

Secondary Conditions
Preventions & Treatment:
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SCI & Sexuality

Produced by:

**The Research
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Introduction

The word "sexuality" is impossible to define in one sentence because it means many different things to different people. In this booklet "sexuality" will be used in a *holistic* way that includes many areas of living life as a sexual being. Sexuality is how you feel and think about yourself and how you present yourself to others as a man or woman. It is how you dress, move, and speak, and what being masculine or feminine means to you. It is how and with whom you choose to flirt, have sexual relations, and fall in love. It is your beliefs and attitudes about having sex, and how you like to explore your own or your partner's body. It is whether or how you choose to become a parent and raise children.

This booklet focuses on challenges and pleasures of sexuality for people with spinal cord injury (SCI). People with other types of disabilities such as multiple sclerosis (MS) or cerebral palsy will find much here that is relevant to their situation. However, the match will not be perfect since each type of disability affects the body differently. The book "Enabling Romance" by Kroll and Kroll (see Resources) discusses sexuality in the context of a number of different disabilities.

A Note on Diversity and Morality

Sex can be wonderful fun, but it also requires people to act responsibly towards others. Being respectful of others means being honest with a sexual partner about your real sexual and emotional needs—for example, not talking about love when you really want sex, or vice versa. Be clear and your partner will respect your honesty. Respect for yourself and others also means taking steps to stop the spread of sexually-transmitted diseases, including HIV/AIDS, for which there is still no cure. It means honoring another person's practice of birth control, or of abstinence from sex. When mutual respect is present, consenting adults can find many ways to share their sexuality with one another, in the style and manner they find most enjoyable.

Part I: Psychological and Emotional Concerns

Although a great deal has changed both socially and legally for people with disabilities during the past several decades, many myths about disability remain. One myth is that people with SCI or other disabilities are not sexual human beings. This is far from the truth! Studies have shown that although the frequency of sexual activity generally decreases to some degree following SCI, a majority of men and women continue to have sexual relations.^{1,2}

Working With Negative and Positive Beliefs

Unfortunately, some people with disabilities start to believe the myths that they are not, should not be, or cannot be sexual beings. These beliefs can become

a bigger problem than the actual disability. It is important to remember that beliefs and facts are two different things. Accepting popular beliefs about sex and attractiveness can hurt your self esteem if you don't happen to fit society's mainstream view of what is good, valued, or beautiful.

Mood and personality can also influence a person's beliefs. For example, someone who tends to be optimistic will generally expect the best, and someone who tends to view the glass as being half empty will often expect the worst. Confusing a negative *belief* with a *fact* and then acting as if that *belief* is actually true can get anyone in trouble. On the other hand, recognizing that *beliefs can change* can help a person act and feel differently in the world.

For example, imagine a man named George who believes others will automatically reject him because he has acquired a disability. Because of his belief, George may avoid activities with others, and not reach out to potential partners. In this way, his *belief* may actually lead to the loneliness he fears. Now compare George's beliefs to those of Betty. Betty knows that some people might reject her because of her disability—after all, there *are* people who run the other way at the sight of a wheelchair. Betty also knows she is basically likeable. She realizes she cannot read other people's minds and cannot predict who will reject her and who will find her attractive and interesting. She dresses and grooms herself to look her best and looks for opportunities to meet new people. Others see her as someone who enjoys people and life. Which person would you predict would be more likely to find a partner?

It might be helpful to take a moment and reflect on how you see yourself now, after your SCI. Are you letting negative beliefs run your life, or are you open to the possibility of success, even with all of society's stereotypes? As you continue to read about, think about, and explore your sexuality, it might be useful to keep exploring whether something you assume or fear to be true is a fact or just a belief that you can choose to put aside.

SCI and Marriage

Many married people with SCI worry that their marriage will suffer because of their disability. People with SCI who have not yet found a long-term partner may fear that now they never will. Sources consulted for this booklet presented slightly different viewpoints concerning marriage and SCI^{3,4} However, statistics from all the studies on this topic show that acquired disability does not *automatically* lead to one outcome or another. An individual marriage is not a statistic; each marriage is a unique relationship between two people. Good communication, a willingness to give and take in a relationship, and counseling (when needed) can all help a new or long-term marriage to survive and flourish. Yet, no matter how strong a relationship is, perhaps it is not realistic to think that a spinal cord injury will not affect it in one way or another. People with SCI and their partners who have successful marriages have shared the following experiences and wise ideas:

- Some people say it is not a good idea for a non-disabled partner to play the dual role of "lover" and "caretaker." This can lead to strain and resentment on the part of the "caretaker", and guilt and resentment on the part of the person with SCI. Some people with SCI who require help with aspects of daily living say they prefer having many of these taken care of by a personal assistant. Of course, there are exceptions. All couples have different comfort levels regarding personal care. It is important to talk about these issues with your partner.

- Again and again people stress the need for *good communication*. People with SCI who enjoy sexual relations with their spouses generally discuss their abilities and limitations openly and cooperate to find compromises. You might find that communication has become even more important following SCI. It may take some time and practice.

- Humor is a valuable ingredient. It is required in large supply in any marriage. For example, one person told a story of how humor turned potential despair into laughter. After she had a bladder accident and soaked the bed her husband left the room – then returned wearing his raincoat! "That's exactly what I needed," she said, "to laugh, not to cry."

- Spouses who do not have a disability sometimes experience lack of support for the marriage from their families and friends, especially at the beginning. Relatives may wonder whether or not a person with SCI can be an effective parent, and whether he or she is a sexual human being. Or... they may simply believe that *no one* (including an Olympic athlete, a beauty queen, or a Nobel Prize winner) could be perfect enough for their very special daughter, son, or best friend. Although negative reactions from your spouse's family are not pleasant, people with SCI are not the only ones to have conflicts with in-laws!

- Sometimes people with SCI experience surprise or lack of support from members of their own families, who may not see them as sexual beings or potential parents. Unfortunately, one's own family is not immune to stereotypes.

With members of both your own family and your partner's, it may be helpful to check out whether feelings you have of not being understood or supported are coming from your own assumptions or those of others. Especially if you have enjoyed a close relationship with someone prior to your injury, it may help to bring up the topic in an open, non-confrontational manner, stating how you feel and asking for the other person's response.

- *Every* relationship needs to be cultivated. This means taking time every day to spend time together, listen to one another, and offer support and encouragement during difficult times. Every couple and individual needs to spend some time away from routine responsibilities and worries, such as taking a vacation away from home or going to see a movie.

- Unfortunately, for many people with disabilities the decision to get or remain married is based on finances. At the time this booklet was written, in order to qualify for nursing and/or personal assistant services from Medicaid a person

must have little or no income. This means that if you have a disability and marry someone who works and makes wages, it is possible to lose important health benefits. Thus, people's decisions about whether to marry or remain married are sometimes based on finances instead of love. If you require health benefits such as a personal attendant and are making decisions about marriage, it may be helpful to check on how your health benefits might be affected.

- Gay and lesbian couples in which one or both partners has a disability often face a double dose of prejudice from people around them. Support from a larger community may be especially important to validate your sexuality and choice of a partner.

Finding a New Relationship

Single people with SCI and other disabilities often worry about whether they will be able to find sexual partners or a spouse. While it is true that some people (both non-disabled and disabled) will not consider having a sexual or romantic relationship with a person who has a disability, others are more open-minded. Physical "perfection" is important to many people, so it may be realistic to expect that finding partners is generally more difficult for individuals with a disability than for those without. However, in the realm of relationships, quality is more important than quantity. Many men and women with SCI find lovers, long-term relationships, and marriage.

