeling of sexual well-being, it helps to understand how your body works after SCI. A good understanding of your body can be achieved through a variety of methods, such as formal sex education, informal discussions with your doctor or other clinician, discussions with other people with SCI, experimentation and discovery with a partner, or masturbation. Masturbation can be useful for learning about your body and your sexual responses after SCI.

Education

LEARNING ABOUT SEXUALITY AFTER SCI

Your health-care providers not only can give you information about the physical and relationship aspects of sexuality after SCI, they also can help you in making sure that your sexual life after injury is enjoyable and fulfilling to you and your partner.

Sometimes, after experiencing a traumatic event like a spinal cord injury, people feel vulnerable and find it difficult to talk about feelings and personal matters, such as relationships and sexuality. Only you and your spouse or partner, friends, lovers, or family members can decide how and how much to communicate about these matters. Remember, talking about such matters is not easy for anyone, but communication is important and will help to improve the quality of your relationship and your sexual experiences.

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A good starting point can be to think of specific questions about sex that you have for your health-care provider. Most people wonder how sex will be different for them now and whether it will still be satisfying for their partner.

It may be important to consider how old you were when you were injured. If you were injured at a very young age, you may not have had sexual experiences or education about sex before your SCI. In that case, you might want more extensive information about sex, sexuality, pregnancy, and reproductive health. On the other hand, if you were injured later in life, you may have had sexual experiences and want information more specific to sexual activity *after* SCI or information related to conceiving children or how the effects of getting older may affect sexuality.

Although you can certainly talk with your health-care provider, it is important to remember that health-care providers (e.g., doctors, nurses, psychologists, physical therapists, etc.) must maintain professional boundaries at all times. It is never acceptable for any member of your health-care team to suggest, encourage, or engage in sexual activity with patients. If you ever feel uncomfortable with a health-care provider, it is important to report the provider to someone else and take whatever precautions are necessary for your own well-being.

COMMUNICATION

In this section, let's look at some suggestions for clear communication between you and your health-care team and between you and your sexual partner so that you can get the information that you want and need.

If you feel comfortable, try to initiate and maintain an open discussion with your health-care team about sex and ask any questions you might have about sexual activity and fertility. These questions may be about erections, ejaculation, orgasm, pain, fertility, birth control, or sexually transmitted diseases. Your health-care team can be an excellent resource for information about sex. If you don't feel you're getting the information you need, try not to become discouraged. As with many health issues, some health-care providers are more knowledgeable and are better at communicating their knowledge than others. If you're not comfortable talking about sex with your current doctor, try to find another medical professional with whom you *do* feel comfortable talking so that you can get the information you need.

If for any reason you are not comfortable discussing sexuality or sexual functioning (let's face it: many of us have not had to *talk* much about sex), look for ways to make it easier. The following are some suggestions that might help:

- Write down your questions and take them with you to your doctor's appointment.
- Ask your partner, spouse, or a friend to go with you when you see your doctor.
- Take this consumer guide (or other written materials) with you to your appointment and show it to your doctor.

For example, you can open this consumer guide and say, "It says here it's important for us to talk about sexual function. I want to be sure we cover these issues as part of my treatment."

EXPLICIT EDUCATIONAL MATERIALS

Some sex educators find using explicit educational materials—materials that show people engaging in sexual activity after SCI—to be useful for teaching people about sex after injury. These materials can be videos, pictures, books, magazines, etc. Visual illustration of people with SCI talking about sex or having sex can be instructional; however, while sexually explicit information may be helpful for some people, others may prefer not to view these kinds of materials. Be sure to express your personal choice if presented with the option of looking at sexual materials for instructional purposes. If you choose to view such materials, it's a good idea to discuss them with your partner or with a professional. Otherwise, viewing such material could lead to some confusion or anxiety about sex.

Sexual Response and Enjoyment

EFFECT OF INJURY ON SEXUAL FUNCTION, RESPONSIVENESS, AND EXPRESSION

The temporary loss of sexual desire can be expected after any traumatic occurrence, such as spinal cord injury. However, if this loss of desire lasts for an extended period of time, it may be a sign that you are experiencing an unrecognized medical condition, such as a urinary tract infection, hormone deficiencies, depression, or negative side effects from medications. It is important to talk to your doctor if your desire for sexual activity

does not return once you begin to resume other regular aspects of your life. Also, if you are experiencing pain or discomfort during sexual activity, your desire for sex is naturally going to be diminished. Your health-care providers can help you with these problems.

After experiencing SCI, people lose sensation in various parts of their body; this can include the penis, testicles, vagina, or clitoris. It is important to recognize that other parts of the body can provide sensual pleasure when sensation in the genitals has been compromised by injury. After SCI, other parts of your body, such as ears, neck, underarms, lips, tongue, hands, fingers, feet, toes, and face can be sources of sensual and sexual pleasure. These parts of the body are often used for sensual pleasure, and for some people after injury, they may be more sensitive.

Also, the area of your chest where the sensation changes is often found to be a sensitive area that can provide sensual pleasure. A sufficient amount of stimulation of any of these areas may result in sexual pleasure. In general, the amount of stimulation necessary for sexual arousal will vary from person to person depending on both physical and psychological factors. Remember, however, it takes time and lots of experimentation to figure out what works best for you.

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EXPLORING ALL YOUR SENSES

To enhance sexual pleasure after SCI, it is often helpful to think about all your available senses. That is to say, if you are a person who has lost sensation in your sexual organs, try to enhance your sexual pleasure by using other senses. Some examples include:

Hearing: Talking about your desires, fantasies, and feelings can enhance sexual interactions. This kind of talk can include expressing your care and love for your partner. Also, many people use music to set a mood and bring to mind positive memories and feelings.

Sight: People are often stimulated by watching sexual contact, penetration, or pleasure experienced by another person.

Many people can become sexually stimulated by watching their partner become aroused (a hand mirror may be useful when immobility makes it difficult to see parts of the body). Images in movies or books can also be sexually arousing. Lighting (candles or dimming lamps) may enhance the mood.

Smell: The smells associated with sexual activity can be arousing. For some people, the use of perfume, room fragrances, scented candles, or incense can help create an erotic atmosphere.

Taste: The tastes associated with kissing, licking, or oral stimulation can be sexually arousing. Many people find certain foods and flavors sexually stimulating, for example, certain fruit, chocolates, or alcoholic beverages. *Remember:* you need to be sure that anything you eat or drink does not interfere with any medications you are taking or negatively impact health conditions you may have.

Touch: The level of physical sensation (touch) you can feel after SCI is related to your level of injury. Be sure to work with your health-care providers as well as sexual partner to find out where on your body you can feel sensation. After SCI, you may want to explore the possibility of *new* erogenous zones—places on your body that, when touched, can be sexually stimulating—such as the neck, face, underarms, nipples, etc. Many activities, such as kissing, massaging, holding hands, or being held, may provide a sense of intimacy and sensuality. Try to be open and use your creativity in exploring new things. Also, if touch or stimulation in a certain area is not pleasant and is uncomfortable, it is important to communicate this to your partner as well.

Imagination: Your imagination can be extremely powerful and sexually stimulating. Concentrating on your own private fantasies or sharing fantasies with a sexual partner can be very sexually satisfying.

GENITAL AROUSAL AND ORGASM IN WOMEN

A woman's ability to become sexually aroused and experience orgasm after SCI depends to some degree on her specific injury, level of injury, and the amount of sensation retained in the genitals and other sex organs. There are many triggers for

sexual arousal (emotional, psychological, visual, physical, etc.). It is possible that after SCI a woman will need more prolonged stimulation to become aroused and to reach orgasm. Experimenting with your body through masturbation or with a partner are two ways to figure out how your body works post-injury and what works best and feels best.

