
Spinal Cord Injury Manual (English)

Regional Spinal Cord Injury Center of the
Delaware Valley Spinal Cord Injury Manual

2009

Sexuality-Spinal Cord Injury Manual

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Regional Spinal Cord Injury Center of the Delaware Valley
NIDRR-designated

Spinal Cord Injury Manual

A publication of the
Regional Spinal Cord Injury Center
of the Delaware Valley

The Regional Spinal Cord Injury Center of the Delaware Valley provides a comprehensive program of patient care, community education, and research. It is a federally designated program of Thomas Jefferson University and its affiliated institutions of Thomas Jefferson University Hospital and Magee Rehabilitation Hospital.



Spinal Cord Injury Patient-Family Teaching Manual

**A Publication of the
Regional Spinal Cord Injury Center
of the Delaware Valley**

Researched and prepared by the clinical
personnel of Thomas Jefferson University
Hospital and Magee Rehabilitation Hospital

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Dedication

The Handbook Committee of the RSCICDV gratefully acknowledges the assistance and dedication of all who contributed to this manual, and all the others who worked so hard to make this Handbook a reality.

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Sexuality

Introduction

In this section, you will learn how spinal cord impairments can affect the way that you feel about yourself as a man or woman as well as how spinal cord impairments can affect the way that you function sexually. Information on sexuality, sexual functioning, birth control, erectile dysfunction and having a baby may be important to you today, or these issues may be something that you choose to put away and think about at another time. In either case, this information is just a starting point. Feel free to ask questions and share your concerns and thoughts with the staff. If the staff doesn't know the answers to your questions, they will find someone who does.

Sexuality

When you hear the word *sexuality* what do you think of? For some people, it means “having sex.” For others, it includes thoughts and feelings about body image, self-esteem, appearance, communication skills, beliefs and values, relationships, and sexual function. The definitions of sexuality are different from person to person, and there is no right or wrong one. Webster's dictionary defines sexuality as “the quality of being sexual.” But what does that mean? Whatever makes you feel like a sexual person is a part of that word's definition.

Let's take a look at what some of these other concepts mean.

Body Image

Body image is a term that you have probably heard more since your spinal cord impairment than any other time in your life. It is a psychological term that refers to how you see your body and how you feel about your body. Chances are, since your injury, there have been some visible changes to your body. How you include these changes into your everyday life is a part of adapting to your injury.

Often times after a spinal cord injury, you may not feel very good about yourself. It may be difficult to look in the mirror and see how you have changed. Give yourself a little time to get used to the “new” you that you are looking at in the mirror. Think of ways that may help you feel better about what you see in the mirror. Would a hair cut, a change in make-up or a change of clothes make you feel better about what you see? What about a change in posture or weight (loss or gain)?

Anything that makes you feel better about who you are and what you look like will help to increase your body image.

Improving Your Appearance

We are taught from a very young age that the young, beautiful people are the ones that we hope to be. Wheelchairs, braces, catheters and dependence are not a part of this image.

It is important to take some time and think about what you value in yourself and other people. Then, start working slowly to change the things that you can change. Remember, not everything can be changed overnight.

You need to start by thinking about the things that you like about yourself. Your hair, the clothes you wear and make-up don't have to change just because you may be in a wheelchair.

How you present yourself tells the world how you feel about yourself. If you look good, others will see that.

Self-Esteem

Self-esteem is the value that you place on yourself as a person. It includes the confidence that you have in yourself as well as your attitude about yourself. After spinal cord impairment, your confidence may be shaken. Suddenly being dependent on others, even temporarily, goes against everything that we have been taught. It takes time to become comfortable with asking for help. You may want to start with people that you trust and gradually begin to learn how to ask those you don't know as well. Use your time in rehabilitation to start this learning. And most of all, take time to learn how to ask for help in a polite, clear and firm way. All of these things will help you to gain control over your life again and make you begin to feel better about who you are.

Last but not least, focus on your strengths and the things that you **can** do. It is much easier to point out the things that you are no longer able to do. Make a list of the things that you like about yourself and what you have accomplished since your injury. Build on your strengths and take stock of the things that you can feel good about. Remind yourself of these often and gradually you will find that there are more things that you like than you don't.

Beliefs and Values

What you believe about sexuality and sexual functioning may impact how you feel about yourself now. Our cultural

background, religious beliefs, education, family values and values of our friends all impact our belief system. Becoming disabled may impact this belief system. If what you value is someone who “has it all,” you may no longer feel as though you fit in this category. If you believe that you have some qualities that make you a good person regardless of your disability, you may feel better about yourself. Confusion over values and beliefs is common after a SCI.

You may need to talk to a professional, clergy member or trusted friend to help sort out some of these issues.

How Do I Feel More Like a Man / Woman?

Spinal cord impairment does not make you any less of a person. However, many people question themselves. Take some time and look at what you believe makes you a man / woman. Although our thoughts about this may include our muscles, bodies, the activities that we like doing and our sex organs, these are only symbols of who we are. Your masculinity and femininity really is much more involved than that. Our masculinity and femininity is shown in everything that we do, say and are. It’s a part of our personality and how we share ourselves with others. These things don’t have to change after a spinal cord trauma.

Dating

The thought of going out on a date now that you have a disability may be very frightening to you. Questions that you have may include: Who would find me attractive?, When do I explain the extent of my injury?, How do I get people to look past the wheelchair? and How do I find a partner?

There are no right or wrong answers to these questions. Let’s take a look at each one and see what other people may suggest as ways to solve these possible problems.

Who Would Find Me Attractive?

The thought that you are not good enough or don’t deserve to find someone to have a relationship with is a common thought. It is negative also. If you don’t value yourself, others won’t value you. It can put you in danger of attracting abusive partners also.

It is very important to realize that every person has strengths and weaknesses. Spinal cord disabilities don’t change this. Talk with other people who have been through the same things that you are going through, join a support group, talk with your

friends and family. Begin to go to places that you enjoyed before your injury. All of these suggestions may help you to gain confidence in yourself. Attractiveness is subjective. What one person finds attractive, another may not. However, confidence is usually seen as an attractive trait by most.

When you begin to feel better about yourself, others will want to be around you, too.

When Do I Tell a Partner About the Extent of My Injury?

Spinal cord disabilities are generally visible. You may find yourself telling your partner about the impact your disability has on some of your body early on in the relationship. Other aspects of your disability you may feel are personal and may want to discuss as the relationship evolves. Take cues from your partner. Answer questions as they come up honestly. Keep the lines of communication open. And don't overwhelm your partner with details he or she may not be ready to handle yet. Remember, it took some time for you to get comfortable with your new body. Give your partner the same respect.

How Do I Get People to Look Past the Wheelchair?

Looking good and feeling good about yourself is certainly a place to start. Develop your own style. Decide what clothes, hairstyle and makeup make you feel better about yourself. If you believe in who you are, you can convey your attractiveness to others. Talk with others who have been in similar situations and get some ideas from them.

You may need to become a little more outgoing and friendly. Start conversations with people. Encourage others to get to know you. Get out and do activities — sports, movies, volunteering. Or, go back to work or school. Share your interests with others. If you show other people that you are someone who is worth getting to know, relationships may develop. This style may take time for you to get used to. There may be times when you get frustrated. But, it's important to keep trying.

How Do I Find a Partner?

Finding a partner is a question that is often asked. What many people have found is that the same places that worked before your disability may work after your disability. Get out and go the grocery store, the mall and get involved in activities. Take

classes, volunteer, get active in church/synagogue, join a hobby club. Get back into life!

You may feel more comfortable having family or friends go with you on your first outings. Once you get used to being out in public, try some new spots — places that you may have wanted to go to, but never got to. Strike up conversations with people.

Keep in mind though that no matter where you go, people will have a natural curiosity about you and your injury. Think about what you are willing to share and do it in a friendly, open way. Many people have shared that they are comfortable sharing some aspects of their disability with anyone, keeping some parts of it private. Each person develops his or her own style and way of handling questions. Try different ways until you get comfortable with who you are.