People with disabilities find partners in many different ways and places. Many agree on the following points:

- The person with the disability often has to be the one to reach out more in the beginning of the relationship. Even people who may be interested in getting to know you might have incorrect assumptions and stereotypes at first. People who use wheelchairs sometimes remark that others tend to notice their wheel-chair before noticing them. Because this can be the case, it can take courage to get past that first hurdle. Taking the lead can be especially difficult for women because of cultural beliefs that women are supposed to be passive. Yet many people with SCI – both men and women—have found that no matter how scary it feels, taking the risk of being the first person to smile and say "hello" can be worth it. This is difficult for almost everyone.

- Some people advise you to bring up the topic of your disability early in the process of getting to know someone. Others question the need to discuss one's disability until you reach a certain level of trust with someone and feel sure that you want to get to know them better. Experiment to find the approach that feels most comfortable for you.

- Finding a partner is not easy. Whether or not you have a disability you won't meet anyone while sitting home alone! Cultivate your interests. Get out and do things that are important to you and can help you meet others, such as finding a faith community, joining a club, volunteering, or taking a class.

- Finding a partner is not only about how another person feels about you. It is also about what kind of person you want as a partner! What qualities are most important to you in another person? Many people with SCI find that the ability to communicate well is the most important trait of all. Some people with SCI find they can be very close to a partner who does not have a disability, as long as there is mutual respect. Others say that having a relationship with another person with a disability brings a special kind of intimacy, because each partner has a natural understanding of the other's issues and experiences.

- The important thing to remember is: Finding a partner is possible!

When Someone Else is "Not Interested"

At some point in time, almost everyone faces rejection from someone with whom they would like to be more intimate. The possibility always exists that a person you like very much will not be interested in pursuing a relationship. In reality, many people are frightened of, or have stereotypes about disability. Often it is not possible to know why a person doesn't want to get to know you better. Several people with SCI have shared the wisdom that when someone says "no" *the reason is not necessarily your wheelchair.*

Similar and Different Challenges For Men and Women

Although the obstacles facing men and women with SCI overlap, some issues may be particular to each gender. In spite of many of the social changes that have occurred in recent decades, society still has different expectations and stereotypes about men and women that affect their sexuality.

Issues of "Masculinity"

Stereotypes of masculinity are still alive and well. They include beliefs that the man should be the primary breadwinner, that he is supposed to be the "active" partner and "pursuer" in relationships and sex, and that a "real man" never fails to have an erection. Some men think the romantic, tender aspects of love and sex are fine for women, but not for them. In fact, many men learn to equate touch with sex. Like all stereotypes, these are not true for all men. Yet to some degree we all internalize the values around us.

Many people view someone who requires help from others in a negative light, especially if that person is male. SCI sometimes requires assistance from others and the ability to request help when needed. It also typically affects sexual "performance," including the ability to have erections and to ejaculate.

All of these expectations and changes can cause anger, sadness, and a profound sense of loss. Yet many men adjust well to these changes and enjoy their sex lives and relationships.

An excellent resource for men is the chapter "Living with a Disability: A Man's Perspective."⁵ The author of the chapter is a man with SCI who shares personal experiences and also suggests additional readings about different aspects

of "masculinity" in society. He also gives good advice for adjusting to disability and maintaining self-esteem in spite of society's stereotypes and expectations of how men are "supposed" to be.

The support of friends and family, communication with other men who have SCI, and a competent and understanding therapist can all be of help. However your best ally will be your own willingness to approach sex and life in new ways and to consider alternative beliefs about sex and sexuality.

Issues of "Femininity"

Three separate but related societal beliefs about women pose particular challenges for women with SCI.

- **Myth #1:** A woman's value in the world depends on how well her physical appearance mirrors current societal standards.

The Rebuttal: Life has many layers and textures. Admittedly, the world of advertising gives powerful messages that many people believe. Still, women who value their own inner qualities are likely to find others who also value them.

- **Myth #2:** Women are "passive" rather than "active" in many aspects of life, including sexual relations.

The Rebuttal: It is difficult to imagine that any woman who truly enjoys sex would describe her experience of it as passive.

- **Myth #3:** Women with SCI have fewer sexual difficulties and adjustments than men with SCI.

The Rebuttal: How could anyone know whether a man's or woman's sense of sexuality is more or less devastated by SCI unless they had the experience of being both male and female? Women must deal with cultural values that often determine their worth by how close they come to looking like the young, skinny, physically fit models on magazine covers, a standard not equally applied to men. Also, pregnancy and childbearing are part of human sexuality, and are not easy for *any* woman. A woman with an obvious physical disability will most likely have to face the negative attitudes of many people who have beliefs that women with disabilities should not or cannot become mothers.

An excellent resource for women is the chapter "Living with a Disability: A Woman's Perspective."⁶ The author is a woman with a cervical spinal cord injury who shares personal experiences and discusses research and that has been done about female sexuality and SCI. The 1998 version of "Our Bodies Ourselves"⁷ has a special section on women and disability. It also discusses issues such as body image and sexual function that may be of interest.

Depression and Anger

Not everyone will experience a period of depression or anger after spinal cord injury, but some people do. Often talking about your feelings with people you are close to or simply letting time pass is enough to feel better. When strong, negative feelings do not go away, or when there is no positive outlet for them, they

can create a vicious cycle of further negative feelings and that place great strain on a relationship. For example, a depressed person may withdraw from his or her partner without explaining why. Since the partner doesn't understand the reason for the distance, he or she might feel rejected and act angry or uninterested. The first person may end up feeling even more unhappy and alone.

It is natural and normal to feel angry when something that happens in life, like an accident, does not seem fair. Most people who experience trauma ask the question, "Why me?" Anger is not in itself unhealthy. However, anger that lingers for months, lasts most of the day, or causes you to lash out verbally or physically towards people who have not caused your problems is not healthy in the long run. Like depression, anger can cause difficulties in a relationship if it is not managed well. It is beyond the scope of this booklet to go into detail about the signs and symptoms or the many ways of treating emotional challenges. However, a number of useful books are listed in the References section.

A cycle of negative emotions can often be avoided and overcome through increasing your self-awareness and communicating your feelings *to* your partner rather than acting them out *against* your partner. Speaking to friends, family, and/or a professional can also help. So can changing your state of mind by focusing on something other than your anger or depression, such as listening to your favorite music or cooking a delicious meal.

When nothing you do seems to help your depression, it may be time to explore psychotherapy and/or medication. If anger is your dominant experience or if you are prone to sudden impulses of rage, professional help may be needed to talk out what is making you so angry and to learn how to manage your anger. Seek help immediately if you have become physically or sexually violent. Abuse should never be tolerated. It destroys intimacy in a relationship. It is also a crime for which you can be arrested.

If you are the victim of sexual or other physical abuse, there are local resources to turn to for support in some communities. For example a community women's shelter or local independent living center may be able to provide you with resources for protection and/or alternative living arrangements. Unfortunately, due to lack of funds and knowledge many women's shelters are not fully accessible to women with disabilities. For information about resources in your community, Kaminker⁸ suggests to look in the local Yellow Pages under headings such as "Domestic Violence," "Battered Women," "Victim Services," and/or "Sexual Assault Services. Two toll-free national numbers to call are 1-800-799-7233 (The National Domestic Abuse Hotline) and 1-800-537-2238 (National Resource Center on Domestic Violence).

Loss of Sexual Enjoyment.

The ability to become and stay sexually aroused can be affected by a variety of feelings or situations that may accompany SCI. The trauma of injury or surgery, some medications, feelings of anxiety or depression, low self-esteem,

fears about having an “accident,” and feelings of vulnerability can all make it difficult for a person to enjoy sex. Because problems related to arousal can be caused by so many different things, you must sometimes search for solutions as if you are a detective investigating a mystery. If your problem seems to be emotional, discussing it with people who are close to you or with a mental health professional may help. When talking doesn’t help, there are medications that can help reduce anxiety and depression. However, some medications can also reduce sexual arousal and pleasure. It is always a good idea to speak to a knowledgeable doctor about possible side effects of any medications you are taking.