Sometimes a vibrator or other sexual device can also add sexual pleasure for either partner. Some women have found that external devices, such as the EROS™ Clitoral Therapy Device (CTD), can be helpful in achieving arousal and orgasm. The EROS CTD is a battery-operated device that creates suction around the external genitalia, thus increasing blood flow to the clitoris and increasing sexual arousal. Usually the device uses a cuplike apparatus that is placed over the clitoris. When a vacuum is created, increased blood flow creates clitoral engorgement. Increased blood flow to the genitalia leads to increased vaginal lubrication and enhanced ability to achieve orgasm. These devices require a doctor's prescription and are usually not covered by health insurance.

EJACULATION AND ORGASM IN MEN

Men with SCI who are unable to ejaculate during intercourse sometimes find they can achieve ejaculation and orgasm during masturbation or with stimulation from a partner or vibrator. The use of a vibrator on either genital or nongenital areas may significantly improve the chances for ejaculation. Vibrators designed specifically for people with SCI are available for this purpose (these are used both to retrieve sperm in clinical settings and for pleasure). These require a doctor's prescription, but less expensive vibrators are available online or in stores that specialize in sexual aids.

Many men with SCI describe pleasurable sensations that they characterize as orgasms, even if they are not able to ejaculate. **People with injuries at T6 and above must be aware that sexual stimulation increases the chance of developing autonomic dysreflexia (AD), a sudden rise in blood pressure that is a serious life-threatening condition, so it is important to be aware of the symptoms and take precautions as necessary.**

ERECTIONS

Men normally have two kinds of erections: 1) psychogenic erections or 2) reflex erections. A psychogenic erection begins in the brain, when a man sees, feels, or hears something that is sexually stimulating. This message is sent to the brain, which produces signals that are sent through the nerves of the spinal cord and triggers a reaction in the penis (an erection).

A reflex erection is involuntary and can occur *without* sexually specific thoughts or sexually specific stimulation. A reflex erection can occur as a result of direct physical contact to the penis or other erotic area (such as ears, nipples, or neck) without any sexual intent. Such contact can occur, for example, when a blanket or article of clothing rubs against a part of one's body. Men with SCI may experience reflex erections, which usually go away on their own after a short period of time—less than 5 minutes—or when the physical contact stops. Reflex erections may not be adequate for intercourse because of difficulty maintaining the erections.

ERECTILE DYSFUNCTION

Erectile dysfunction (ED) is the inability to achieve and/or maintain an erection. There are many different ways to treat ED, and it is important to have your doctor thoroughly assess your condition so that the best treatment method can be prescribed. You can help your doctor diagnose your condition by letting him or her know if you can achieve an erection through genital stimulation or stimulation to other parts of your body. If you can achieve an erection, it may be helpful for your doctor to know how long you can maintain an erection or if you have problems keeping the erection. This information will help your doctor determine which type of treatment may help your situation.

When SCI is the primary cause of your sexual difficulties, your doctor will most likely want you to try the least invasive method of treatment first and then use more advanced treatments later on if needed. Usually, in this kind of situation, a doctor will start with the easiest remedy and then progress, if necessary, to more complicated ways of easing the problem.

TESTOSTERONE

Testosterone is a hormone produced in the testicles (or testes). A lack of testosterone can affect your sex drive and your ability to achieve and maintain an erection. Testosterone deficiency occurs for a variety of reasons in men whether there has been injury to the spinal cord or not, but it occurs somewhat more commonly in men with SCI. Sometimes it is a condition that existed before SCI but was not recognized until after the injury.

There are many possible reasons a man's body may produce less testosterone after SCI, including chronic illnesses, bladder and testicular infections, brain injury, problems with the pituitary gland, metabolic problems, diabetes, and use of medications that have the unintended side effect of suppressing testosterone (e.g., narcotics or gastrointestinal medications). Treatment of these illnesses and/or adjustment of medications may lead to a return of normal testosterone levels. If this does not occur, you may need treatment specifically for testosterone deficiency.

TESTOSTERONE REPLACEMENT THERAPY

If you are experiencing erectile dysfunction (ED) or an unusual lack of sexual desire, it may be the result of a testosterone deficiency. This means that your body is not producing a sufficient amount of the hormone testosterone. Your doctor can measure your testosterone level using blood tests. Testosterone replacement therapy is used for men who have been diagnosed with testosterone deficiency (also referred to as "hypogonadism"). Testosterone deficiency can affect your overall physical health (i.e., cardiovascular, bone health, and body fat composition), as well as your mood, fertility levels, and sexual function. If you are placed on testosterone replacement therapy, your doctor will monitor testosterone levels using blood tests in order to ensure that your body is maintaining a healthy level of the hormone testosterone.

Testosterone replacement therapy in men with SCI should be considered only after your doctor determines that you do in fact have a testosterone deficiency. Your doctor will want to consider both observable symptoms (such as fatigue, lack of

sexual desire, declining strength, or loss of bone density) and will want to get laboratory confirmation by testing your blood to confirm that testosterone levels are truly below normal.

ORAL MEDICATIONS TO TREAT ED

A class of medications called “phosphodiesterase type 5 inhibitors” (PDE5s) is highly effective for treating ED in men with SCI. PDE5s include the medications Sildenafil (Viagra®), Vardenafil (Levitra, as needed), and Tadalafil (Cialis®, once daily), which you may have heard of. Since these medications have been so well accepted, it is very likely that new ED medications will be developed in the future.

Men who take nitrates (for a heart condition), certain alpha blockers (for high blood pressure), or have the condition called “retinitis pigmentosa” (a hereditary eye disease) should not take current erection medications. Also, if you take nitropaste for the treatment of autonomic dysreflexia, the use of PDE5 medications could cause life-threatening hypotension, or low blood pressure. *You probably should not take erection medications if you have been diagnosed with hypotension or if you are using other erection-enhancement therapies.* Your doctor is the best judge of what is safe for your individual case. Be sure he or she knows your medical history and knows exactly what medications and therapies you are using when considering the use of medications for erectile dysfunction.

PDE5 medications do not create an erection without physical or mental stimulation; rather, they assist men in gaining more penile rigidity and in sustaining an erection for longer periods of time. PDE5s are taken orally, usually about 1 to 2 hours before sexual activity. Sometimes these medications may not work the first time and your doctor may make some adjustments in how much medication you take and how soon you take it before sex.

A possible complication with various erection medications is a condition called “priapism.” Priapism is a serious medical condition in which the erect penis does not return to its flaccid state within 4 hours despite the absence of physical and psychological stimulation. **Priapism is considered a serious medical condition that should be treated by a qualified medical professional immediately.**

INTRACAVERNOSAL INJECTIONS TO TREAT ED

Intracavernosal injections are used to treat ED and can be a good alternative when oral medications don't work or if you cannot take oral medications because of other health issues. With this method of erectile enhancement, medicine is injected into the penis either by the man with SCI or his partner. Sometimes men with sensation in the penis experience a short period of minor pain at the injection site. Your doctor or other health-care professionals will provide you and/or your partner with instructions on the penile injection method.

With this method of treatment, you will have to work with your doctor to determine the correct dose and strength of the medication. If used properly, intracavernosal injection should allow for an erection to occur within 5 to 10 minutes after injection and last approximately 1 hour. When pills are not effective for improving an erection, such injections are usually the next best choice.

As with oral medications, a possible complication with intracavernosal injections is priapism, a condition in which the penis does not return to its flaccid state within 4 hours. Priapism should be treated by a qualified medical professional immediately.

VACUUM DEVICES TO TREAT ED

A vacuum constrictive device (VCD) for the treatment of ED consists of a long tube with an elastic penile ring. The VCD is placed over the shaft of the penis in order to create a vacuum (suction). The suction causes blood to flow to the penis making it become hard. Once the penis is hard, the elastic penile ring is slipped off the tube and placed over the base of the penis to maintain an erection that will be sufficient for sexual intercourse.