Sexual Functioning

Spinal cord dysfunction does cause changes in sexual functioning for most people. Since everyone's injury is different, keep in mind that the changes you experience are different also. Before we talk about how spinal cord dysfunction affects sexual functioning, you will need to understand how you functioned before your disability. Then, in order to meet as many people's needs as possible, this section will be divided up into three distinct areas: changes that affect men, changes that affect women and changes that affect men and women.

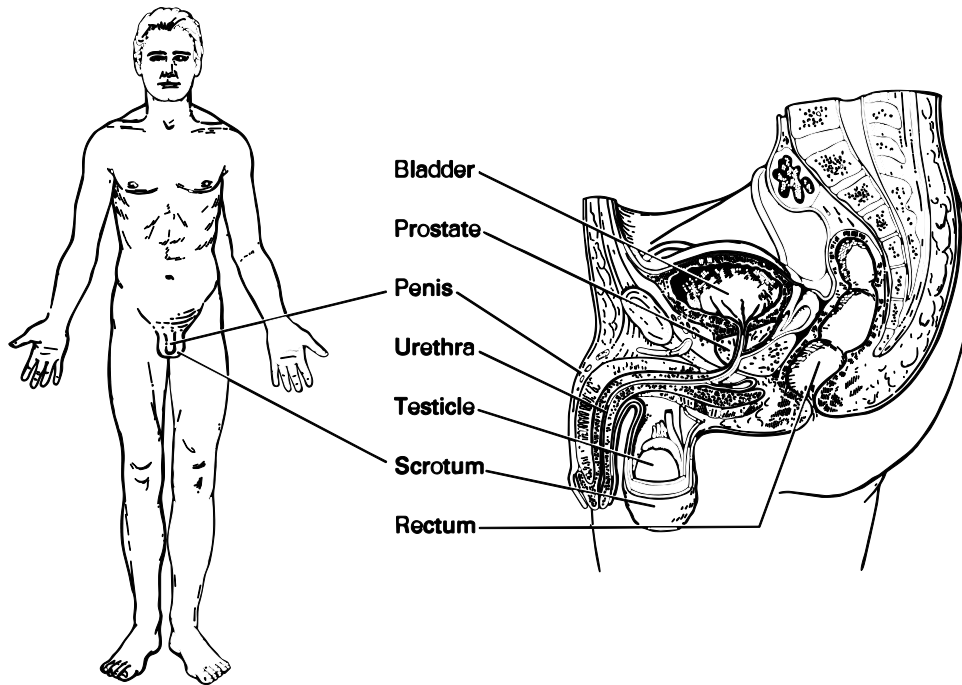
Normal Anatomy of Sexual Functioning: Men

Having spinal cord dysfunction does not affect the sexual anatomy of men. It does affect the way a man is able to respond sexually to stimulation.

Male sexual anatomy is a combination of tubes, valves, muscles and glands that work together to produce sperm, house sperm and deliver sperm outside the body.

The sexual organ that is most likely to come to mind for a man is his penis.

Male Sexual Anatomy



(Printed with Permission from Ducharme SH, Gill KM: Sexuality After Spinal Cord Injury: Answers to Your Questions, Baltimore, MD, 1997, Paul H Brookes Publishing Company.)

The penis is an organ that is made up of three spongy cylinders that have spaces in them. Blood is drawn into two of these spaces during sexual excitement and helps to maintain an erection. The third cylinder is underneath the penis and is where the urethra is housed.

The urethra is a tube that leads from the passageway where sperm are housed (the testicles) and allows for ejaculation (the expulsion of sperm).

Hanging below the penis is a sack called the scrotum. The scrotum is divided into two parts. Each part has a testicle. The testicle is where sperm are produced and housed.

The prostate gland is the part of the system that is responsible for producing the semen (the liquid that transports the sperm out of the body).

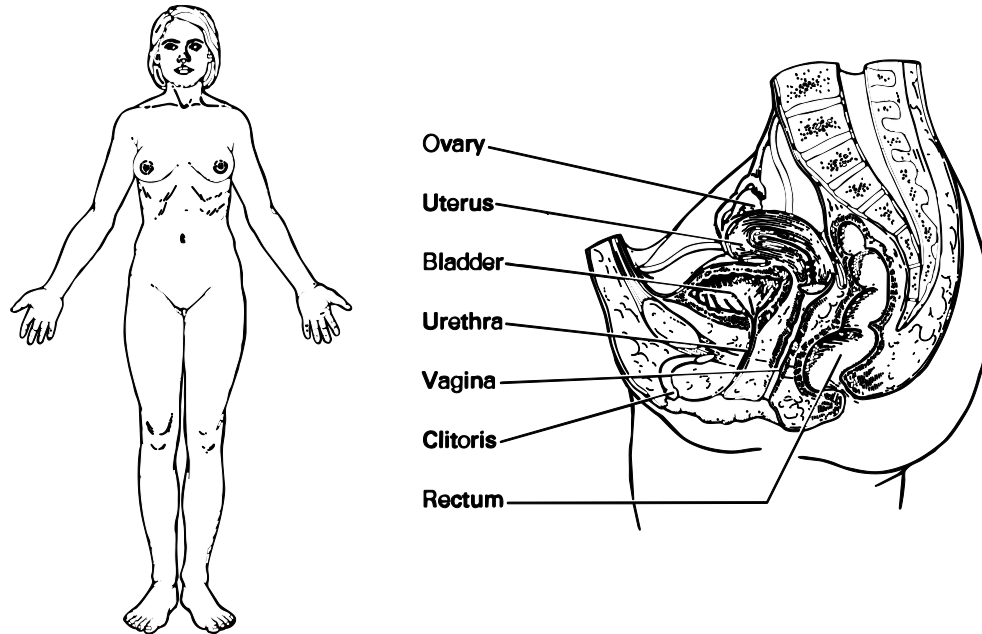
The largest sexual organ that men have is the brain. The brain is responsible for coordinating the reflex responses that help to make up the sexual response cycle. The brain, in conjunction with the spinal cord, helps the system to run smoothly.

Changes in sexual function after spinal cord impairment occur as a result of the changes in the nervous system connections.

Normal Anatomy of Sexual Functioning: Women

Having spinal cord dysfunction does not affect the sexual anatomy of women. It does affect the way a woman is able to respond sexually to stimulation.

Female Sexual Anatomy

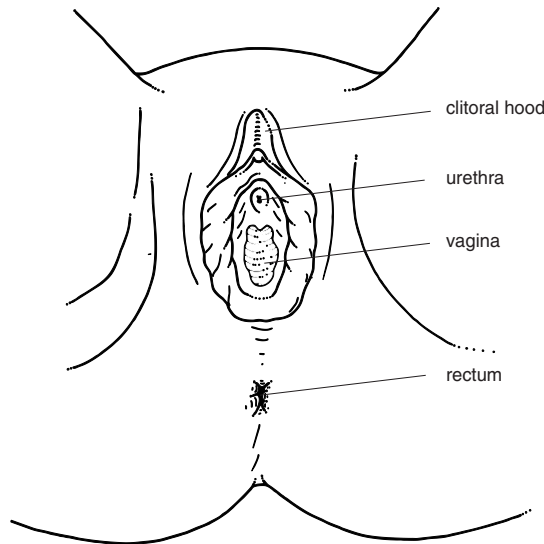


(Printed with Permission from Ducharme SH, Gill KM: *Sexuality After Spinal Cord Injury: Answers to Your Questions*, Baltimore, MD, 1997, Paul H Brookes Publishing Company.)

The vagina is a soft tube that is several inches long and is extended during intercourse. The outer edges of the vagina are sensitive to stimulation. The lining of the vagina is soft and moist. The fluid that makes the vagina moist is produced in the cells that line the vagina. This fluid is important during sexual intercourse because it provides lubrication.

The clitoris is similar to the penis. It contains many nerve fibers and blood vessels. During intercourse, the clitoris becomes erect.