Seeking Professional Counseling

Although not everyone with sexual problems chooses to call on professionals, a good counselor or therapist can be helpful for both practical and emotional concerns. Rehabilitation services often have a number of professionals such as social workers, psychologists and nurses who know a great deal about SCI and sexuality and can answer questions or direct you to further resources. Community mental health centers, private practitioners, centers for independent living, urology departments, and support groups are other options.

The type of professional you seek will depend on your particular questions. For example, if the problem for which you seek help is related to genital function, you may want to speak to a specialist such as a rehabilitation doctor or nurse, an urologist, or a neurologist. On the other hand, if the problem is mostly related to emotions or communication in your relationship, it would make sense to speak to a psychotherapist such as a social worker, psychologist, or psychiatrist who is knowledgeable about sexuality and disability.

Hammond, et al.⁹ suggest that you ask questions about the counselor’s sexual counseling experience, professional degree, knowledge and experience regarding people with SCI, and cost and length of treatment. If the counselor doesn’t have experience working with people with SCI, it will be important to know if he or she has an interest in working with a client with a disability, and if he or she is willing to seek education on the topic of disability and sexuality.

Body, Mind, and Self-Knowledge

As time passes many people find there can be positive aspects of SCI. The physical changes you experience may lead you to learn more about how your body works, and how to communicate with a partner. If you viewed sexuality primarily in terms of sexual intercourse before, this can be an opportunity to consider a broader meaning. Perhaps the most important thing of all is to be aware of what you want in a sexual relationship so you can make conscious choices. For example, many people go through periods in which they are uninterested in sex. This is natural. The question is: Have you lost interest in sex because you are concentrating on other things in life (such as healing, creative endeavors, or

spirituality) or have you lost interest because you are afraid you are unlovable or unattractive? Some people wish to resume sexual relations as soon as possible following SCI or try very hard to find a new sexual relationship. The question is: Do you want to be sexual at this time in order to “prove” you are still a desirable man or woman, or do you truly feel a desire to be sexual and loving with someone? Exploring questions like these within your own mind or with the help and understanding of others can make a big difference in your quality of life.

Part II: Physical Concerns

No matter how high or low a person’s self-esteem and optimism are, the fact is that SCI can present physical and practical obstacles that oftentimes cannot be avoided if a person wants to express and share his or her sexuality as fully and enjoyably as possible. The topics discussed in this section include the male and female sex organs, sexual stimulation and arousal, sexual intercourse and other methods of sexual relations, fertility and birth control, and several practical topics related to sexual relations (such as bladder and bowel management). It is beyond the scope of this booklet to go into detail concerning pregnancy and parenting. However, several excellent resources are listed in the References section.

The Male and Female Sexual Organs and Their Care

Figures 2 and 3 (pages 15, 17) show the male and female sex organs. For all men, maintaining the health and hygiene of the sex organs includes washing of the penis and scrotum and regular checking of these areas for irritation or infections. A mirror can help in self-evaluation while in bed or in the shower. Regular examination of the male sexual organs can also help detect penile or testicular cancer. Any thickened areas should be seen by a physician. Men can also speak with their physicians about how often they should be tested for prostate cancer. The suggested frequency for this kind of test varies with age. A urologist is the medical specialist men usually consult concerning their sexual organs, although other doctors can be helpful too.

For all women, the vaginal area should be washed at least daily with soap and water. Some vaginal discharge is normal and healthy. However, if the discharge changes noticeably over time and has a cheesy texture or foul odor, an infection may be present and a gynecologist should be consulted. Although the world of advertising tries to convince women to use douches, it is usually healthier *not* to use them. Douches can upset the natural biological balance of the vagina. In general, the vagina is very good at cleaning itself.

The female menstrual cycle is discussed in the Fertility section (pages 22-23). During menstruation frequent changing of sanitary napkins or tampons is important to prevent skin irritation and infection. If you are not able to change your own napkins or tampons, a personal care attendant may be able to help. Some adaptive devices are also available. The professional most likely to be

knowledgeable about this is an occupational therapist who specializes in rehabilitation.

Sometimes a woman who is sure she does not want to have a child in the future decides to have her uterus removed. This surgery ends menstruation and prevents pregnancy. Because the ovaries remain intact, female hormones continue to be produced. Every woman has a special relationship with her own body. Some women do not like to think of any part of their female anatomy being removed, while others are happy to be rid of the monthly obstacles associated with menstruation. If you are considering this procedure discuss it with a gynecologist or nurse who is knowledgeable about SCI.

Monthly breast self-exam is important for women, because when cancer is detected early it is much more treatable. Many good books and brochures show how to do a breast self-exam (BSE). The Breast Cancer Network, at 800-ACS-2345 is one excellent source of such materials. A doctor or nurse can also instruct you, your partner, or your personal assistant to examine your breasts.

There is disagreement in the medical field about how often a woman should get a *mammogram*— an “x-ray” of the breast that can help detect cancer even before a lump can be felt with the fingertips. When a woman should get her first or next mammogram depends on her age and family medical history. Ask your doctor for updated information that is relevant to your age group.

Generally, the primary specialist women consult regarding their sexual organs is the gynecologist. This is changing as many urologists are now also treating women’s sexual difficulties.

How Can Spinal Cord Injury Affect Sexual Intercourse?

Although sexual intercourse is not the only way for people to enjoy sex, it is an important type of sexual expression for many people. SCI can affect sexual function in a number of ways, depending on the level of the injury, whether it is complete or incomplete, how long ago it occurred, the age of the person, and the many psychological factors discussed in the previous section. In order to understand how SCI can affect *genital* (sex organ) function, it is first necessary to understand a little bit about the anatomy and physiology of sex.

According to many sources, both men and women experience a series of stages of sexual excitement. These general stages were first described by Masters and Johnson during the 1960s.

The *excitement* stage is the phase of sexual excitement when a person begins to feel pleasurable sexual sensations. Blood pressure, heart rate, and breathing rate increase. The nipples may become erect. If the necessary nerve connections are intact, a man often gets an erection and a woman’s vagina begins to moisten. The woman’s clitoris and the erectile tissue around it become engorged and sensitive to touch.

In the *plateau* stage, sexual excitement is more intense. If the necessary nerve connections are intact, a man’s erection may harden, and sometimes a pre-

ejaculation secretion comes out of the penis. A woman’s vagina expands and continues to moisten and her nipples and breasts may feel even more sensitive.

For men with intact spinal cords the pleasurable sensations of the *orgasm* stage are generally accompanied by ejaculation. SCI can affect a man’s ability to feel orgasm in his genitals as well as his ability to ejaculate. Some men with SCI can experience an orgasm without having an erection or ejaculation, while others have reported ejaculating without reaching orgasm. Not all men with SCI are able to experience either orgasm or ejaculation.

Women who experience climax or orgasm feel a series of pleasurable contractions in the genital area. Often this good feeling extends to other parts of the body as well. Some women can experience several orgasms in a row (multiple orgasms). The experience of and perceived importance of orgasm varies widely. Some women with SCI become unable to achieve orgasm. Others (even those with complete injuries) are able to have orgasms even when they can’t directly feel the stimulation of their genitals. Women have experienced orgasms from stimulation of their breasts or other areas of the upper body.¹⁰

During the final or *resolution* phase a person returns to his or her “resting” state. This is usually a time of relaxation, and for many couples it can be a time for affection and closeness. In general, women go through this stage more gradually than men.

Not everyone goes through these stages in a linear order. Also, two lovers may enter into these stages at different times, so that their levels of excitement are not perfectly matched. This is not unusual, and “perfect timing” is not required for lovemaking to be a positive experience for both partners. Finally, whether or not they have SCI, many people do not achieve orgasm every time they make love. A person who does not have an orgasm can still enjoy the many other aspects of sex such as excitement, touch, and close physical contact.