VCDs use a pump that is either manually powered or powered by battery. In order to use a VCD, you usually have to transfer out of your wheelchair and lie down so that the VCD can create a good vacuum seal at the base of the penis. Using a VCD requires some manual dexterity. If you have limited use of your hands and/or are tetraplegic, your sexual partner can assist with the process. **The elastic penile ring should never be left in place for more than 30 minutes. If you leave the ring on the penis for too long or fall**

asleep with the ring in place, you may develop more serious complications from blood beginning to clot in the penis. This is a severe complication that can cause permanent damage to the penis and should never be taken lightly. For this reason, it is not a good idea to use a ring if you have been drinking alcohol or using any form of recreational drugs. Vacuum devices tend to be more acceptable for people who are in established sexual relationships where spontaneity is not a major issue. Many people tend to feel that the vacuum device seems unnatural and is clumsy to use. It is not a good idea to use these devices if you are taking blood thinners or have been diagnosed with sickle cell disease.

VIBRATORS AND PENILE RINGS

Vibrators purchased online or at a store that specializes in sexual aids sometimes provide the stimulation necessary for a man to achieve an erection. Even if the erection does not occur, a vibrator may be a good source of sensual pleasure for both men and women. Many men also use a simple rubber band or a penis ring, purchased online or at a store that specializes in sexual aids, to improve their erections. These bands are slipped around the base of the penis and keep the penis hard by preventing the blood from leaving the penis. **As with a VCD, rings left on the penis for more than 30 minutes may lead to more serious complications from blood beginning to clot in the penis, which can cause permanent damage. For this reason, it is not a good idea to use a ring if you have been drinking alcohol or using any form of recreational drugs.**

PENILE IMPLANTS TO TREAT ED

Penile implants can be very effective and satisfying for the treatment of ED. However, a penile implant is usually considered a last option for restoring sexual function because the procedure is permanent. That is, once put in place, the implant destroys the surrounding tissue in the penis so if the implant is removed, alternative methods for treating ED are no longer an option. As with any permanent medical procedure, people need to very carefully consider the decision to insert a penile

implant. This is something to talk about at length with your partner.

There are two kinds of implants available: a flexible silicone device and a more complex inflatable hydraulic device. With the flexible device, the penis is always semi-rigid and only needs to be moved into the right position for sexual intercourse. The inflatable hydraulic device employs a more complex design, which some people prefer because after use the penis returns to a natural flaccid position.

ALTERNATIVES TO VAGINAL INTERCOURSE

For all people, sex and sexual expression includes a variety of activities—not simply penis-vagina intercourse. People with SCI may need or want to explore a wider range of sexual activities in order to find sexual pleasure. Limiting sexual activity strictly to intercourse may greatly reduce the opportunities for sexual satisfaction and pleasure. Be creative and open your mind to trying different things in your sexual life.

Limiting sexual activity strictly to intercourse may greatly reduce the opportunities for sexual satisfaction and pleasure.

There are many options for sexual expression and pleasure for people with SCI. It is important to find a safe and comfortable place where you can explore new or different sexual practices or positions to enhance sexual experiences and pleasure. This may be done alone or with a partner. You may want to try different or alternative sexual positions or use the mouth, tongue, or hands for sexual pleasure.

Erotic pleasure from touching, kissing, licking, and intimate stroking is an important part of a healthy sexual experience. After SCI, sensual exploration between partners gives couples important information about how erotic pleasure can be achieved and enjoyed. Sometimes touching and caressing parts of the body that have actually lost sensation can be sensual, sexually arousing, and pleasurable, and discovering this is often a matter of trial and error. For other people, touching areas where sensation is intact also can be pleasurable. It is important to realize that finding ways to enjoy sexual pleasure after SCI may take some time and experimentation, so be patient.

MASTURBATION

For some people, masturbation is associated with negative societal, religious, or cultural connotations; however, masturbation offers a safe method of self-pleasuring and self-exploration. It is a positive and healthy way to learn about your own sexual responsiveness—what works and what doesn't—without the potential stress of including another person. It can be especially important early after injury when learning about your body is an important thing to do. Whether or not you are in a relationship, masturbation can be a healthy, enjoyable method to achieve sexual pleasure and to enjoy sexual arousal.

NONPRESCRIPTION SEXUAL REMEDIES

If you watch TV, surf the Internet, or listen to the radio, you are probably aware that there are many over-the-counter treatments for erectile dysfunction and sexual enhancement. These may include herbal remedies, devices to enlarge the penis, various penile stretching exercises, and other devices that have not been approved by the Federal Drug Administration (FDA). You should be aware that these devices, supplements, and medicines may not be safe if they have not obtained FDA approval.

Medications sold via the Internet may not be approved by the FDA, may be considered illegal by the U.S. government, and may contain unknown and potentially dangerous substances. Also, nonprescription treatments may not include a list of all ingredients, so you won't know if you might be allergic to them or if they can negatively interact with other medications that you are taking. Before you try any nonprescription medications or remedies, take the time to discuss them with your doctor. **Your doctor may be able to suggest safer alternatives and can alert you to potential dangers. It's important to be a cautious consumer and to maintain a healthy degree of skepticism about nonprescription alternatives.**

SEX TOYS

Sexual assistive devices (more commonly known as "sex toys") are sometimes used to enhance sexual experiences.

Many people with SCI find sexual assistive devices, such as vibrators or penis rings, helpful in improving sexual fulfillment and pleasure. Such devices can often help to make up for the lack of sensation or movement in some parts of your body. For some people with SCI, using vibrators or other sexual devices may be preferred over more traditional prescribed medical treatments to enhance sexual pleasure and/or orgasm.

If you are considering using sex toys, it's a good idea to first talk to your health-care provider in order to find out about the possible complications associated with such devices. For example, penile rings can help men to keep an erection, but they can also interfere with normal blood flow in the penis (and should never be kept in place for more than 30 minutes). Vibrators can also help achieve an erection and can help women to become sexually stimulated; however, they may cause autonomic dysreflexia in individuals with injuries at T6 and above.

Any device that causes friction on the skin can potentially lead to skin breakdown. It's important to be aware *if any red spots begin to develop*. **Ask your health-care provider about precautions to take to protect your skin, prevent prolonged penile constriction, and to prevent autonomic dysreflexia.**

Female Reproductive Health and Fertility

MENSTRUATION

Sometimes women don't start menstruating again for a while after experiencing SCI (usually about six months post-injury), so if you're at an age at which you are menstruating, it's a good idea to get information about using feminine hygiene products before the end of your initial rehabilitation. Your health-care team can help you to figure out the best and easiest way to use tampons or sanitary pads with consideration to your level of dexterity and personal preferences. Some women may just not be able to use their hands to manipulate sanitary products. In this case your health-care team can help you learn how to instruct attendants or partners on how to best help you with these products.

Some women may experience more severe premenstrual and menstrual symptoms after SCI as compared to before their injury. Symptoms, such as menstrual cramps or a group of symptoms called “dysmenorrhea,” which can include sharp, throbbing, or dull pain, nausea, or burning, may become more intense post-injury. These menstrual symptoms can be treated with anti-inflammatory medications, such as naproxen, ibuprofen, or mefenamic acid (your doctor can recommend the best over-the-counter or prescription medication for your specific symptoms).

GYNECOLOGICAL HEALTH

Gynecological concerns for women with SCI are generally the same as those for women without SCI. However, there are some issues specific to women who have experienced spinal cord injury—in particular, not feeling discomfort or pain that might prompt a woman without SCI to seek medical attention. For this reason (and for overall health) it is very important for women with SCI to schedule regular routine gynecological exams—these should include screening for reproductive health issues (pelvic exams, Pap smear, breast exams, etc.). These regular exams can help prevent problems before they occur or before they become serious. Remember to inquire about an accessible examination table and office when you call to set up an appointment. Also, it is a good idea to ask whether the doctor has experience treating women with disabilities.