Female Sexual Anatomy



(Adapted with Permission from Cull, P: The Source Book of Medical Illustration, Park Ridge, NJ, 1989, Parthenon Publishing Group, Inc.)

The ovaries are the major reproductive organs in a woman. The ovaries are responsible for producing eggs. These eggs, in combination with a sperm, form a baby.

The fallopian tubes transport the egg from the ovary to the uterus. The uterus is the organ that will house a baby for the nine-month period before it is born. The uterus has a blood-filled lining that helps to provide babies with nutrition.

The largest sexual organ that women have is the brain. The brain is responsible for coordinating the reflex responses that help to make up the sexual response cycle. The brain, in conjunction with the spinal cord, helps the system to run smoothly. Changes in sexual function after spinal cord injury occur as a result of the changes in the nervous system connections.

Sexual Response Cycle

In 1966, Masters and Johnson reported on scientific studies that described the physical changes that occur when men and women are sexually stimulated. What Masters and Johnson described is a four-phase cycle. Although some of the physical changes that occur during sexual stimulation are the same for

both men and women, there are some differences. These differences will be pointed out in each step of the cycle.

Phase One: Excitement

Stage one is the period of time in which sexual excitement begins to grow. This can happen quickly or may take some time. As stimulation increases, the penis and vaginal area are touched. You will notice a stronger desire for sexual release. As you become aroused, there is an increase in heart rate, blood pressure and breathing rate. The nipples of both men and women may become erect. As the excitement builds, a man's penis hardens (becomes erect) and the vaginal area begins to moisten.

Phase Two: Plateau

In the plateau phase, there is a continuing of the feelings that individual's experience. You will notice an increasing intensity of your feelings of excitement. There continues to be an increase in heart rate, blood pressure and breathing rate. The nipples become more erect. The penis becomes hard enough for penetration and the vaginal area expands and becomes more moist. You may notice an increase in muscle tension and spasms. Your body becomes increasingly sensitive to touch. The urge for stimulation of the genitals becomes overwhelming.

Phase Three: Orgasm

As the sexual excitement increases, you begin to reach a point in which climax is expected. There is a sense of urgency in this phase. The bodily changes continue to increase. During intercourse, the thrusting of the man's penis becomes rapid and deep and a man may experience ongoing rhythmic contractions. Women also may experience rhythmic contractions in the vaginal area. The intensity of your body's sensations depends on the several factors, including fatigue, medications you are on and the feelings that you may have for your partner.

Phase Four: Resolution

During this phase, both partner's bodies begin to return to the pre-excitement state. All of the physical changes that occurred during intercourse begin to fade away. Emotionally, this is often a time in which the couple may

feel very close and enjoy the special intimacy of being together.

For men, this pre-excitement state can return quickly. Generally, men are able to have one orgasm and then need a period of time to pass before they are able to have another erection. This is called a refractory period. The period of time that they need to achieve another erection varies from person to person and can be anywhere from ten minutes to several hours.

Many women report that it takes them some time to return to their pre-excitement state. Women do not have a refractory period. Many women experience orgasms still.

Spinal Cord Impairment Changes that Affect Both Men and Women

Every person with a spinal cord injury faces his or her own set of concerns in the sexuality and sexual functioning part of his or her life. For some people, this area is not of concern early after their injury. For others, it is one of the first things that pops into their head after being injured. Whichever group you fall in, there are some important things to remember.

In order to find out which parts of your sexual functioning may have been affected by your spinal cord injury, it is important for you to take the time to explore your own body. Discover which areas feel good when they are touched. Physical intimacy can include such activities as holding hands, kissing and touching. These are activities that can help you to become more comfortable with the “new” you.

Spinal cord injury does not effect our need for being physically close to another person. This physical intimacy (even just being held) is an important part of our health. Foreplay (the simple acts of holding, kissing, touching) are as important now as they ever were. We encourage you to use the tools that you have to explore who you are now as a sexual person.

Changes in Sensation

Depending on the level of your spinal cord injury, different areas of your body may have decreased or absent sensation. Despite this, many people report that they still have some areas where they can be stimulated and enjoy the intimacy of the moment.

Experiment and see what feels good to you. Try different areas than you may have used before your injury. For example, for some people with spinal cord impairments the area near their

level of injury may be very sensitive to touch. This includes the area on the front and back of your body near the vertebrae level where the injury occurred. For other people, that area may be too sensitive. You will need to find out for yourself what areas work and which areas don't.

Some other areas that may respond to sexual stimulation include the back of the neck, behind the ears, around the nipple area and the sides of your legs near the genital area.

Most important of all, when you find an area that does respond to stimulation, communicate what feels good and what doesn't to your partner.

Changes in Movement

Depending on your level of injury, areas of your body may not be able to move the way they did before your injury. You will need to discover which positions may work for you and what positions won't. The only way to do this is to try different positions and see what works.

You may find that using the hospital bed gives you better balance. Try making love in the wheelchair. Use whatever you can to make moving easier. This may include things like side rails or pillows. Use a pillow to support you in a position. Anything that works for you and your partner is fair game.

Bowel and Bladder Involvement

The nerves S2, S3 and S4 are the nerves that make you empty your bowel and bladder and also are responsible for some sexual responses. It is possible that you may have a bowel or bladder "accident" during sexual intimacy. Because of this, it is important that you maintain your bowel program and empty your bladder before you begin sexual activity. This should help to prevent problems from occurring.

The sexual responses that these nerves are responsible for include *reflex erections* and part of the *ejaculatory response* in men as well as *reflex lubrication* in women. If your spinal cord impairment has left this reflex arc intact, then your sexual functioning will be affected one way. If this reflex arc is not intact, then you will have other sexual functioning issues. Either way, there are techniques that can be used to enhance your sexual functioning. We will go into these impairments and techniques later in this chapter.

You and your partner need to understand that no matter how well prepared you may be, there is a chance that you may have a

bowel or bladder “accident.” Many people have shared that keeping supplies near by and discussing this possibility helps to make this less traumatic if it should occur.

Spasticity

If you have spasticity, you know that certain positions and activities can increase the level of spasticity that you may have. What you might not know is that the medications that you are on that help to decrease spasticity also may affect your sexual drive. This is especially true if you are on more than one medication for spasms.

Some people have said that their spasms can enhance their sexual abilities. This seems to be the case for individuals who are able to “trigger” their spasms to help them move or transfer. The important thing to remember is that each person is an individual and the way spasms affect you is individual.

Medications

A possible side effect of some of the medicines that you may be taking is a decrease in sexual desire. This seems to be especially true when you are taking more than one medicine with this side effect. After you get home and in a routine, if you notice that your sex drive is much less than before your injury, you may want to discuss the medicines that you are taking with your doctor. He may be able to change some of them or discontinue them.

The medications that are known to have this side effect include: anti-spasticity drugs, some high blood pressure medications, heart medicines and anti-depressants.

Autonomic Dysreflexia

Remember, if your injury is at T6 or higher, you are at risk for developing autonomic dysreflexia with any type of stimulation below your level of injury. Sexual intercourse may lead to autonomic dysreflexia, which is characterized by a pounding headache, sweating, goose bumps, etc.

Should this happen, what you need to do is stop the activity at once. Wait until the symptoms go away. You can resume sexual activity, but try a different position. Should it re-occur, speak with your doctor. He may be able to give you some medication that you can take before sexual activity that will decrease the symptoms.

Depression

Some people experience depression after having had a spinal cord injury. When you are depressed, you are more likely to have no interest in sexual activity. If you find, especially after going home, that you are very sad all of the time and don't have any interest in doing anything, you may be depressed. Speak to your doctor, nurse, psychologist or case manager and he or she may be able to assist you in finding some resources that can help you deal with your depression. Most people report that as they become less depressed, interest in activities, including sex, increases. There is no need to suffer with depression anymore.

Ability to Have an Orgasm

Years ago, the thought among health care providers was that if you had a spinal cord impairment, then you would not be able to experience an orgasm. Research and discussion with thousands of survivors has shown this to be false.