Although these stages of sexual arousal are generally accepted, other models have also been described. The book “Our Bodies, Ourselves”⁷ summarizes several other viewpoints that focus on the more subjective and spiritual aspects of sexual arousal.

Sensation

SCI can affect sensation in the genital area, as well as a person’s ability to experience orgasm in the way he or she did prior to injury. If you have little or no sensation in your genital region, you may not be able to experience sexual pleasure in the “traditional” way. However both men and women with SCI find fulfilling ways to enjoy sex.

Even when they can’t experience the same type of genital sensations they could prior to injury, many people have spoken about being “flooded” with feelings in other parts of their body. It is not usual for people with little or no genital sensation to find that other areas of their body have become *erogenous*

zones—areas where they can experience wonderful feelings. Common erogenous zones include the nipples, the lips, parts of the face, the arms, and the neck.

Imagination can be an important part of sexual enjoyment. If you were able to achieve orgasm prior to injury but can no longer do so, you may be able to remember the feeling and fantasize an enjoyable orgasm. Sexual pleasure also comes from giving your partner gratification by using your hands or your tongue. Many people say that watching and listening to their partner enjoy sex also gives them tremendous sexual gratification.

It is common after SCI for people to say that having sex with another person is a more intimate, emotional, and/or spiritual experience than it was before. Because sex is no longer so closely tied to only one part of the body, it may now be easier to view sex as a relationship between two people rather than two body parts. Touching, kissing, caressing, licking, nibbling, and exploring new ways to have sex can bring partners together in sexual bliss.

Sexual Intercourse Following Spinal Cord Injury

The most common physical *genital* changes following SCI are changes in sensation, erection, ejaculation, lubrication, and orgasm. If you face challenges in one or more of these areas but are still interested in having sexual intercourse with your partner, a number of techniques and products can help. This section will explore the anatomy and physiology of sexual intercourse, and offer potential solutions for the challenges you or your partner may face. Finally, we'll suggest some pleasurable alternatives for both men and women.

A Few Words About Self-Exploration

Taking the time to explore your own body can be pleasurable for its own sake and also help you enjoy your sexuality when a partner is not available. Because everyone's body reacts uniquely to SCI, often the best way to find out exactly what your sexual abilities and limitations are is to explore your own body over a long period of time. The more you know about what gives your body pleasure and where you feel that pleasure the most, the more you can share this knowledge with a partner.

Sexual Intercourse: Barriers For Men

Approximately 80% of spinal cord injuries happen to males, often when they are relatively young. As we discussed previously, for many men beliefs about "masculinity" are closely connected to their ability to be an active sexual partner and to have a penis that works well. Many men also wish to father children. Therefore, problems that are common for men following SCI such as decreased ability or inability to have an erection and/or ejaculate, and decreased fertility can be a devastating blow to a man's self-confidence and self esteem. Yet, remember that the beliefs most of us grow up with about "masculinity" and "being a man" are only beliefs. With determination, openness to acting and feeling in new ways,

and a good sense of humor, sexuality can be an enjoyable part of life and fatherhood is possible.

Erections

For men who have an intact spinal cord, two types of erection are possible. A *psychogenic erection* begins in the most important sexual organ of all – the brain. It can result from seeing a person you find sexually attractive, reading or viewing erotic material, or fantasizing. Some men with an incomplete injury in the lower lumbar or sacral area (see Figure 1) or an incomplete injury above the T12 level will be able to experience this type of erection. A man with a complete injury above the sacral segments of the spine, will not be able to have a psychogenic erection. However, he can still feel sexual excitement in areas of the body above the injury, and may also feel sexual excitement in the penis and scrotum.

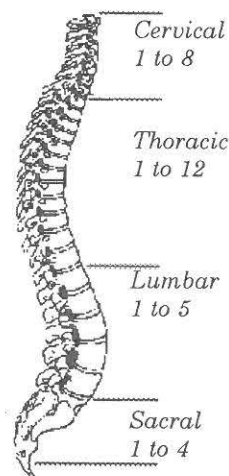


Figure 1.

A *reflexogenic erection* occurs without any input from the brain. Nerves in the sacral segments of the spinal cord control this type of erection, so men whose cord is intact in this area can have one. A reflexogenic erection is an automatic response. It can happen with any direct stimulation to the penis or to the areas around it such as the scrotum or anus, even if the stimulation is not sexual. For example, it may occur when a man washes himself in this area or during a medical examination. Reflexogenic erections can also happen in response to contact with other areas of the body that are potentially erotic, such as the nipples or ears. For some men reflexogenic erections can last a long time if the source of stimulation is not removed. In fact, it is not healthy for your penis to be hard for longer than one or two hours.

Some men who can have either type of erection may successfully have sexual intercourse with few or no problems. Others find that their erections do not last long enough or are not hard enough for sexual intercourse.

Some men who are unable to have an erection or have erections that do not allow for sexual intercourse concentrate on other aspects of sexuality they can enjoy more easily (see pages 18-19). Other men continue to desire sexual intercourse for a number of reasons. For example, they may feel more masculine or like their "old selves" when they have intercourse, or may want to please a partner. *There is no "right" solution* – only the one that works best for you.

There are several options for men who want help in having or maintaining an erection. Before using any of the aids or products listed below, get a thorough physical exam by an urologist who is familiar with erectile problems related to

SCI. Not all erectile problems are purely neurological in origin. For example, anxiety and some medications can cause erectile problems.

It is also important to understand why having an erection is important to you. The ability to have an erection will almost never solve difficulties that people are having in a relationship. If you lack sensation in your penis, an erection will not make this better. If you are not able to ejaculate, getting an erection with one of the methods below will not change this. If you wish to have an erection mostly to please your partner, have you discussed your thoughts and feelings with that person? Your partner may not care as much as you would think about your ability to have sexual intercourse. For example, many women actually find it easier to become aroused and have an orgasm through manual or oral stimulation than through sexual intercourse.

Because there are so many possibilities to consider when choosing a method to improve your erections, it may be helpful to speak to health professionals about the advantages and disadvantages of each option, and to ask about new products that might have become available since this booklet was printed. Other men with spinal cord injuries and their partners will also be excellent sources of information. Finally, most of the aids listed below will require a doctor's prescription and some training in their use. Even if a prescription is not required, it's best to discuss your strategy with a knowledgeable professional. These aids can be very helpful, but can also have unwanted side effects when not used correctly.

Injectible medication can cause a temporary erection. The man or his partner uses a fine needle to inject a small amount of medication directly into the shaft of the penis. This causes an immediate erection that lasts from 30 minutes to an hour. *It is very important to obtain and remember clear instructions from your doctor about how to inject the medication.* Your doctor will show you or your partner where to inject the medication, how long to apply pressure to the injection site, and the exact dosage (amount) to use.

Some advantages to this method are that it causes an immediate erection that lasts long enough to have sexual intercourse. Once a man or his partner learns how to do the injection properly, it can be done at home. Disadvantages are that some men do not feel comfortable with the idea of sticking a needle into their penis. The amount of medication injected must be carefully measured so *priapism* (a condition in which the penis remains hard for longer than normal) does not occur. Priapism can be painful and cause damage to local arteries and penile tissue. For some men repeated injections cause bruising or scarring of the penis. Injections are also expensive.