Gynecological concerns for women with SCI are generally the same as those for women without SCI.

BIRTH CONTROL

Important considerations when choosing the best form of birth control include quality of circulation in the lower extremities, clotting abnormalities, remaining genital sensation, manual dexterity, potential problems with menstrual hygiene, and avoidance of skin breakdown (e.g., diaphragms for example may cause irritation to the lining inside the vagina).

Estimates indicate that more than 70 percent of women use birth control after SCI. The most popular form of birth control for women with SCI is the penile condom. The second most popular form of birth control is a permanent surgical procedure,

such as tubal ligation. **However, before making a decision to undergo permanent birth control procedures, you need to think about how sure you are that you do not want to become pregnant in the future.**

Oral contraception (“the pill”) is the third-most popular form of birth control for women with SCI. While there is no indication that the pill is more risky for women with SCI, any kind of hormonal birth control needs to be prescribed with caution. In general, your doctor should make sure there are no health risks specific to your birth control preference.

Intrauterine devices (IUDs) are associated with higher risk of pelvic inflammatory disease, which is a greater risk in women with SCI. Because you may not be able to detect pain as readily as before SCI, any internal device that may cause infection (or become dislodged) may be a poor choice. Again, discuss these issues with your doctor or health-care professional to determine what makes the most sense for you.

PREGNANCY

Some research has shown that the quality of life for a woman with SCI increases after childbirth—even though having a child creates additional demands and challenges, the positive aspects usually outweigh the difficulties. Women with SCI face unique challenges with pregnancy, and, unfortunately, some health-care providers do not provide enough information about becoming pregnant after SCI. For example, pregnant women with SCI have an increased risk of urinary tract infections, may experience breathing problems, and have a significant risk of experiencing autonomic dysreflexia.

During pregnancy you will definitely need expert help to adjust your wheelchair as your body changes throughout pregnancy. Some women with SCI need extra assistance during pregnancy for such activities as transferring in and out of the wheelchair, dressing, monitoring skin surfaces, and bowel and bladder care.

Along with all the physical changes, pregnancy also brings psychological changes due to hormonal fluctuations and the knowledge that soon you will be responsible for taking care of a baby (this can be both wonderful and scary). It is important to try to consider all these issues—the good and the bad—

and to talk to a specialist (and other women with SCI) prior to making the decision to become pregnant. Having a child is also stressful for the father as well. This is a time when open, honest communication between the couple is essential. Communicating with each other and having as much information as possible from providers helps to ensure that you and your partner will make an informed decision as to what is best for the two of you.

Prenatal care should begin as soon as you decide to become pregnant. Early involvement with an obstetrician is very important in order to get the best information about nutrition, vitamin supplements, and medication compliance. For most women, weight gain, immobility, bladder and bowel incontinence, digestive issues, and respiratory difficulties may accompany pregnancy (some of these problems may be worse for women with SCI). For women with SCI skin breakdown is also an important complication that should be monitored regularly.

All pregnant women should eat properly and refrain from smoking, drinking alcohol, or using illegal substances or any medications not approved by their obstetrician.

While pregnant, keep in mind that the techniques and strategies you used for movement before pregnancy may no longer work because of changes in body size, shape, and weight distribution. For example, some women who previously were able to enter the bathtub without assistance may need a tub bench and special assistance during pregnancy. It is best to err on the side of caution and take things slowly while pregnant.

Keep in mind that the techniques and strategies you used for movement before pregnancy may no longer work because of changes in body size, shape, and weight distribution.

Be sure to talk to your doctor about your bladder and bowel programs to determine whether or not you need to change your usual practices while pregnant. For example, indwelling catheters may need to be replaced by intermittent catheters and bowel programs may need to be adjusted during your pregnancy. Women who typically use a standard bed may need a hospital bed at some time during pregnancy.

Seatbelts and other driving equipment will probably have to be moved or adjusted to accommodate your changing size.

Also, joints are more at risk during pregnancy, particularly during the last trimester, due to hormonal changes and weight gain. For all these reasons it is very important to maintain open communication with your doctors, therapists, family, and partner during your pregnancy. All of these people can be important and helpful resources to you throughout your pregnancy.

CHILDBIRTH

As soon as you decide to have a baby you should see an obstetrician who has experience treating women with SCI. Talk to your doctor about how labor and delivery will be managed and be sure to make your doctor aware of your concerns and preferences. Some women with SCI need to be hospitalized before labor begins. For some pregnant women with SCI, it is difficult to know when labor begins because they may not feel the labor pains that a woman without SCI would feel. Talk to your doctor about how to recognize the onset of labor.

Some women become depressed after having a baby; this is characterized as “postpartum” depression. It is helpful to be aware in advance that this could happen to you. If you begin to feel sad or hopeless or have thoughts of hurting yourself or your child, contact your doctor immediately. There are excellent treatments available to help you through postpartum depression and enable you to enjoy your new baby and your new role as a mother.

AUTONOMIC DYSREFLEXIA AND CHILDBIRTH

For many women with SCI, the most serious complication related to labor and delivery is autonomic dysreflexia. Your doctor should be aware of this potential problem, but be sure to talk about it with your doctor to be absolutely sure he or she knows how to diagnose it and treat it if it does occur.

Autonomic dysreflexia can have symptoms that are similar to pre-eclampsia, which occurs with the same frequency in both able-bodied women and women with SCI. Pre-eclampsia is diagnosed when a pregnant woman develops high blood pressure and an abnormal amount of protein is detected in a

urine sample. **Both pre-eclampsia (which is the precursor to eclampsia) and autonomic dysreflexia are serious conditions; be sure your doctor understands the differences between the conditions and knows what to do if either is detected.**

MENOPAUSE

Research studies have demonstrated that there are no significant differences in the menopausal symptoms of women with SCI and those without SCI—in both cases symptoms and time of onset vary greatly from one person to the next. Some common symptoms of menopause are depressed mood or unusual fluctuations in mood, headaches, trouble sleeping, hot flashes, memory problems, bladder changes, dryness of the mucous membrane, and changes in skin. For women with SCI, symptoms of menopause may be the same as symptoms related to injury (and so may not be menopause at all). For this reason, talk to your doctor about any symptoms that you think may be related to menopause so that he or she can determine the cause and treat them correctly.

Male Fertility

Generally, the amount of sperm in the semen of men with SCI falls within the normal range; therefore, most men with SCI have sperm that can fertilize an ovum (egg) in order to achieve pregnancy. However, sperm *motility* (meaning the sperm's ability to move spontaneously in order to increase the chances of fertilizing an egg) tends to be slowed in men with SCI. This means the sperm in men with SCI may not be as likely to find its way to an egg for fertilization. For this reason, couples in which the man has SCI may need to use medical fertility procedures to achieve pregnancy (for example, in vitro fertilization).

Also, because men with SCI are more likely to experience some kind of ejaculatory difficulties, medical assistance with fertility for biological fatherhood is often advisable. The likelihood for men with SCI to achieve natural ejaculation and insemination with vaginal intercourse depends on many factors related to the injury. These include the level of injury, completeness of injury, and type of injury.

Many men with SCI have pointed out that their ability to ejaculate seems to improve over time after injury. You may find that with frequent sexual activity you are able to get closer and closer to ejaculation. Try adjusting the amount of stimulation on your penis to see if it helps your chances to have an ejaculation. Also, try stimulating different areas close to the penis and testicles, especially if you have some partial sensation in those areas. As always, experimenting and trying new things will, over time, give you the best chance of ejaculating.