Many people report that they do indeed experience a different feeling, similar to an orgasm. The intensity and length of this feeling may not be as strong, but there are certainly some feelings of pleasure with sexual contact. Other people report that they need more stimulation than they did prior to their injury to achieve this feeling.

So the news is, that for many people, having a spinal cord impairment means that you need to rediscover what feels good and what doesn't, what areas turn you on and how much stimulation you need to get pleasure from the experience. We encourage you to explore your body and find what works for you and your partner. You will need to communicate this to your partner and work together to find right things for you.

Safe Sex

Sexually transmitted diseases such as syphilis, gonorrhea, hepatitis, herpes and HIV continue to be a part of today's health care arena. These diseases are given to a person from another person who has them. All sexually transmitted diseases are transmitted by having contact with another person's body fluids (blood, saliva, semen or vaginal secretions). It is important to realize that your spinal cord impairment does not make you immune to these diseases. Keeping yourself safe from these diseases is your responsibility, and practicing safe sex is just as important now as it was before your injury! This includes decreasing the number of partners that you have, having honest discussions between you and the

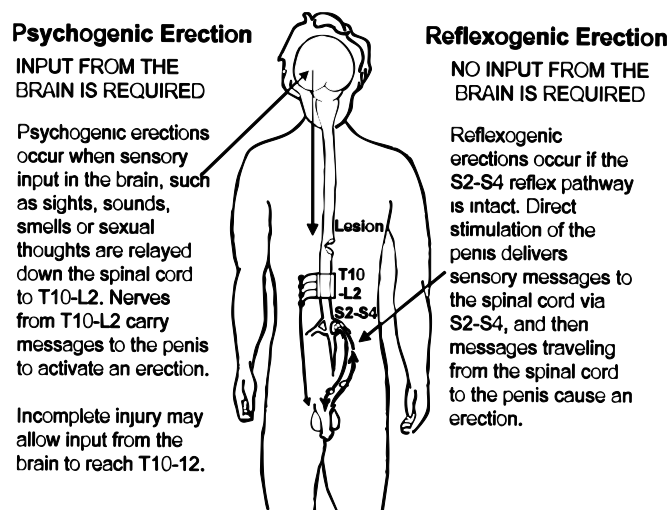
partner(s) that you do have regarding sexual history, using condoms during intercourse and, if necessary, being tested periodically for sexually transmitted diseases.

You alone are responsible for your health!

Spinal Cord Impairment Changes that Affect Men

Erectile Function

Many men with spinal cord impairments have difficulties with erectile function. This can include having problems getting an erection, maintaining an erection or both. During sexual activity, the penis fills with blood and becomes hard. There are two types of erections and they usually work together to give you a firm and lasting erection. These are *reflexogenic* and *psychogenic*.



(Printed with Permission from Amador MJ, Lynne CM, Brackett NL: *A Guide and Resource Directory to Male Fertility Following Spinal Cord Injury/Dysfunction*, Miami, FL, 2000, Miami Project to Cure Paralysis.)

Reflexogenic erections are coordinated by the spinal cord in the area of S2, S3 and S4. A reflexogenic erection occurs with direct stimulation to the penis or by internal stimulation such as a full bladder. Reflex erections need the spinal cord reflex of S2, S3 and S4 to be intact.

Psychogenic erections occur when sensory input turns you on. This stimulation can take the form of seeing or visualizing something that is pleasing to you sexually. The brain sends down a message to the spinal cord at T10 through L2 to give you an erection. Psychogenic erections need the connection between the brain and spinal cord to be intact.

After spinal cord impairment, the nerve pathways to and from the brain are completely or partially damaged. The injury may prevent messages in the brain from reaching the T10 through L2 nerves that control psychogenic erections. If you have an incomplete injury, these pathways may have been spared or may be partially working. If so, you may still have the ability to get erections from seeing or visualizing something.

Many men with spinal cord impairments still have the reflex arc of S2, S3 and S4 working. If this is the case, your ability to have and maintain an erection will be there. However, the quality of the erection may be different from what you remember before your injury.

Erectile Management

There are several different ways to treat erectile dysfunction. Some of the treatments are more invasive than others. Below is a description of several options that you may have. You will need to discuss treatment options with your doctor. Keep in mind that your choice of management should be acceptable to you and your partner. Insurance coverage for some of these methods may be limited, which also may affect your choice.

Oral Medications

Viagra[®] (Sildenafil), Cialis[®] (Tadalafil) and Levitra[®] (Vardenafil) are pills available to treat erectile dysfunction. They are taken 30 to 60 minutes before engaging in sexual activity. Several studies done on men with spinal cord impairments show that these medications work for 65 to 75 percent of the men who tried it. It is generally well tolerated. However, it does have as a side effect of lowering your blood pressure. This may be a problem for some spinal cord impaired men, since a low blood pressure is a complication of spinal cord impairment. These medications can not be taken if you are on certain heart medications. The medication does not work for everyone, but is one option to explore.

These pills enhance a chemical messenger in the body that relaxes smooth muscles in the penis, which increases the amount of blood and allows an erection in response to sexual stimulation. These medications do not automatically produce an erection. Instead, they allow an erection to occur after physical and psychological stimulation.

Priapism (an erection that lasts longer than four hours) is a possible side effect of these medications. While this sounds like a great benefit, it can actually cause problems for you such as

skin breakdown on your penis. Priapism can lead to autonomic dysreflexia also. Priapism is considered a medical emergency and requires immediate attention.

Urethral Suppositories

The drug in MUSE (Medicated Urethral System for Erection) is Alprostadil[®] which is identical to a substance that occurs naturally in the penis and aids in achieving an erection. Directly inserted into the penis, the urethral suppository is absorbed by the tissue and relax muscles in the penis allowing blood flow to increase and create an erection. A man generally will get an erection within 10 to 15 minutes and will last about 30 to 60 minutes. Urethral suppositories can be used twice in any 24 hour period.

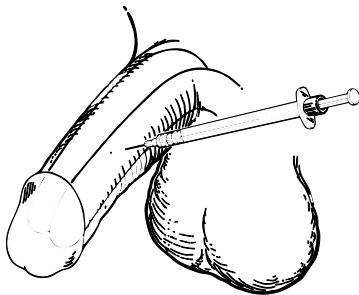
Injectable Medication

There are some medications that can be injected into the shaft of the penis. These medications help the blood vessels to open and the penis to fill with blood. Injection therapy typically uses a combination of drugs prescribed by a doctor, usually a Urologist. The most common drugs are Papavaril[®], Phentolamine[®] and Alprostadil[®]. The doctor may combine two (bi-mix) or three (tri-mix) of the drugs. Your doctor carefully prescribes the amount of medication that you use after he has given you a trial in his office. The amount of medication that is used should give you an erection that lasts between two and four hours.

A complication of using injectable medications is a condition called *priapism*. Priapism occurs when the blood does not drain from the penis, causing an erection that lasts longer than four hours. If this condition is not treated, permanent damage to the penis can occur. Priapism is considered a medical emergency and requires immediate treatment.

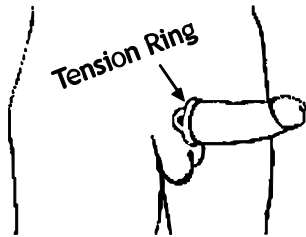
There are some other complications that can occur if you use injectable medications. These include bruising, infections and scarring of the penis. One way to prevent scarring is to limit the use of the medication to once or twice a week and rotate the places you inject. Since this may be unacceptable to you and your partner, there may be other methods that you might want to consider.

Penile Injection System



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Tension Ring



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Tension Rings

Tension rings are an option for men who are able to get an erection, but unable to keep it. Tension rings are made of rubber or silicone and are placed around the base of the penis. Tension rings trap the blood in the penis, allowing the penis to stay erect.