Vacuum devices are non-surgical devices that help many men attain an erection that is satisfactory for sexual intercourse. The device is a tube placed around the penis. Air pumped out of the tube causes blood to flow into the penis, and this causes an erection. Once the man has an erection, he or his partner place a

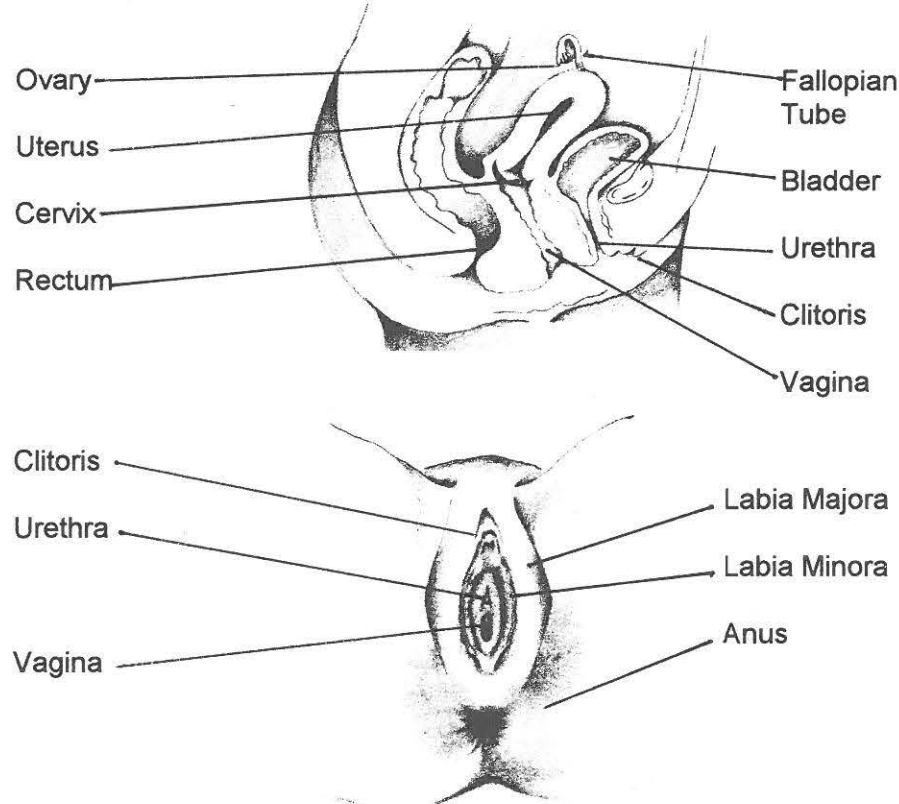


Figure 2.

constriction ring or band (similar to a thick rubber band) around the base of his penis to maintain the erection. Some devices must be pumped by hand, while others are battery operated.

Among the advantages of this method are that it can be used every day if desired. The ring or band that maintains the erection also prevents urinary leakage. This method is non-invasive, since nothing is injected or placed inside the body. Units can be obtained for less than \$500. They may be partially covered by Medicaid and Medicare, depending on the state in which you live.

Some of the disadvantages are that the constriction ring should not be left on the penis longer than a half hour, which means that the erection can last for only a half hour as well. Leaving the ring on longer can damage the erectile tissue of the penis. Also, the ring can make it more difficult to ejaculate and may not allow *semen* out of the penis. Clearly this can be a problem for a couple that wants to have a child. The vacuum units can sometimes cause bruising. They can also cause the penis to temporarily change color or feel colder than usual. Finally, this method does not work equally well for everyone.

Penile implants are devices surgically placed inside the penis to maintain hardness. They are inserted into spaces on both sides of the penis. Several types of implants are successfully used by many men. The benefits and shortcomings of each are best discussed with a health professional (e.g., an urologist) who has some experience with them and can show you what they look like and how they work. Some insurance plans cover at least some of the cost of an implant while others do not.

One advantage of implants is that if the surgery is done correctly they can last up to ten years (sometimes longer). They also provide a dependable way of attaining an erection. A disadvantage is that implants often need to be replaced after ten years. This process is expensive and generally requires hospitalization. The most serious side effect occurs when an implant becomes dislodged and begins to push out through the skin. There is some risk of infection, and in the case of infection the implant might have to be removed. Unfortunately, such complications are not rare. Finally, installing an implant destroys the penis's erectile tissue, so once a man gets an implant he may not be able to have an erection without an implant in the future. Because this method requires surgery, many urologists recommend waiting at least a year after injury before getting an implant, and trying a less invasive method (like a vacuum device) first.

Oral Medications. Viagra (oral sildenafil) recently appeared on the market. It requires a doctor's prescription. When taken prior to sex it can help many men attain a more satisfactory erection. *Because it does not cause an erection*, it will not be of help to a man whose nerve damage makes it impossible to have an erection without medication.

Usually Viagra takes effect within an hour. Its effects last for several hours. During that time a man may achieve multiple erections. Viagra is being touted as a wonder drug for impotency. However, it has already shown some side effects that are of concern for men with SCI. Some common side effects so far are upset stomach (including diarrhea) and urinary tract infections – both of which can create unpleasant problems in bowel and bladder programs. Viagra interacts with a number of other medications, so it is very important for anyone taking it to review all other medications he is taking with his doctor. At the time this booklet was printed, Viagra was expensive, costing between \$8 and \$10 per pill. Because Viagra is so new and other new oral medications are expected to become available soon, men who are interested in knowing more about this topic should discuss it with a physician who specializes in SCI.

Of course, there is no rule against combining techniques or devices described above. For example, oral medication can be taken in conjunction with using a vacuum pump. Because unwanted side effects can and do happen, keep in touch with your doctor as you experiment to find what works best for you.

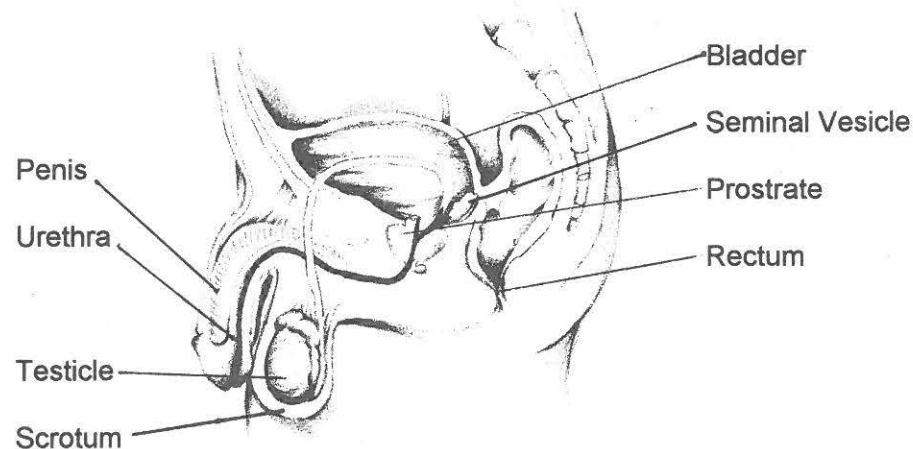


Figure 3.

Sexual Intercourse: Challenges for Women

Less is known about the sexual responses of women with SCI than men with SCI. This is true for several reasons. Because most spinal cord injuries occur in men, fewer women are available to participate in studies in rehabilitation centers around the country. Most of a woman's sexual response occurs internally and is therefore difficult to observe. Fertility is generally not impaired for women with SCI. In contrast, men with SCI often face serious obstacles to fatherhood. Also, a woman's fertility is not dependent on her ability to respond sexually (e.g., to become lubricated or have an orgasm). Last, but not least, many people still believe sexual enjoyment is not very important to women and women are "passive" in sexual relations. As more women raise their voices to be heard as sexual human beings and become medical professionals and researchers, research time and funds devoted to the sexuality of women with SCI will undoubtedly increase, a phenomenon that has already begun.