Fortunately, if fathering a child is a goal, there are a lot of options for semen retrieval if ejaculation is not possible. These include the use of medications and gentle vibrator methods, such as the use of a showerhead. Other more intense methods of sperm retrieval include vibrostimulation with special vibrators and electroejaculation. Electroejaculation can only be used in clinical settings where a physician is available to perform the procedure. Most men with SCI prefer vibrostimulation rather than undergoing electroejaculation for semen retrieval. Surgical sperm retrieval can be used if less invasive procedures are not effective. Usually, a urologist is the specialist that can help you with issues related to fertility or ejaculation. Over the past several years, more and more men with SCI have been fathering children. Although it may seem complicated and frustrating to find a method that works for you, it usually is not a complicated process and can be done fairly easily. The difficulty may be in finding a doctor who is knowledgeable about this aspect of SCI and can help you find a solution.

Practical Considerations for Sexual Activity

PHYSICAL CONSIDERATIONS

After SCI there are physical and practical considerations that you need to understand in order to stay safe and healthy during sexual activity. Basic issues, such as “how do I move my body to get into position?” “what do I do if I have a bladder accident?” or “what do I do with my equipment?” are important questions that need to be answered. Physical, occupational and recreational therapists, nurses, as well as peers who have also experienced a

spinal cord injury can be excellent resources for practical advice. Before becoming sexually active after your injury, it's good to have some understanding of potential difficulties and possible solutions. Each person and every injury is unique, so experience is often the best teacher.

SEXUALITY IN INPATIENT SETTINGS

If you are living in an inpatient setting, you may want to request a separate apartment or room that allows you to be intimate without interruption. If this is not available, ask a staff member to put a “Do Not Disturb” sign on the door. For many couples, cuddling together or lying in bed is the best way to build intimacy during the recovery period. Try to take things slowly until you build confidence and know your body better and how it will respond to sexual stimulation.

OPTIMAL SETTINGS AND POSITIONING FOR SEXUAL ACTIVITY AFTER SCI

After you have been discharged from an inpatient setting, you may need a hospital bed at home to make it easier for you to make transfers from your wheelchair or to reposition yourself for various activities. You may also want to use a more accessible room in your home as the “bedroom” if your original bedroom is not wheelchair accessible. Eventually you may be able to transition back to a regular bed and to your original bedroom. The ultimate goal is to make your life more comfortable and more convenient.

For many people, using a queen- or king-sized bed is just as versatile as a hospital type bed for sexual activities. **It is very helpful for a professional SCI health-care provider to do a home assessment after your discharge from an inpatient setting** to look at such options as providing privacy—possibly using curtains or other screening devices if you use an alternative room as a bedroom, setting up an area for private phone or Internet conversations, and using rooms not previously considered for sexual activity.

Additional suggestions for home modifications may include arranging furniture to increase accessibility, encouraging transfers to a sofa where you and your partner may sit together, and using remote controls to dim lights, operate televisions,

or turn on music. More unconventional locations for sexual activity may be considered (e.g., tables, sofas, or vans); however, safety must come first.

Your health-care providers can discuss the best positioning for sexual activity depending on your specific injury and your range of motion after your injury. It is important for health-care providers to demonstrate various *safe* positions and help you practice them (with or without your partner). Physical and occupational therapists are often trained to determine, explain, and demonstrate techniques for the best positioning.

Your health-care providers can discuss the best positioning for sexual activity depending on your specific injury and your range of motion after your injury.

The extent to which you want this kind of advice from members of your health-care team depends on what kind of information you feel you need and your level of comfort discussing sexual activity. However, it may be worth considering that having this kind of discussion may be uncomfortable in the short-term, but in the long run it can be very helpful, and to remember that these types of demonstrations are always done with all parties fully clothed. If you have a partner, it may be helpful for that person to know how to help you get into the best and most comfortable positions for sexual activity.

When the male partner has SCI, it can be easier to engage in intercourse when he is supported by a backrest and is in a seated position; therefore, the wheelchair is potentially a good location for sexual activity. When the female partner has SCI, it can be more difficult to use the wheelchair during sexual intercourse. However, other sexual activities while the woman is seated in the chair may include manual or oral stimulation, use of sexual devices, kissing, touching, and hugging.

In general, staying in the wheelchair during sexual activity can be a good option for sexual activities, especially if you have a high-level injury, because this eliminates the need to transfer and provides stability and support. Always take measures to prevent slipping out of your chair, tipping your chair, or other mishaps during sexual activity. Some safety measures you can take include securing chair locks, using “anti-tip” bars for stabilization, making sure the power is off

(if your wheelchair is electric), protecting any electronic devices from damage (or from getting wet), complying with weight limits of your chair, and positioning the chair next to a sturdy piece of furniture or a wall for stability. This may seem like a lot to do, but once you make it part of your routine, it can become second nature and can save you and your partner from unnecessary injury.

Some individuals and couples find that the slippery effect of soap and water can enhance sensual pleasure and arousal. Using soap and water to facilitate body exploration or stimulation can increase intimacy and enhance sensation. The increased visual stimulation of shared showering can also increase sexual pleasure. Adjustable showerheads (e.g., jets and vibratory water massage) can facilitate sexual stimulation and arousal. However, keep in mind that showers or baths can be less stable and are slippery environments so it's especially important to prevent slipping or falling. Also, if there are areas on your body with little or no sensation, you may not be able to feel very hot water, so take precautions to lessen the risk of getting burned, such as having someone else, such as an attendant, check the water temperature before entering the shower.

HELP WITH OPTIMAL POSITIONING FOR SEXUAL ACTIVITY

Depending on your injury and your general physical condition, it may be helpful for caregivers to provide some physical assistance prior to sexual activity. This may be especially true for people with tetraplegia, some people with high-level paraplegia, and people with impaired hand mobility, elderly individuals, or people who may be carrying extra weight. In these cases, caregivers may be able to help with undressing, preparation (such as application of lubricating gels or condom placement), and positioning for sexual activity. The amount of assistance provided depends on the skills, training, and professional characteristics of the caregiver as well as the comfort levels of you and your partner.

In cases where assistance is helpful, it is best to have an open and honest discussion prior to the sexual encounter. Personal care attendants or assistants should be prepared to discuss their roles related to sexuality, including their limits. Remember, this can be a sensitive topic for everyone and

many people may feel uncomfortable providing assistance with such personal matters.

Physical Health Issues

TAKING CARE OF YOUR SPINE AFTER INJURY

Intimacy and affection can be tremendously “healing” after a spinal cord injury. Being sexual again is a psychological boost for most people after an injury. However, during the period immediately after injury, your doctor might advise you to limit your movement and take other special precautions to promote proper spine healing and to avoid any additional injury. Be sure to talk to your health-care team about the safest positioning for sexual activity based on your specific injury and any surgical procedures you may have had after your injury. During your initial healing period, more gentle activities, such as touching, kissing, and intimate stroking, may be preferable to sexual activities that require repositioning and movement. With time, your spine will reach its optimal healing level and sexual activity will become less restricted. Sometimes partners of people with SCI often are afraid of further hurting the spine by participating in sexual activity. However, additional injuries are unlikely once healing has occurred.

Sometimes partners of people with SCI often are afraid of further hurting the spine by participating in sexual activity. However, additional injuries are unlikely once healing has occurred.

YOUR SEXUAL HISTORY

Your doctor or other members of your health-care team will likely ask you for information about your sexual history. It is important that you provide the most accurate information about your past sexual and reproductive experiences that you can. If your doctor or other trusted member of your health-care team does *not* bring up the topic of your sexual history, ask your doctor when this information will be discussed. It is important that your health-care team understands your past so that you can work together to address your future sexual functioning.

Some people who experience SCI had sexual or reproductive difficulties before their injury occurred. Other people may have experienced traumatic events, such as sexual abuse, molestation,

or rape. It is important to talk to your doctor or another member of your health-care team about any difficulties, traumas, or concerns you had before your SCI as well as questions you have now and about your future.