If you are able to use a tension ring, you must carefully check the skin around the penis prior to placing the ring on. Since tension rings trap the blood in the penis, there is a chance of bruising and skin breakdown if the ring is left on too long. The recommended amount of time that you can leave a tension ring in place is no more than 30 minutes. You can, however, remove the ring and allow the blood to flow. Once you have allowed some normal circulation to occur, you can reuse the ring. This option is especially important for couples who have an active sex life and do not want to limit their sexual activity to once or twice a week.

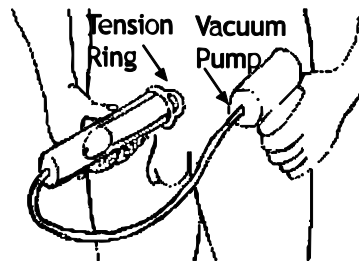
Vacuum Devices

A vacuum device can be used when someone is unable to get an erection and maintain an erection. These devices consist of a plastic cylinder placed over the penis. The cylinder is attached to a pump that creates a negative pressure (or vacuum). This negative pressure draws blood into the penis and gives you an erection. You then place a tension ring at the base of the penis to keep the erection. The cylinder is then removed.

There are the same concerns with a vacuum device and tension ring combination that there are if you only use a tension ring. Since tension rings trap the blood in the penis, there is a chance of bruising and skin breakdown if the ring is left on too long. The recommended amount of time that you can leave a tension ring in place is no more than 30 minutes. You can, however, remove the ring and allow the blood to flow. Once you have allowed some normal circulation to occur, you can reuse the ring. This option is especially important for couples who have an active sex life and do not want to limit their sexual activity to once or twice a week.

There are a variety of tension rings and vacuum devices to choose from. Vacuum devices come in two models: a manual pump, which requires more hand function and a battery operated pump, which requires less hand function. It is important to ask your doctor or nurse practitioner which devices he or she recommends for use. Some of these products

Vacuum Device



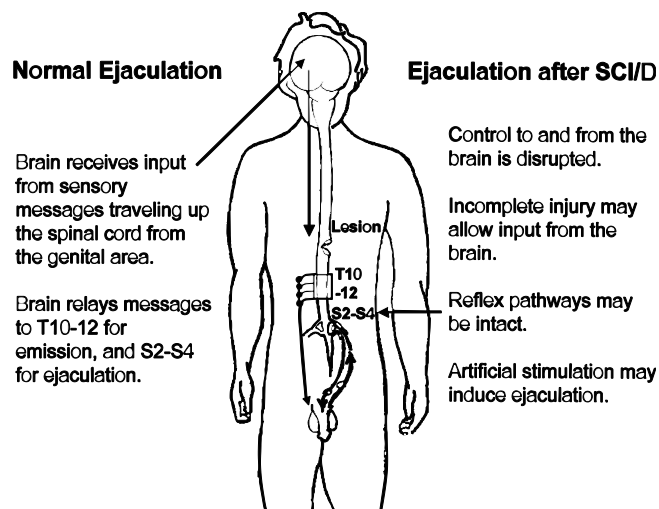
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can be bought over the counter. However, these may not meet medical guidelines.

Ejaculatory Function

Ejaculation is a complex process. Ejaculation occurs when the semen is expelled from the urethra. In a non-spinal cord impaired man, vertebrae levels T10-L2 are responsible for semen being released from the testicles into the urethra. S2, S3 and S4 are responsible for propelling the semen out of the urethra. This process is coordinated by a nerve center in the brain that receives information from sight, sound and smell. The center also receives information when the penis or body is touched in a sensual way. The coordination center in the brain relays messages to the spinal cord to stimulate erection and ejaculation.

After spinal cord impairment, input to and from the brain does not usually occur. Your injury makes it difficult to respond to sexual stimulation and to ejaculate in a “normal” way. However, since the ability to have an erection and to ejaculate involves reflexes, if the nerves are not damaged, there are ways to stimulate an erection and to retrieve semen.



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Many people think of ejaculation as an orgasm. While it is a part of the experience, ejaculation is not the same as orgasm. You can still have an orgasm without ejaculating. Research has shown that the feelings anyone experiences during orgasm come not only from the physical release of ejaculating, but from

the brain also. During sexual arousal, our brains are able to make chemicals called *endorphins*, which make us feel good (or high). Your spinal cord injury has not taken this ability away. Many spinal cord injured men report that they experience something similar to an orgasm during physical intimacy. It may be the same feelings — more intense or less sensation — but there is something that is experienced.

Retrieving Sperm

There are several ways that your sperm can be retrieved if you and your partner wish to have a child. Keep in mind that none of these techniques will guarantee a pregnancy. They only improve your chances of getting pregnant. Also, it is important to know that these treatments are done only if you are trying to become a parent.

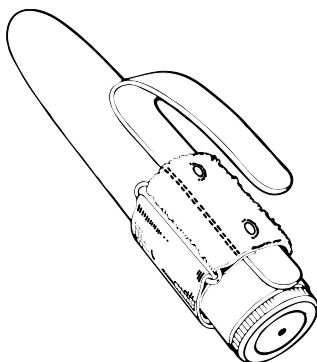
The first step in trying to get pregnant is to see if you can ejaculate on your own. You can try to find this out by masturbating or by having sexual intercourse. Please keep in mind that no matter what type of spinal cord injury you have, your spinal cord injury is not birth control. Remember that it only takes one sperm and one egg to make a baby. So please take precautions if you and your partner are not ready to be parents.

If you are unable to ejaculate, the next step is to see your doctor. After talking with you and your partner, he or she will make suggestions as to what the next steps should be.

Most of the time, couples are referred to a fertility specialist. Make sure that the specialist you go to has experience with individuals who have spinal cord impairments. Fertility specialists will have both partners tested to make sure that any problem that may make it difficult for you to get pregnant is addressed.

Some of the options that may be given to you and your partner may include the following: penile vibratory stimulation, rectal probe ejaculation and needle aspiration retrieval. A brief discussion of these methods of sperm retrieval will follow.

Vibrator adapted for an individual with limited hand use



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Penile Vibratory Stimulation (PVS)

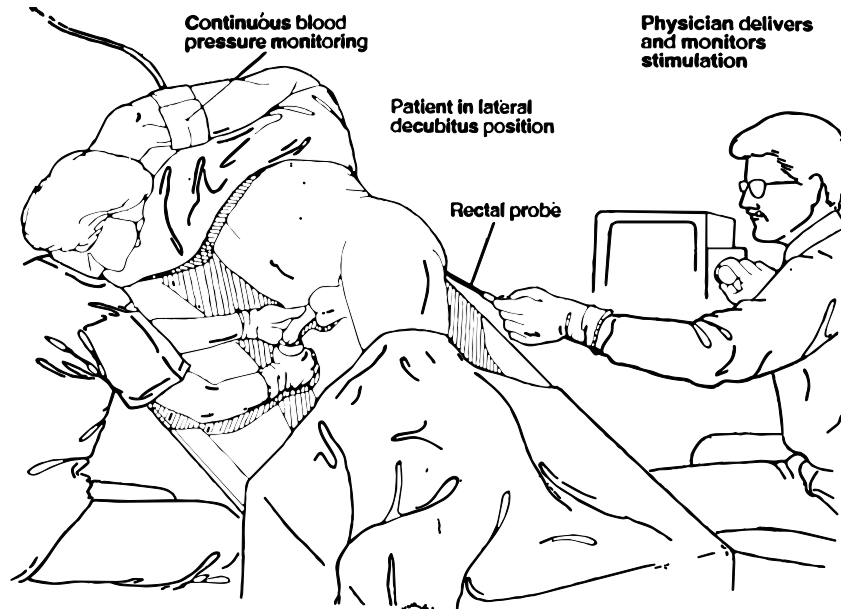
This is a method where a vibrator is placed on the head of the penis to stimulate ejaculation. Since you have spinal cord impairment, you need to use a high amplitude vibrator to get the best results. High amplitude vibrators are available only by prescription. Low amplitude vibrators are available without prescription and may be called “massagers.”