On a purely "mechanical" level, most women with SCI are able to have sexual intercourse. The most common obstacles are those related to sensation, lubrication and positioning. As mentioned earlier, many women with SCI are able to experience orgasm. Sometimes this takes longer than it did prior to injury, and you may find (as many women without injury do) that sexual intercourse is NOT the easiest way to "come." The best way to know if you are physically capable of orgasm is to experiment with your own body or ask a partner to help you experiment. For example, try stimulating (by rubbing, stroking, etc.) your clitoris and some of the areas around it and inside your vagina as well as your cervix. Inserting a vibrator into the vagina can also be pleasurable. Some women can also achieve orgasm through stimulation of erogenous zones in other areas of the body, such as the breasts or sensitive areas of the abdomen.

As is the case with men, some women who do not typically reach orgasm during intercourse or lack genital sensation may decide against having sexual

intercourse anymore, and instead explore alternate ways to express their sexuality. Others might decide to have intercourse for a number of reasons, including enjoyment of bodily contact with a partner, giving pleasure to a partner, or a desire to become pregnant.

Vaginal lubrication is most likely controlled by the same segments of the spinal cord that control erection in men. This topic has not been fully documented so consider the following explanations to be general guidelines only. *Reflex* lubrication may occur through direct stimulation of the genital area. Women whose spinal cord injuries are above the sacral area will generally be capable of reflex lubrication, while those with sacral cord injuries generally will not. *Psychogenic lubrication* originates in the brain, when a woman becomes aroused by something or someone sexy she sees, hears, or thinks about.

To increase vaginal lubrication, a woman or her partner can apply a *water-based* lubricant directly inside her vagina or on her partner's penis or fingers. Never use Vaseline™ or any other oil-based lubricant for this purpose. An oil-based lubricant does not dissolve in water. It can build up inside the vagina and cause infection. A number of water-based lubricants are available in drug stores, pharmacies, or from your gynecologist. These include K-Y™, Today™, and Astroglide™.

Words of caution for women with SCI at or above T6:

Orgasm can sometimes cause autonomic dysreflexia (AD, also known as autonomic hyperreflexia) in some women with SCI at or above T6. Because AD can have serious consequences, be sure to know the signs and symptoms of AD and how to treat it.

If you are a women with SCI of childbearing age and do not want to get pregnant it is as necessary to use birth control now as it was before your injury. Sometimes women stop menstruating several months to a year after spinal cord injury. During this time it may still be possible to become pregnant.

Alternatives to Sexual Intercourse for Men and Women

The Joys of "Foreplay"

The "fore" in the word "foreplay" implies that it comes "before" the main event, which is traditionally assumed to be sexual intercourse. People usually use the word "foreplay" to describe the kissing, fondling, and other sexual activities that people enjoy together before "the final act."

Perhaps it's time to decree out loud what many ardent lovers have always recognized – *foreplay can be the best play of all!* So forget about the "fore" and concentrate instead on the "play." Foreplay can be as varied as the people who practice it. A prolonged kiss, the gentle stroking, licking or other oral stimulation

of any body part that gives a person pleasure, sexy words, and sharing fantasies are just a few types of foreplay that can be delicious and delectable.

After spinal cord injury some people continue to experience erotic sensations in the genital area while others do not. Many people report that following SCI, some areas of the body above the level of injury become even more capable of responding erotically. A person's arms, fingers, neck, ears, face, scalp, and other areas can respond pleurably to stimulation.

Many people with SCI say that being challenged to approach sex in a new way and to learn more about their bodies has added to their appreciation of their sexuality. They have come to approach sex as a *holistic* experience that includes all the senses and many levels of communication, rather than a release of genital tension. Often, they have had to do hard work to put aside negative *beliefs* about themselves, sex in general, and how others will respond to them (see pages 1-2).

People who enjoy their sexuality following SCI frequently mention a variety of "ingredients" that help make sex fun and pleasurable. Some do not even require sensation or touch. One major ingredient of good sex is the enjoyment of a partner's sexual pleasure. The sight of your partner in the midst of an orgasm or the sound of his or her happy groans while excitement builds can add to your own sexual pleasure. Some people enjoy sex talk, sharing sexual fantasies, or watching erotic films together. Pleasant sights, sounds, and scents can enhance sexual feelings. Try lighting a candle, or using a favorite brand of incense or perfume.

For a man who does not get erections and does not want to use artificial devices on or in his penis, there are a number of other ways to please a sexual partner who enjoys being penetrated. A penis-shaped vibrator or a dildo (a sexual aid made of rubber or plastic in the shape and size of an erect penis) can both give a partner a great deal of pleasure. Dildos can be bought at sex shops and through mail order catalogues. Vibrators are available from a wider variety of sources such as department stores and sometimes variety and appliance stores.

There are also many other types of sexual aids and other products on the market. For example, sexy undergarments, arousing videos, and flavored condoms are used by people with or without disabilities. The Xandria collection (see Resources) offers a catalogue specifically for persons with disabilities.

Fertility Issues for Men and Women

Fertility Issues for Men

The majority of men with SCI are fertile. In other words, their bodies produce sperm that are capable of impregnating a woman. However, men with SCI face a number of problems related to ejaculation, so even when sperm is produced the man may be unable to deposit it inside a woman's vagina. For men with SCI who are able to ejaculate, "mother nature" may be all the help that is necessary to become a father. For men who are unable to ejaculate or who

ejaculate only rarely, a variety of techniques and methods can increase the chances of biological fatherhood.

Ejaculation

Spinal cord injury does not usually affect a man's *testosterone* (male hormone) levels, or his ability to produce sperm. However, all the sperm in the world cannot help make a baby if it remains inside the man's body! Normally, sperm is released during ejaculation, when the urethra and pelvic muscles contract to push sperm through the penis and out through its tip. During the first stage of ejaculation (called *emission*), fluids including sperm that make up semen are deposited in the posterior urethra—the same tube that urine goes through when a man empties his bladder. These fluids come from the seminal vesicles, the vasal ampulla, and the prostate (Figure 3) when these structures contract.

As the semen is deposited, the urinary sphincter contracts to trap the semen between the bladder neck and the sphincter as pressure builds up to the point of release. In order for the man to ejaculate (or “come”) so that his semen comes out through the penis, the bladder neck must close so that the semen does not travel *backwards* into the bladder during ejaculation. If this closure doesn't happen because the necessary nerves cannot function, the semen can take the shorter route into the bladder instead of the longer route into the urethra and out of the penis. This is called *retrograde ejaculation* and is a common problem for men with SCI.

Because ejaculation requires functional nerves at several levels of the spinal cord as well as communication between levels, most men with SCI will not be able to ejaculate as easily as before, will experience *retrograde ejaculation*, or will be unable to ejaculate. Men who want to father a child but have problems with ejaculation can explore the various techniques listed and described below.

SCI and Sperm

Men with SCI may *generally* assume they are producing healthy sperm. If you are able to ejaculate or have any “pre-ejaculate” fluid come out of your penis during sex and your female partner does not want to become pregnant, it is necessary to use some form of birth control. If you and your partner have been trying to have a child and have been unsuccessful, your sperm can be tested by an urologist or other fertility specialist.

Stimulating Ejaculation and Collecting Sperm

Some men who cannot usually ejaculate during sex or ordinary masturbation are able to ejaculate with a little extra help from modern technology. The two most widely used techniques for stimulating ejaculation are *penile vibratory stimulation* (PVS) and *electroejaculation*.

In PVS a vibrator is placed under the head of the penis. If the stimulation is strong enough, sensory nerves will transmit information to the ejaculatory reflex

center which can in turn orchestrate ejaculation. In order for the ejaculatory reflex center to do its work, certain nerves in the region of T10-T12 must be functional. PVS appears to be ineffective for men whose injuries are below T10.

Words of caution for men with SCI at or above T6:

Ejaculation and the use of vibrators can cause autonomic dysreflexia (AD, also known as autonomic hyperreflexia) in some men with SCI at or above T6. Because AD can have serious consequences, be sure to know the signs and symptoms of AD and how to treat it.