Consider the following questions—these issues are important to address with your health-care team:

- Were you sexually active before your injury?
- Did you have any sexual problems before you were injured?
- What are your concerns about sex now that you have experienced a spinal cord injury?
- What are your worries about future sexual activity?
- Have you ever experienced any kind of sexual trauma (such as rape or other molestation)?
- Have you ever experienced sexual dysfunction (such as pain during sex, the inability to have an orgasm, or the inability to have an erection)?
- Do you have any sexually transmitted diseases (such as herpes or HIV/AIDS)?
- Do you have any biological or adopted children?
- Do you want to have your own biological children?
- Do you want to adopt children?

MAINTAINING YOUR SEXUAL HEALTH

Regular, thorough examinations of your sexual organs are an important part of your overall health-care regimen. For women it is important to have regular breast and pelvic exams (including screening for ovarian, breast, uterine, and cervical diseases). Men should have regular exams of the penis, prostate, and testicles. It is becoming routine in many health-care settings for sexually active men and women to be screened for HIV/AIDS and other sexually transmitted diseases (early detection leads to more effective treatment). Women may also want to ask their doctors about screening and/or immunization for the human papillomavirus (HPV).

Also don't forget to ask your doctor to provide you with regular neurological assessments. Neurological changes over

time may affect sexual function and the sooner any such changes are detected, the better.

AUTONOMIC DYSREFLEXIA

(See the Consortium for Spinal Cord Medicine’s consumer guide: *Autonomic Dysreflexia: What You Should Know*, 1997, available at www.pva.org/cpgs.)

Sexual activity, especially orgasm and ejaculation, can increase the likelihood that autonomic dysreflexia (AD) may occur in people with injuries at T6 or above. Other stimuli that can trigger the onset of AD include wounds (such as pressure ulcers), harmful stimulation of the skin, bladder and bowel problems, and joint or bone injury. In general, any stimulus below the level of injury has the potential to cause AD. Anal sex can also raise the potential for both AD and bowel accidents.

Autonomic dysreflexia is a condition that can be experienced by people with injuries at the T6 level or above and is considered a medical emergency. AD can occur when the autonomic nervous system experiences a period of severe overactivity. This “overactivity” can cause the sudden onset of dangerous symptoms, such as very high blood pressure, which, if not treated, can cause seizures, stroke, or even death. Some symptoms of AD (which are caused by the unusually high blood pressure) can be a pounding headache, sweating, goose bumps, a slowed pulse, nasal congestion, being flushed or a reddening of the face or blotchy skin, body hair standing on end, restlessness, feeling nauseated, clammy cold skin, blurred vision, and, of course, high blood pressure.

Autonomic dysreflexia is a condition that can be experienced by people with injuries at the T6 level or above and is considered a medical emergency.

Unfortunately, AD can occur without any symptoms that you notice—this is sometimes called “silent” autonomic dysreflexia. These symptoms (or silent AD) may be more severe with ejaculation and orgasm. Because AD is such a serious condition, it is important to talk to your doctor to discuss precautions to take before and during sexual activity to prevent the onset of AD and to know what to do if AD occurs or you suspect

you are experiencing the symptoms of it. (Consumer Guide *Autonomic Dysreflexia: What You Should Know*, 1997.)

There are medications your doctor may prescribe to help reduce your chances of experiencing AD. Knowledge is your most important tool; talk to your doctor and your partner so that you are ready for AD if it should occur. If you begin to experience the symptoms of AD during sexual activity, the activity should be stopped and your plan of action (including seeking medical attention) should be set in motion.

SPASTICITY

Muscle spasms may or may not occur after a spinal cord injury; each person is unique. Muscle spasms, or “spasticity,” can occur any time the body is stimulated below the point of injury. After experiencing SCI, muscles can contract or become hyperactive (this is called a spasm). These spasms can be difficult to control. This is particularly likely when muscles are stretched or something is touching or irritating the body below the injury. Regular range of motion exercises can help your muscles and joints become more flexible and can help to control spasticity. Still, some spasticity may always be present.

There are some benefits to spasticity. It can serve as a warning mechanism to identify injury or problems in areas where there is no sensation. Many people know when a urinary tract infection is coming on by the increase in muscle spasms. Spasticity also helps to maintain muscle size and bone strength. Spasticity helps maintain circulation in the legs and can be used to improve certain functional activities, such as performing transfers or walking with braces. For these reasons, treatment is usually started only when spasticity interferes with sleep or limits an individual’s functional capacity.

For some people with SCI, spasticity can interfere with sexual activity; however, other people find they can use spasticity to help with functional mobility or stability. Sometimes spasticity can facilitate sexual activity through movements that can stimulate your partner. Your ability to use or control spasticity in other situations may help you determine if or how you can use or handle spasticity during sexual encounters.

In any case, you need to be aware that orgasm can affect your muscle tone, causing instability. In other cases, increased spasticity may be caused by body position or different sensations related to sexual activity. If possible, approach the issue of spasticity with an open mind to better understand whether it can add to or enhance the sexual experience. Be sure to discuss all factors that may increase or decrease muscle tone with your health-care provider when considering treatments for spasticity.

EFFECTS OF MEDICATIONS

Some medications can affect sexual response and fertility. With certain medications you may notice a loss of sexual interest, more problems in becoming aroused, or added difficulty in reaching an orgasm. Usually your doctor or pharmacist will let you know if the medications prescribed to you are known to cause sexual side effects. If you begin to experience unwanted sexual side effects while taking certain medications, consult your doctor as soon as possible. He or she may be able to change the medication or dosage in order to remedy the problem. *It is never wise to stop taking prescription medications or to alter the dose you're taking without first consulting your doctor.*

Over-the-counter medications and herbal remedies can also affect sexual response and reproductive health. Make sure your medical team knows of any over-the-counter medications and/or herbs that you are taking.

RISK OF PENILE TRAUMA

Men with SCI are at a higher risk for penile bending (Peyronie's disease) because of a lack of sensation or no sensation in the penis. During sexual activity, unintentional blunt force on the erect penis may go unnoticed in men with SCI because you cannot feel the pain. **For this reason it is a good idea to inspect your penis after sexual activity to check for any kind of injury, including skin irritation. If you find any sign of penile trauma, consult your doctor.**

BLADDER AND BOWEL

It is very important to find bladder and bowel management practices that work well for you. Maintaining good bowel and bladder function will keep you healthier and more comfortable.

Maintaining good bowel and bladder function will keep you healthier and more comfortable.

Sometimes it will require trying several methods before you find the ones that best suit your particular needs, but it's well worth the effort. If the programs that were started during your rehabilitation are not working well for you, let your doctor know.

For some people with SCI, the thought of losing control of bladder or bowel function during sexual activity can cause anxiety for fear of embarrassment. Such anxiety can make sex a worry rather than a pleasure. It is important to address any concerns you may have about maintaining bladder or bowel control during sex. You will probably want to talk to your health-care provider in order to find out the best solutions for preventing problems and for dealing with them if they should occur. If you have a regular sex partner, you may want to talk to him or her as well; sometimes talking about potential problems can alleviate anxiety.

For some men having a full bladder helps to get and keep an erection, while for others a full bladder can be an obstacle to getting an erection. You can use this knowledge about your body to determine when to empty your bladder, and trial and error may be your best strategy. However, a full bladder may cause increased risk of AD if your injury is at T6 or above. You should discuss this possibility with your doctor and develop a contingency plan in case autonomic dysreflexia should occur.

If you use an indwelling urethral catheter, you need to take precautions to prevent it from becoming dislodged or getting contaminated during sexual activity. Some people prefer to remove the catheter altogether during sex and then replace it after. This may be a problem if you need help to remove or to reinsert the catheter. Some men who use indwelling catheters fold the tubing down the shaft of the penis or clamp the end of the catheter and then place a condom over the penis and tubing prior to intercourse.