Studies have shown that with the use of high amplitude vibrators, 55 percent of all men with spinal cord dysfunction will ejaculate. Studies also have shown that if your impairment is above T10, you have an 80 percent chance of ejaculating if you use a high amplitude vibrator. More importantly, research has shown that the quality of semen obtained when you are able to ejaculate with the use of a penile vibrator is of better quality than sperm retrieved using the other methods. Penile vibrators are less expensive and take very little time to learn to use. Because of all of this information, penile vibratory stimulation is considered to be the first method you should try before moving on to the more technological methods of rectal probe ejaculation or needle aspiration.

Rectal Probe Electroejaculation (RPE)

During rectal probe electroejaculation, the man with spinal cord impairment has an electrical probe placed into his rectum by a doctor. The doctor controls the amount of stimulation that you will receive. Generally, the probe is left in your rectum for about 10 minutes. Once ejaculation has occurred, the probe is removed from your rectum and the sperm is collected for insemination into your partner.

Rectal Probe Ejaculation



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Needle Aspiration Retrieval

Once you have tried penile vibratory stimulation and rectal probe electroejaculation, the next step is needle aspiration retrieval. A needle is inserted into the testicle, epididymis or vas deferens. A small amount of sperm is then drawn into the needle and used for artificial insemination.

The amount of sperm that is retrieved with this method is small, so advanced reproductive techniques such as in vitro fertilization (or IVF) are recommended. (In-vitro fertilization is a technique where eggs are retrieved from the female and sperm are retrieved from the male. They are placed together in the laboratory where fertilization of the eggs is attempted. The embryos are placed in the woman's uterus, where they will, hopefully, become a baby.)

Problems with Sperm Retrieval

Autonomic Dysreflexia

One of the major complications of any sexual stimulation is autonomic dysreflexia if your spinal cord impairment is at or above T6. If you are prone to autonomic dysreflexia, you need to inform the doctor that you are working with that this is a problem that you experience. Your doctor may choose to prescribe some medication for you that will prevent your blood pressure from climbing during these procedures.

Retrograde Ejaculation

During normal ejaculation, the bladder neck closes and semen is expelled out through the tip of the penis. This process is called *antegrade ejaculation*. In some men with spinal cord impairments, the semen does not exit the penis. Instead, the bladder neck does not close and some or all of the semen enters the bladder. This is called *retrograde ejaculation*. Retrograde ejaculation occurs more commonly with rectal probe electroejaculation, but can occur with masturbation or penile vibratory stimulation. Although the sperm are exposed to urine in the bladder, they can be retrieved by using a catheter and cleansed by laboratory personnel. The sperm retrieved can be used for analysis or for insemination.

Semen Quality

While there are now methods for retrieving sperm from spinal cord impaired men, there is still the problem of poor sperm quality that many spinal impaired men face. Frequently, spinal impaired men have normal sperm counts, but the number of motile sperm (those sperm who are able to swim) is much less than in the non-spinal impaired man. This is the major reason for infertility in spinal impaired men.

Research has helped to take away some of the reasons that were believed to be true. Scientists have found the following information to be true.

Most of the immotile sperm from spinal impaired men are dead. Sperm from spinal impaired men are very fragile and quickly lose their ability to swim. There also does not appear to be any relationship between the level of injury, age, the amount of time after injury or how frequently you ejaculate.

Researchers also know that your semen quality does not decline over years. And most importantly, researchers know that the semen impairments that we see in spinal impaired men are not seen in other infertile men. Once researchers know what causes this semen impairment, treatments can be

Spinal Cord Injury Changes that Affect Woman

developed to help overcome this problem. Look for more information in future years.

Much of the research that has been done on sexual functioning after spinal cord impairment has, until recently, been done on men. There are several reasons for this. It is easier to see what happens on a man. Secondly, the majority of spinal cord impairments from trauma occur to men. And last but not least, much of the initial research was done in the Veteran's Administration Hospitals, which again are predominately male.

The last few years, however, has brought forth much needed and wanted information regarding sexual functioning in women with spinal cord impairments. While this information has assisted many people, there is still much left to be learned.

Interruption of the Menstrual Cycle (Menses)

A traumatic spinal cord injury has no affects on a woman's reproductive abilities. Most women report that their menses does stop for a period of time after a traumatic injury or illness. This time can be anywhere from a week to six months. It does appear that the length of the menstrual cycle and the amount of menstrual bleeding that you have is similar in pattern to your pre-injury cycle.

If you have not started up with your period after six months, you should speak with your doctor. Of major concern in this period of time without your menses is the fact that you can get pregnant. Since we cannot predict the amount of time it takes for your cycle to resume, it is important to practice birth control. If you do not want to become pregnant, you should speak with your doctor about this before getting into a situation where pregnancy could happen.

How Do I Handle My Menstrual Cycle (Menses)?

The biggest problem in dealing with your menses after spinal cord impairment is the amount of dependency that you may have with doing transfers and changing tampons or pads. There is no reason that you cannot use the method of management of your menses that you previously used, unless it is physically impossible for you to do it by yourself.

Lubrication

Many women with spinal cord impairments have difficulties with lubricating their vagina. This can include having problems becoming moist and maintaining the lubrication. During sexual activity, the vagina becomes softer and moist. For this to happen, there are two ways that lubrication occurs, and they usually work together. These are *reflexogenic* and *psychogenic* processes.

Reflexogenic lubrication is a reflex coordinated by the spinal cord in the area of S2, S3 and S4. Reflexogenic lubrication occurs with direct stimulation to the vagina or genital area or by internal stimulation such as a full bladder. Reflex lubrication needs the spinal cord reflex of S2, S3 and S4 to be intact.

Psychogenic lubrication occurs when sensory input alone turns you on. This stimulation can take the form of seeing or visualizing something that is pleasing to you sexually, even smells or sounds (like music). The brain sends down a message to the spinal cord at T10 through L2 to give you lubrication. Psychogenic lubrication needs the connection between the brain and spinal cord to be intact.

After spinal cord impairment, the nerve pathways to and from the brain are completely or partially damaged. The injury may prevent messages in the brain from reaching the T10 through L2 nerves that controls psychogenic lubrication. If you have an incomplete injury, these pathways may have been spared or may be partially working. If so, you may still have the ability to become moist from seeing or visualizing something.

Many women with spinal cord impairments still have the reflex arc of S2, S3 and S4 working. If this is the case, your ability to have and maintain some amount of lubrication will still be there. However, the quality and quantity of the lubrication may be different from what you remember before your injury.

How Do I Handle Incomplete Lubrication?

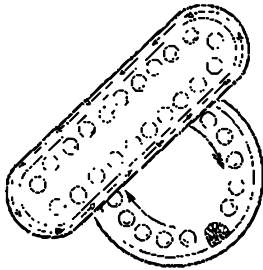
One of the easiest ways of managing incomplete or absent lubrication is to buy some lubricating jelly. Insert some of the jelly into the vagina prior to intercourse. This will help to prevent tearing the vaginal wall and should make intercourse more pleasant for both you and your partner.

If you have limited hand function, you may need to have your partner insert the jelly for you. Many couples report that they have incorporated this into foreplay. You and your partner will have to do what feels comfortable to you.

Contraception (Birth Control)

Generally speaking, the options for birth control for women with spinal cord impairments are the same as for able-bodied women. However, each method of contraception has its own set of issues. Much of your decision of which method of birth control to use will depend on your physical limitations, previous medical problems, what you and your partner are comfortable with and what you have used in the past. Although birth control is generally written about under women's health, men have an equal responsibility. It is important to consider what your partner feels and how much your physical limitations will impact what your partner needs to be responsible for.

Birth Control Pills



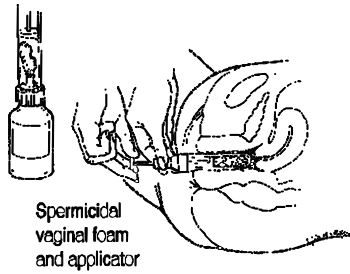
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Birth Control Pills

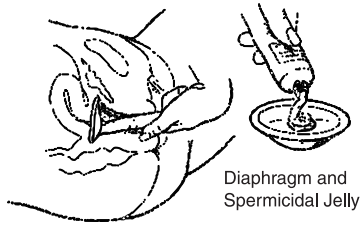
The major concern of using birth control pills is the increased risk of deep vein thrombosis (blood clots) in spinal cord impaired women. Birth control pills carry with them the increased risk of blood clots, so the combination of spinal cord impairment and birth control pills is controversial with many physicians.