Once a man and/or his partner learn how to use PVS, a physician need not be present to collect the semen. When the semen is collected, a number of techniques can be tried to inseminate the woman. Many couples manage the entire insemination process themselves, collecting the semen and then depositing it on the woman's *cervix* with a medicine dropper or turkey baster.

A man whose injuries are at T6 or above is at risk of experiencing autonomic dysreflexia (AD, or hyperreflexia) when using this technique. Because AD can be life-threatening if not properly handled, PVS should always be tried first in a setting where medical help is available. If it is tried several times and does not cause symptoms of AD you are probably safe trying it at home or elsewhere. However, always continue to self-monitor for symptoms.

To achieve *electroejaculation* an electric probe is inserted into the man's rectum. Electroejaculation is generally more successful than PVS but it is also more dangerous (especially for men who are prone to AD) and should be practiced in a medical setting with professionals available who are familiar with both the technique and SCI. Risks include the possibility of AD with higher SCI, and damage to the rectum if the probe is too hot.

Once sperm is obtained through an ejaculatory technique that works, it can be stored or immediately deposited inside the female partner. Since women are only capable of becoming pregnant during *ovulation*, it's important for the woman to learn how to tell when she is ovulating. A gynecologist or fertility specialist can be of help in this area.

Artificial insemination can be done at home (if masturbation or PVS is used) or in a medical setting (if electroejaculation is practiced). Sperm collected and stored in a medical office is preserved and the woman is generally inseminated in a fertility clinic. This process is not always successful, and sometimes the female partner takes medications to precisely time her ovulation. Although artificial insemination can be expensive, some insurance coverage may be available.

In vitro fertilization is a technique in which the man's sperm and the woman's egg are combined outside the woman's body. Fertilization occurs in a

test tube in the laboratory, and then the egg is re-implanted inside the woman's uterus. This method is more reliable and successful than artificial insemination, but it is also more expensive and invasive.

Keep in mind that new methods and devices are constantly being developed. For example, new surgical methods of retrieving sperm are available in some hospitals with infertility programs. Also, there are now vibrators that can be adjusted for amplitude and frequency. To keep up to date with new products and methods, find and keep in touch with a specialist – generally a urologist who specializes in or has experience working with men with SCI. A list of centers that do research on male fertility may be requested from the Arkansas Spinal Cord Commission (see Resources).

Many men will welcome the help of technology. Although it is good to be hopeful, it's important to know that *even though sperm collection and storage techniques continue to improve, the number of successful births that result from these practices is low and the procedures can be expensive and time consuming.* For some men, biological fatherhood is less important than the experience of raising a child. Adoption can be a wonderful alternative (see page 23). A man might also agree to allow his female partner to receive the donor sperm of another man (for example through artificial insemination). Biological fatherhood is only one aspect of fatherhood. It takes only a moment for a sperm and an egg to unite but years to raise and love children.

Pregnancy and Fertility Issues for Women

Hormones are natural substances in the body that are distributed through the blood. Hormones make menstruation and pregnancy possible. Because they do not depend on nerves to function, in the long run a spinal cord injury at any level will not affect a woman's ability to become pregnant.

Until a woman reaches menopause, usually between the ages of 45 and 55, she experiences a monthly cycle usually called the menstrual cycle. The normal menstrual cycle lasts between 25 and 35 days. Usually, a woman is only able to get pregnant for a small part of the cycle – when she is ovulating. During ovulation, one of many eggs leaves the ovary and begins its journey through the fallopian tubes towards the uterus (see Figure 2). This journey takes several days, and if sperm enter the woman's vagina at this time and meets up with the egg, the egg can become fertilized and pregnancy may occur. If the egg is not fertilized, changes occur that cause most of the lining of the uterus to be shed. This process is called menstruation or a woman's period.

It is normal for trauma and stress to affect a woman's menstrual cycle, and about half of spinal cord injured women miss at least some periods right after injury. Usually a woman's cycle returns within several months without any medical help. She may even be able to become pregnant before her period returns, so if she does not want to be pregnant birth control is necessary. Although some women miss their periods for up to a year following injury, this is relatively rare.

If your cycle was affected by injury and it has not become regular after four to six months, consult a gynecologist familiar with SCI to make sure there is not a problem.

The stages of pregnancy are the same for a woman with SCI as they are for any other women, and numerous books on this topic can be found in any large bookstore. Some challenges and risks are particular to SCI. For example pressure sores and other skin problems can worsen due to weight gain during pregnancy. Bowel and bladder management may become more difficult. *As a woman's due date approaches the risk for AD becomes greater. AD can also occur during labor.* Because of these and other potential complications, it is very important to find medical professionals who are familiar with SCI and to keep in touch with them throughout pregnancy.

Pregnant women with SCI sometimes find that others (including health professionals) question their judgment and discriminate against them due to beliefs that women with disabilities cannot manage pregnancy and motherhood. This is another good reason for insisting that the health professionals who work with you, including delivery of your baby, are familiar with SCI and able to support your decision. If you are a woman with SCI who would like to have children, rest assured that others have gone before you and have become good mothers. It is beyond the scope of this booklet to discuss the issues of parenthood that sometimes face people with SCI, however a number of informative references are listed in the Resources section.

Considering Adoption

Not every person with SCI can or wants to have his or her own children. Some women decide they don't want to experience the stress of pregnancy, and some men who cannot easily ejaculate decide that the artificiality or expense of sperm collection techniques is not worth the bother. Other couples try to have a baby and do not succeed. Adoption can be a wonderful solution not only for a couple, but for a child who needs a home and loving parents. Adoption programs can help you find a child to adopt and also inform you about legal procedures.

Just as is the case with having biological children, you may run into people who will question your ability to adopt and care for a child. Remember that legally you cannot be discriminated against because you have a disability. If you think an adoption program has denied you services because of your SCI you can take the same kind of legal action you would take after being denied any kind of service or access.

Deciding About Parenthood

The ultimate decision about whether or not to become a parent is yours. Still, some experts suggest you wait *at least* six months to a year after injury before deciding whether you want to be a biological or adoptive parent. During that time period you will make many changes and adjustments. You will know

more about how independent your lifestyle can be, and how accepting your partner is concerning your disability. Being a parent is not for everyone, whether or not a person has a disability. If you decide against parenthood or want more time to think about it, many options for birth control are available.

Birth Control Techniques for Men and Women

A wide variety of birth control methods are available. The one(s) you choose will depend on your personal preference and that of your partner. *The latex condom, especially when used with Nonoxidal 9, is the only birth control device that offers protection against a number of sexually transmitted diseases, including HIV/AIDS.*

Total sexual abstinence/celebrity. Clearly this is the most foolproof method of birth control available. Some people, for religious or moral reasons, do not believe in engaging in sex without being married or at least deeply in love with a partner. But religion and morality are not the only reasons some people chose to be celibate. For example, sometimes right after injury people concentrate on aspects of daily life and activities other than sexuality, and require time to adjust to how their body has changed. There is nothing wrong with NOT having sex. However, if you have “given up” sex due to depression or low self-esteem, it is worthwhile to seek help from a therapist or counselor.

Abstinence from sexual intercourse. As discussed on pages 18-19, many pleasurable sexual activities do not involve sexual intercourse and will not lead to pregnancy. Some people may decide that the obstacles they must overcome in order to have sexual intercourse are not worth the bother, especially if they have little or no sensation in their genitals. There is nothing wrong with concentrating on other aspects of sexual expression, such as kissing, caressing, oral sex, and love/sex talk.