If you use the technique of leaving the catheter in place, you should be aware that it can damage the catheter's balloon port tubing, causing the balloon to remain inflated. Damage to the balloon port may cause bladder distention, ultimately resulting in a urinary tract infection, sepsis, or AD in men with injuries at T6 and above. Because of the issues associated with indwelling catheters, some people with SCI switch to suprapubic catheters, which can be more conducive to sexual activity. It is important to ensure that your catheter is clean before and after sexual activity.

Emptying leg bags prior to sexual activity can go a long way in preventing spills if breakage occurs. Towels or disposable protective bed pads can be very useful should leakage or bodily discharge occur.

Some people prefer to empty their bowels prior to sexual activity; however, even with an empty bowel, residual bowel or mucus discharge can occur as a result of digital rectal stimulation or some medications, such as bisacodyl. Stimulating the anus during sexual activity can be a source of pleasure but may also increase the possibility of an accident. Being prepared for such an event can reduce anxiety and minimize the disruption that a bowel accident may cause during intimate moments. It is usually helpful to discuss the possibility of unplanned bowel discharge with your partner in order to reduce anxiety as well as the element of surprise. In a sexual situation, reduction of anxiety will lead to a more positive experience. Try to have a sense of humor about the whole situation. Your partner will look for your reaction. If you can stay relaxed, chances are that your partner will, too.

SKIN CARE

After SCI your ability to feel pressure, tearing, or friction on your skin can be greatly reduced. During sexual activity there is usually an increase in friction on various areas of your body that can lead to injury. **It is especially important to inspect your skin after sexual activity (with the help of a partner or caregiver if needed).** Skin breakdown (scrapes, cuts, abrasions) can be treated much more effectively when

caught early. With early intervention more serious wounds or pressure ulcers can be prevented, or their severity lessened.

One way to help prevent skin breakdown during sexual activity is to ensure that there is plenty of lubrication in the areas that are being stimulated. After SCI, women may experience decreased or absent genital lubrication and men may experience decreased pre-ejaculatory fluid—these factors may result in irritation of the skin during intercourse (or other sexual activity). Using water-soluble lubricants (preferably gels) can provide additional lubrication. It is best to use lubricants that are water-based with no added color or flavor.

It is not advised to use warming gels since you may not be able to detect temperature changes. Silicone gels are also more difficult to wash off as compared to water-based gels. The gel should be applied to the genitals prior to intercourse and used on any other part of your body that will receive extra friction during sexual activity. You may need to reapply gel during prolonged sexual activity.

If you develop a pressure ulcer, you do not necessarily have to abstain from sexual activity. However, while the pressure ulcer is healing, sexual activity should be modified and appropriate precautions taken to avoid additional injury to your skin. You will need to eliminate excess pressure on the area of your ulcer. Try to be especially careful with the dressings used to treat your wound so that they do not become dislodged or loosened during sexual activity. Bandages that *do* become loosened or damaged need to be replaced after sex.

While the pressure ulcer is healing, sexual activity should be modified and appropriate precautions taken to avoid additional injury to your skin.

PROTECTING YOUR LIMBS DURING SEX

After experiencing SCI, it is common to lose some flexibility or range of motion. Loss of flexibility or range of motion combined with bone density loss (which is more common after SCI) can make it easier to damage, dislocate, or even break limbs. To help prevent this unwanted outcome, support limbs with pillows or bolsters during sexual activity. Try to avoid any forceful pressure when positioning your body for sexual activity. It is worth a little extra effort and experimentation to figure out the best placement of your body and the best ways

to support yourself with pillows or bolsters to alleviate worry about limb injury, increase your comfort (and the comfort of your partner), and ultimately improve sexual encounters.

SEXUALLY TRANSMITTED DISEASES

Anyone who is sexually active should be educated about sexually transmitted diseases (STDs). This is no less true for people with SCI. Using condoms (male or female condoms) can reduce the risk of contracting or transmitting STDs. Some individuals may be allergic to latex materials. If you are, talk with your doctor or pharmacist about possible alternatives to latex materials. You should always use a condom when engaging in vaginal, oral, or anal sex unless 1) you are in an exclusive relationship (in which you are sure that neither you nor your partner are having sex outside the relationship) and 2) you are certain that neither of you already has an STD (as determined by blood test results). However, this should be a mutual decision based on trust and verifiable knowledge of yourself and your partner. It is very reasonable and common for people who are becoming sexually involved with each other to have a series of blood test to confirm the absence of STDs.

If you decide to use a condom, be sure you know how to correctly place it for maximum protection. Your doctor or other members of your health-care team can help with education as needed. For some people with SCI, physical limitations of the arms and hands may make proper placement of a condom difficult. Your partner may be able to help and, in fact, placement of the condom can be a mutually satisfying aspect of the sexual encounter.

The risk of contracting an STD is greatly increased when people have sex with multiple partners, have sex with a person whose sexual history is not known, or have sex with strangers. The use of alcohol or other drugs can impair judgment, thus increasing the risk of engaging in potentially dangerous sexual behavior. Let's face it: sometimes it is difficult to ask a new partner about personal sexual practices; however, it is important to have the conversation—in the long run it is less stressful to talk about STDs before having sex than after.

Early diagnosis is very important for people who do contract an STD. There are effective treatments for most sexually transmitted diseases (although these are not necessarily cures) and they can be more effective if started soon after the infection is contracted. So request screening for STDs whenever you have concerns. Women may want to ask about HPV vaccination or screening.

Psychological Health Considerations

COUNSELING AND SEX THERAPY FOR UNRESOLVED SEXUAL ISSUES

For some people sexuality can be associated with negative experiences, such as early trauma or abuse as a child or as an adult. As a result, these individuals have prior issues that may make sex more complicated for them and that can make the sexual adjustment more difficult after SCI. If you feel that there are other personal issues interfering with your sex life, consider talking to a counselor or sex therapist. Therapists or counselors can also help with difficult relationships—whether the difficulty started before or after your injury. In the United States, sex counselors and sex therapists are certified by the American Association of Sexuality Educators, Counselors and Therapists.

These professionals are trained to help people with sexual difficulties and have experience providing suggestions aimed at improving sexual health and well-being. Many people with SCI find that professional assistance in this area is especially helpful in the months following discharge from the hospital when issues regarding sexual activity may begin to surface.

DEPRESSION

Try to be aware of changes in your mood. It is normal for people to feel sad or depressed at different times—especially in response to adverse events. It is certainly understandable to feel sad and scared after experiencing a major physical trauma, such as SCI. Work with your medical team, your friends, and family, and/or your partner to get the comfort

and help you need during your period of recovery and rehabilitation. As time passes, however, you may begin to feel more hopeful and positive about the future. Generally, two weeks is considered too long to feel depressed before getting help. If you experience such symptoms as an unusual disinterest in sexual activity, poor concentration, persistent tiredness, thoughts of suicide or hurting yourself, or changes in your sleeping or eating habits (feeling like you want to eat too much or not at all), you may be suffering from depression. Depression can be dangerous. It is a condition that *can* be treated and your doctor can help you. No one should simply suffer through a bout of depression—depression can negatively affect your work life, your social life, and your sex life.

If you experience symptoms of unusual disinterest in sexual activity, poor concentration, persistent tiredness, thoughts of suicide or hurting yourself, or changes in your sleeping or eating habits, you may be suffering from depression.

AGING AND SEXUALITY

As we age, our physical dexterity can become more limited and some people experience pain and have less mobility. Aging for some people is also sometimes associated with diminished desire for sexual activity or more difficulty with sexual function. Whether or not these changes will occur for you depends on your individual health issues, your personality, and your personal and emotional reactions to the changes that come with age.

If you find you are having sexual problems as you get older, your health-care provider can help. A physical therapist can suggest exercises and different ways of moving that can make positioning during sexual activity easier. Physical and occupational therapists may also recommend adaptive equipment, such as mechanical transfer lifts to make moving from place to place less difficult and less strenuous. If indicated, your doctor may prescribe medications to help with erectile dysfunction if that becomes a problem associated with age.