Although the progesterone only pills are less effective than the estrogen-progesterone combination pills, the progesterone only pills do have less of a risk of deep vein thrombosis. Used in combination with condoms, the progesterone only pills are an alternative for many spinal cord impaired women. (Progesterone is a hormone.)

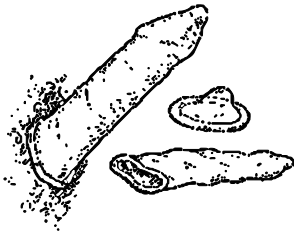
Barrier Methods



Spermicidal vaginal foam and applicator

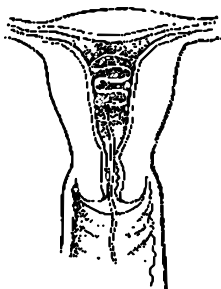


Diaphragm and Spermicidal Jelly



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IUD



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Barrier Methods

Barrier methods are methods that prevent the sperm and egg from physically meeting. Barrier methods include such options as the diaphragm, cervical cap, foams, jellies and condoms.

When using a barrier method, they are more effective if both partners use one. For example, if the woman is using a diaphragm, the man should use a condom. Using two barrier methods increases the effectiveness of barrier methods as much as 99 percent.

Barrier methods have several potential problems for spinal cord-impaired women. Barrier methods require good hand function to place them correctly. This may be a problem for some women. Having your partner place the diaphragm or cervical cap in place can manage this. Hypersensitivity in the genital area may be another issue for some women. If this is the case, using a diaphragm or cervical cap is not a good option for you. Lastly, many people who have been around latex products, such as catheters and gloves, may have a latex sensitivity. If this is the case, then barrier methods are not the right choice for you.

Intra-uterine Devices (IUD)

An intra-uterine device (IUD) is a device that is inserted into the uterus and causes a low-grade infection to occur. This low-grade infection makes the uterus a hostile place for an embryo to grow and thus prevents pregnancy. The IUDs that are currently on the market contain medications that appear more effective and decrease the amount of menstrual bleeding that you have.

One of the major problems with IUDs are that they can cause an infection called pelvic inflammatory disease. If you don't have sensation, you may not be aware of this infection until you are very sick. The signs of pelvic inflammatory disease include abdominal pain, severe cramping, an unexplained fever and a foul smelling discharge. If an infection occurs, the IUD should be removed and antibiotics given to clear up the infection.

Birth Control Implants

The Norplant[®] implant is a small implantable device, which contains a progesterone medication that is slowly released over a period of time. The implants are generally placed in the upper arm. The implants generally have the same effectiveness as the progesterone only pills. One of the problems with the implants is that menstrual bleeding may become irregular, which makes it difficult to plan for care.

Basal Body Temperature

Every woman has several days in her menstrual cycle where she is fertile. At the beginning of this fertile time, there is an increase in your body temperature. This increase in temperature is slight (less than a degree), but by using a special thermometer and taking your temperature at the same time everyday, you can begin to see a cycle (or rhythm). Using this cycle, you can either increase your chances of becoming pregnant or decrease them. This method has been called the rhythm method and is considered a “natural” method for family planning.

However, using your basal body temperature as a means of natural family planning is not recommended after a spinal cord impairment. This is because of the impaired ability of your body to maintain a well-controlled basal body temperature.

As you can see, the options for birth control may be limited depending on the methods that you and your partner have previously used and your current functional ability. However, working with your health care provider, new ideas may come to mind. Remember to ask questions and get information prior to making any decisions.

Pregnancy

Your spinal cord impairment does not provide you protection from becoming pregnant. There have been many studies done that show a woman’s fertility is not affected by spinal cord trauma.

Should you decide that you want to become a parent, it is helpful to discuss several things with your health care provider. The following list is meant to provide some guidelines for the types of questions that you might want to ask. It is by no means complete and you may have others that come to mind.

Some of the concerns that need to be addressed include:

- Will my disability be increased as a result of my pregnancy?
- Are there any medications that I need to come off of before I get pregnant?
- How will my independence be affected by a pregnancy?
- Will my bowel and bladder programs be affected by a pregnancy and how will I adjust them?
- Will my spasticity level be affected by my pregnancy?
- Are there any special problems that I may have as a result of becoming pregnant? (e.g., increase of autonomic dysreflexia or urinary tract infections)
- Who should I use as my primary health care provider during my pregnancy?
- Are there any special pregnancy programs that are available to work with disabled women?
- What are the issues that I may face as a parent with a disability?

If you and your partner have decided to try to become parents, there are a few issues that you should be aware of that may occur while you are pregnant.

Increase in Urinary Tract Infections

Since your spinal cord impairment, you may have experienced an increase in the number of urinary tract infections that you have. A normal complication of pregnancy is also an increase in urinary tract infections. You will have to be more diligent in managing your bladder program and recognize that you may experience an increase in the number of UTIs that you have during this time.

Changes in Balance

As your pregnancy progresses, you will notice that your center of gravity changes. This can affect the way that you do transfers, bed mobility and a variety of activities of daily living. You and your partner may need to prepare ahead of time for a period of increased dependence at the end of the pregnancy.

Changes in Spasticity

Since many of the spasticity medications that you may be on are not good for the baby, many doctors recommend that you be weaned off of these until you have delivered. Just be prepared that as the pregnancy proceeds, you may experience an increase in spasticity.

Equipment Changes

As your pregnancy progresses, it may become more difficult for you to propel a manual wheelchair or to assist in transfers. These changes may make it necessary to use a transfer board or assistive device or a power wheelchair. Just as any woman who is pregnant, you will need to make some accommodations for the changes your body is going through.

Autonomic Dysreflexia

If you are prone to autonomic dysreflexia, pregnancy may put you at greater risk for experiencing it. The increase pressure on the bladder may increase the number of episodes you experience, particularly as the pregnancy progresses.

Premature Labor

It is not uncommon for women with spinal cord impairments to go into labor early, possibly due to an increase in urinary tract infections. It is important for spinal cord-impaired women to know possible signs and symptoms of labor and to check for these earlier than on able-bodied women. Signs of labor in a woman with a spinal cord impairment include: an increase in abdominal spasticity, a feeling of something about to happen, an increase in urinary incontinence or urgency and autonomic dysreflexia.

Respiratory Discomforts

For some people, respiratory function improves with pregnancy. The baby acts like a corset and makes it easier to breathe. For other people, the added pressure of the baby on the diaphragm makes it more difficult to breathe. Changing positions and using nose-mouth breathing may help this. If the problem becomes more intense, your doctor may suggest a respiratory therapy consult.

Skin Care Issues

With the changes in weight, there may be changes in the way that your weight is distributed. Weight shifts may become more difficult as your pregnancy progresses. It is important to continue with your skin care program and to monitor your skin closely to prevent problems.

While your disability may make pregnancy and parenting more challenging, there are many women who have gone before you. Feel free to ask to speak with someone who has been there. (Use the Peer Mentor Program or the Spinal Cord Injury Follow-Up Clinic's registered nurses.)

Menopause

As women age, they enter pre-menopause and menopause. A spinal cord impairment does not appear to have a huge impact on this. However, some studies have reported that women with spinal cord impairments do enter menopause a year or two earlier than their able-bodied friends and family. There are some spinal cord impairment symptoms that are increased when women are menopausal. This includes an increase in spasticity, an increase in autonomic dysreflexia and an increase in bladder spasms. You also will have some of the signs of menopause that your able-bodied friends have: hot flashes, mood swings and abdominal discomfort. If you are experiencing these symptoms and are in your mid- to late forties, you may be pre-menopausal.

One of the major concerns for women who are in menopause is the problem of osteoporosis. Since your spinal cord impairment may place you at a higher risk for this already, it is important to discuss with your health care provider options for helping to prevent this complication. This may include the option of hormone replacement therapy. Speak with your health care provider to determine if this may be helpful for you.

Maintaining Your Sexual Health

Whether you are a man or a woman, your sexual health needs don't change as a result of your spinal cord impairment. For women, this includes getting a yearly PAP test, doing monthly self-breast examinations and getting mammograms at the appropriate times. For men, this includes self-testicular examinations and prostate checks.

PAP Test

A PAP test is done in your doctor's office (Gynecologist). It is a screening procedure for cervical cancer (the cervix is where the uterus and vagina meet). Since a problem in the cervix does not usually have any symptoms during the early stages, this is a good way to detect these changes.

A PAP test is done by having you lie on an exam table. An instrument called a speculum is used to gently open your vagina. A cell sample is taken from your cervix. Generally, you will receive the results of your test within a few weeks. You need to check with your health care provider to find out how you will get the results. Some people send a copy of the test results to you. Others will call you. It is your responsibility to find out the results. Generally, it is recommended that you have a PAP test once a year.

For women with a spinal cord disability, it may be difficult to find a gynecologist who has an accessible office and is familiar with the potential problems that you may have, such as spasticity, frequent urinary tract infections, difficulties transferring to an examination table and difficulty positioning in footrests or stirrups. Check with your spinal cord care provider to find a gynecologist who may be more aware of some of the issues that you may have. Your spinal cord disability does not take away the need for a PAP test.

Self-Breast Examinations

Self-breast examinations are the best way to find changes in your breasts that may be cancerous. Self-breast examinations are painless and simple to do. They only take a few moments each month. A self-breast examination should be done once a month. The best time of the month to do this is usually a day or two after your menstrual period. It is a good idea to do a self-breast exam at the same time each month. This makes sure that the breast tissue is consistent from one month to the next.

In front of a mirror, check the size and shape of both breasts. Gently squeeze each nipple to check for discharge. Feel each breast for unusual lumps and bumps. Use the three middle fingers of one hand, moving in a circular motion. For more specific directions, check with your health care provider.

If you are physically unable to do this yourself, you will need to have an attendant or partner do this for you.

Self-Testicular Examination

Men have a responsibility to check their testicles each month for any changes that may occur. These changes may show that you have testicular cancer. You need to gently squeeze each testicle. Then, using two fingers, gently move across each testicle and the scrotum (sack), checking for any lumps or bumps that are not normal for you.

If you are physically unable to do this for yourself, you will need to have an attendant or partner do this for you.

Prostate Examinations

Men have the responsibility of having a yearly prostate examination once they are fifty years old. (Forty years old if you have a family history of prostate cancer or if you are African-American.) This examination is done by a doctor gently inserting his or her finger into your rectum to feel for your prostate gland. Your doctor may order a blood test called a PSA (Prostate Specific Antigen) also. This test measures the amount of PSA in your blood and is a good indicator of prostate problems.

Your spinal cord injury may hide some of the symptoms of prostate problems. These symptoms include frequent urination, especially at night and difficulty starting a stream.

Prostate examinations are done to help detect prostatitis (an infection of your prostate gland), benign prostatic hypertrophy (enlargement of the prostate gland that is not cancerous) and prostate cancer. Early detection and treatment of these problems is the key to maintaining the health of your prostate.

Conclusion

Sexuality and sexual functioning are areas that have a lot of emotion tied into them. This chapter has a lot of information in it, hoping to provide some of what you need to know. It does not, however, contain all of the information that you may need. By all means, feel free to ask questions and find out more for those areas that are important to you. Remember, sexuality is as important an area as any of other area of your life. Explore, ask questions and discuss what is important to you.

Glossary

Autonomic Dysreflexia	An exaggerated response from the sympathetic nervous system to stimulation (noxious or negative) below the level of injury. Occurs in individuals with a spinal cord injury at T6 or above and is considered a medical emergency.
Body Image	The image that we have of our body.
Contracture	A permanent shortening of soft tissue, resulting in the limitation in the range of the joint.
Ejaculate	The fluid containing both sperm and semen.
Ejaculation	Expulsion of semen from the urethra.
Erection	Hardening of the penis by blood flow.
Excitement	The first phase of the sexual response cycle. It is the period of time in which sexual excitement begins to grow.
Genital Area	The area where our external sex organs are located.
In-vitro Fertilization	An artificial means of fertilizing an egg with sperm in order to attempt a pregnancy.
Insemination	The introduction of sperm into the vagina, attempting a pregnancy.
Level of Injury	The neurologic level of your spinal cord injury. This includes both sensory levels and motor levels.
Masturbation	Stimulation of the penis or vagina by hand or an artificial device such as a vibrator.
Orgasm	The third phase of the sexual excitement cycle. This phase is the point in which climax occurs.
Osteoporosis	A condition that reduces the amount of bone tissue.
Plateau	The second phase of the sexual response cycle. There is a continuation of the feelings experienced in the excitement phase.
Priapism	An erection that lasts longer than four hours. Such an erection can cause serious medical complications and is considered a medical emergency.

Psychogenic erection	An erection that occurs as a result of stimulating your brain. This stimulation can be in the form of seeing or visualizing something sexually desirable.
Reflex erection	An erection that occurs as a result of direct stimulation to the sex organs. This stimulation can include touching, stroking and pulling.
Retrograde Ejaculation	Process in which the ejaculate enters the bladder instead of being propelled out the urethra.
Resolution	The final phase of the sexual response cycle where everything returns to the pre-excitement state.
Safe sex	Practices used to protect yourself from sexually transmitted diseases, pregnancy (with women) or both.
Self-esteem	The value we place on ourselves as a person.
Sexual Functioning	The ability to perform sexual acts.
Sexual Response Cycle	The physical and psychological changes that occur when men or women are sexually stimulated. It is a four-step cycle.
Sexuality	All of the characteristics that make a person a sexual being.
Semen	Combination of seminal plasma and sperm that is ejaculated from a man's body.
Spasticity	Uncontrolled or involuntary movements of the extremities or increased resistance to passive movement.

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Comments and Feedback

The staff of the center has recently spent a lot of time and effort in revising this manual. However, we realize that those who are actively reading and using the manual can improve it. As a part of our program of continuous quality improvement, we ask you to help guide our efforts to improve the manual.

In the next section of the chapter are two forms. The first form is an overview by chapter that seeks to identify those areas of the manual that could benefit the most from additional work. We also seek to identify any major areas of concern that have not been addressed.

The second section is a more focused questionnaire that has as its goal the specific items that should be targeted. For example, should an item be added to the glossary or the definition changed. Should a drug be added to the discussion of bowel programs?

The more specific the comments are the more likely that we will be able to make the improvements that form the basis of your idea. By communicating with the Regional Spinal Cord Injury Center of the Delaware Valley, however, users grant us permission to use any information, suggestions, ideas, drawings or concerns communicated for any purpose we choose, commercial, public or otherwise, without compensation or acknowledgement whatsoever.

Thank you for taking the time to assist us in improving this manual.

Sincerely,

SCI Manual Committee

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Feedback Form

Rate each chapter by placing an “X” on the scale underneath the term that best captures your opinion. Using the next page, provide specific comments regarding your ratings. Feel free to make copies of the next page.

	No Opinion	Fair	Satisfactory	Good	Excellent
Credits / Front Matter					
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Travel and Transportation					
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Spinal Cord Injury Follow-Up Care System					
Master Glossary					

Suggestions and Comments

Chapter: _____

Page(s): _____

Comments: _____

Any terms that need to be added to the glossary? How would you define the terms?

Any section or paragraph that was not clear?

Any drawing or sketch that would help to illustrate the material being covered?

Any additional topic that should be covered?

Any questions you have that you feel should have been answered by the manual?

What is the question?

What is the suggested answer?

Any references that should be added? Any other resources that should be mentioned?

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