Lifestyle Issues

YOUR COMMUNITY AND CULTURE

Your attitude about sex can have a lot to do with your religion, your spiritual beliefs, your cultural or social environment, and your personal or family history. Your health-care provider can work with you to consider your personal views when providing sexual education and counseling. For example, many people believe that sex is something only to be shared within a marital relationship. Other people believe that sex can be a healthy part of a close relationship or friendship. Some religions or cultures have specific teachings about sex. People's beliefs regarding when, where, and with whom to have sex are as varied as people themselves. It's important that you deal with sexuality in ways that are in line with your personal beliefs.

ALCOHOL AND NONPRESCRIPTION DRUG USE

Drinking alcohol or using “recreational” (or nonprescription) drugs can negatively affect your sexual response and performance and can have negative effects on fertility as well as your overall health. While many people can drink alcohol in moderation without negative side effects, some people cannot. This is an area of life where it is important to be honest with yourself if you think you may be abusing alcohol or drugs. For many people, the capacity to drink alcohol may change after SCI due to medications or bladder-management programs. Talk with your health-care team to determine what is best for you. Pregnant women should not drink alcohol or use drugs.

SMOKING

Smoking cigarettes is a serious health risk for everyone. Because smoking cigarettes affects blood circulation, it can impair sexual response—sexual organs need blood to function. This can be even more problematic for people with spinal cord injury, given that circulation may be somewhat impaired due to the injury and the resulting limitations of movement. Smoking cigarettes makes it harder to achieve healthy circulation throughout the body. Cigarette smoking also greatly increases the chances of getting cancer and developing heart disease. If you want to stop smoking, talk to your doctor about med-

ications or programs aimed at reducing the urge to smoke. Pregnant women should never smoke.

Relationship Issues

EXISTING RELATIONSHIPS

After experiencing spinal cord injury it is common for people to be fearful about the stability of their romantic relationships. Such fears are almost universal after a serious life change. Unfortunately, people are often reluctant to talk about these fears with their spouse or partner and this can hurt a couple's ability to maintain open and honest communication.

Try to begin discussing your concerns with your partner as soon as possible after SCI in order to alleviate undue anxiety and stress. This kind of open discussion can help you identify areas that are a source of anxiety for both of you. Talking about these issues is a good first step in easing your mind and reducing stress. In some cases, you may want to discuss concerns or worries with peer counselors, psychologists, psychiatrists, members of the clergy, or rehabilitation therapists. If this is the case, try to find someone who has experience working with people with SCI. Remember, if you don't feel comfortable with the first counselor you see, continue to seek one who meets your needs.

ESTABLISHING NEW RELATIONSHIPS

People with SCI face certain specific challenges when trying to establish new romantic relationships. Medical issues, wheelchair accessibility, personal care, or other medical issues may present problems when trying to date someone new or develop an intimate relationship. When you have a spinal cord injury, asking for assistance and being able to explain your injury are important skills that will help in developing romantic relationships or even friendships.

The ability to communicate effectively and to be positive about oneself is critical in order to meet new people and establish potentially romantic relationships. Sometimes the best people to talk to about these issues are other people living with SCI. They may have had successful experiences to share with you and may be helpful in problem solving. From their

experiences, they may be able to offer some creative ways to meet new people and form new relationships.

Online dating is an extremely popular way for people to find potential friends and love interests. The Internet offers people access to others who are looking for companionship and a relationship. Many websites provide opportunities to develop online profiles highlighting personal qualities, characteristics, likes, and dislikes, and to describe the kind of relationship you are looking for. There are some websites specifically for individuals with disabilities. Sometimes people meet potential partners through other online forums, such as discussion groups or gaming sites.

The downside to online socializing is that it can increase your chances of being exploited by people with bad intentions. For this reason it is important to take common sense precautions, for example: do not disclose too much personal information (such as your address or phone number) and do not believe everything people say about themselves in an online forum. There are many commonly known websites especially designed for single people to meet other single people. These may provide a safer structure through which to meet people; however, the same precautions must be used.

If you decide to meet someone in person, begin by using a public phone or service to block your number before the decision to meet, only meeting in a public place with which you are very familiar, taking a friend along, and always telling a friend or family member where you are going, with whom, and when you plan to return. Always take your cell phone with you and have a plan for how to get home independently. Your safety should always be the priority.

CAREGIVERS

Individuals who also provide physical assistance to their partner with SCI can develop physical or emotional “burnout” that may negatively affect romantic or sexual relationships. Communication with your partner is the first step to avoiding or alleviating this kind of situation. Talk with your partner to evaluate your priorities and the resources that are available to you for assistance.

Both members of the relationship need to understand and communicate about the physical and emotional issues related to SCI. It is important that this communication be as non-judgmental and as open as possible. If your partner doesn't want to help with a particular aspect of your care, try to find alternate solutions. If you notice that your partner is getting stressed, try to take feedback from them without getting too defensive. Sometimes just adjusting an attitude or being a little less demanding can go a long way in improving how the two of you get along.

As a rule of thumb, whenever possible, see if personal care can be provided by someone other than a romantic partner or significant other. This may help prevent partner “burnout” and maintain romantic feelings in an intimate relationship.

Conclusion

In this guide we have tried to communicate the fact that being sexual is both how you feel about yourself and how your body responds. In addition we have tried to emphasize the importance of learning how your body functions and how it reacts to sexual stimulation after an injury. This is because feeling sexual and having a positive sexual experience after injury requires knowing your body and the changes that have occurred. This takes time and practice. If you have a partner, communicating this information and sharing this knowledge about your feelings and body are just as important.

The ways in which you handle early frustrations and disappointments about sex can make all the difference for your future sex life. Try to remember that although a positive sexual experience is what you are striving for—and is achievable—there may be difficulties along the way. In relationships, try to push beyond your comfort zone and seize opportunities that come your way. Each sexual experience can teach you something important about yourself and about your body after SCI. In doing this, your experiences will get better with time and knowledge. The important thing is to know that you are still a sexual being. With this knowledge and with experience, you can have the kind of sexual life that you desire.

Resources

Websites

Paralyzed Veterans of America: www.pva.org

www.sexualhealth.com

www.spinalcordcentral.org

Books

*Autonomic Dysreflexia: What You Should Know**

*Bladder Management Following Spinal Cord Injury: What You Should Know**

*Neurogenic Bowel: What You Should Know**

*Preservation of Upper Limb Function: What You Should Know**

Sexuality after Spinal Cord Injury-Answers to Your Questions (Spinal Cord Injury Education & Training Foundation), by Stanley H. Ducharme & Kathleen M. Gill

Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide, by Marca L. Sipski & Craig J. Alexander

*Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury**

Magazines

PN, The magazine for wheelchair users: www.PN-magazine.com

New Mobility: www.newmobility.com

* Information is available from Paralyzed Veterans of America at www.pva.org/publications.

Acknowledgments


The Consortium for Spinal Cord Medicine (the Consortium) was founded in 1995 with the goal of improving the quality of life for persons with spinal cord injury by making their care more evidence based and, through concerted outreach efforts, bringing this knowledge to the widest possible audience. The professional health-care, payer, and consumer organizations that comprise the Consortium work in partnership with Paralyzed Veterans research and education team to realize this goal through the publication and dissemination of clinical practice guidelines (CPGs) for health-care providers and companion consumer guides written specifically to provide useful information to consumers of SCI related health care.

Paralyzed Veterans of America is proud to fund and administer the Consortium. We are honored to partner with this esteemed group to continue to provide groundbreaking guidelines that consolidate recommendations from the highest level of experts in the field of SCI.

For more information about the Consortium and Paralyzed Veterans, please visit www.pva.org.

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