The condom. Unless either partner is allergic to latex, the condom can be the easiest method of birth control. A latex condom also offers the best protection against HIV/AIDS. Nowadays condoms can be bought almost anywhere, including the local supermarket. Specialty stores and mail order catalogues sell condoms that come in different colors and flavors. If the woman wants to avoid pregnancy the condom should be placed over the man’s penis as soon as he becomes sexually excited, since small drops of “pre-ejaculation” fluid can contain sperm. The condom can be put on the penis by either the man or the woman. Many lovers make this a part of foreplay.

“The pill”. If taken every day, the birth control pill offers excellent protection against pregnancy. Even though pills of today are safer than they were a decade ago, there may still be an increased risk of thrombophlebitis (blood clots) for some women, especially those who smoke cigarettes. Women who use a wheelchair may already be at greater-than-average risk of blood clots due to inactivity. Experts disagree about whether or not a woman with SCI should use the pill. Some suggest she should not take the pill until six to twelve months

following injury and should avoid it completely if she smokes cigarettes or has a history of blood clots. Others say the newer pills on the market are fairly safe. If you are interested in taking the pill, discuss your options with a health professional you trust.

IUD. An intra-uterine device (IUD) is a device implanted inside the cervix to prevent pregnancy. Many experts caution women with SCI against using IUDs, because they can become dislodged and/or create infections. Since some women are unable to feel symptoms of pain that would ordinarily signal a problem, using this device could lead to serious complications.

Internal Barrier Methods. A diaphragm, sponge, or cervical cap may be inserted inside the vagina prior to intercourse and must be left in afterwards for a number of hours (depending on the method). Barrier methods are generally safe to use, and when used with a spermicide they provide a high degree of protection against pregnancy. Women who do not have full use of their upper extremities may need assistance in putting in these devices and taking them out. If you do not already know how to use one of these methods, your gynecologist or nurse can instruct you.

Norplant. This is a relatively new method of birth control in which hormones are implanted under the skin. Norplant is easy to use if side effects can be tolerated. We did not find any references on the use of Norplant for women with SCI, and recommend that you discuss the most up-to-date information with your physician.

Rhythm. With the rhythm method a woman needs to know when she is ovulating so that the couple avoids sexual intercourse at that time. This is the *least* effective of all birth control methods. Ovulation is not easy to predict, especially if menstrual periods are irregular.

Permanent sterilization. Surgical procedures exist for both men and women who have decided they DEFINITELY do not want to have children. Men can get more information from their urologist and women can consult their gynecologist. *Because the surgery is generally not reversible* you should be absolutely sure that you never want to have a first or another child before you choose to go through with it. Some individuals and centers that perform these procedures require that a person receive counseling before having the surgery.

Self Exploration. No woman has ever gotten pregnant from exploring her own body or watching her partner do the same. Self-exploration can be a pleasant way to gain sexual enjoyment. If you don’t have a sexual partner right now, it can help you “keep in practice” and stay in touch with your sexual desires and feelings. Some couples find it exciting to masturbate together.

Sexually Transmitted Diseases (STDs) and Safe Sex

People with SCI have the same risk as anyone else of contracting a sexually transmitted disease (STD) from sexual contact with a person who is

infected. STDs include syphilis, herpes, genital warts, gonorrhea, and HIV/AIDS. Because at their best STDs can be uncomfortable and at their worst they can be deadly, and because they are easily passed on to partners through sexual contact, it is important for all sexually active people to learn how to protect themselves and others from infection. STDs can be invisible. There is no way of knowing if someone has one just by looking at them. The only way to know for sure if you or your partner has an STD is to be tested.

The best protection against STDs is to avoid sexual intercourse and other practices in which body fluids (such as sperm or blood) mix. For people who have intercourse, the use of a condom with a spermicide that contains the ingredient Nonoxynol-9 offers the best protection. People who trust and know their partner well and have a monogamous relationship often decide not to use protection against STDs. This is a decision each couple must make together.

More information on STDs and safe sex can be obtained through your health practitioner, local Department of Health, or AIDS hotline.

Other Practical Issues Regarding Sex and SCI

Bowel/Bladder Accidents

Having a bowel or bladder accident while engaging in lovemaking is many people's worst nightmare. Don't let the fear of an accident keep you from enjoying your sexuality. There are steps to take to prevent such accidents.

Always maintain a regular bladder and bowel program. Decreasing fluid intake for several hours prior to sex can make accidents less likely. Both men and women should urinate before and after sexual intercourse, especially if a person does not use a catheter and voids on his or her own. To avoid bowel accidents, sex may be timed soon (but not immediately) after your bowel program.

Regardless of preparations, accidents *sometimes* occur, although they are generally not frequent. Some people suggest that a sexual partner should be alerted that an accident *could* happen so that if it does it will be less of a surprise. Others say that a "warning" too early in a relationship could scare away a potential partner. If your partner and you know each other well and/or if both of you have SCI, it is a good bet that an accident will not even come *close* to being the end of the world. As is the case for an accident in any environment, a healthy sense of the many trials and tribulations of being an imperfect human and a good sense of humor will go a long way towards turning a potential mountain into a molehill.

While no one wants or enjoys leakage or accidents, many people get to a point where they consider the possibility a fact of life and learn not to let worry destroy sexual enjoyment. Some people make love with a waterproof pad over the mattress, and keep towels around the bedside in case of accidents. Others simply make love and don't worry very much about accidents.

Urinary Equipment

A common concern of both women and men is what to do about urinary devices. Catheters and other appliances can usually be removed before having sex, although removal is not necessary and not always advisable.

Removing an indwelling (Foley) catheter can work as long as you, your partner, or your attendant know how to remove it and put another back in correctly. Doing this on a regular basis causes bladder infections for some people and can be expensive, since a new catheter should be used each time.

For a man who decides that removing the catheter is not desirable, the tubing can be folded over the end of the penis onto the shaft after the penis is erect. For intercourse, a condom can be stretched over the penis and tubing together. To avoid skin irritation, you may want to add some lubricant around the part of the tubing that comes into contact with the penis. The tubing of suprapubic catheters can be taped out of the way. You may need to experiment with a few types of tapes to find one that doesn't stretch or irritate your skin.

Many men who wear an external type of collecting device (condom) and wish to remove it during sexual relations practice bladder voiding methods and wash their penis prior to sex.

If a woman does not want to remove her Foley catheter, she can tape the tubing to her stomach or upper thigh using tape that has some stretch. Lubricating the exposed portion of the tubing can decrease the chance that it will accidentally be pulled out. For both men and women, using longer connective tubing with a larger volume "night" bag allows for more movement.

Because it is difficult for a woman to see her own genital area without the use of a mirror, some women don't realize that the opening for urination (where the Foley catheter is placed) is completely different from the vaginal opening. Anyone in doubt can look at Figure 2. There is no reason a woman cannot have sexual intercourse with her catheter still in place.

Ostomy Bags

Emptying the bag or avoiding direct pressure on it during sex helps to prevent leakage. So does the application of extra tape or adhesive to hold the bag in place. There are now colored and decorated ostomy bags on the market.

Spontaneity

Due to factors faced by many people with SCI such as the need for regular bowel and bladder care, and the need for other people's help for various aspects of self-care, a big complaint about sex is that it must be planned in advance instead of being spontaneous.

Certain aspects of spinal cord injury must be lived with and can't be changed on the *outside*. However, you can change a lot on the *inside*. Ask yourself "does sex have to be spontaneous to be good?" Think of all the

wonderful things – like vacations, reunions with old friends, and reservations at a popular restaurant – that are planned in advance.

The belief that real love and good sex always mean being swept off your feet by a whirlwind is a stereotype. Women in particular are sometimes taught that they are not supposed to want sex, or at least are not supposed to ADMIT that they want it. As people learn more about sexuality and women communicate more about their experiences, this point of view is becoming less common.

Some realistic details to think about before having sex are:

- Will you need help to handle hygiene, transfer, undress, and find a comfortable position for sex? If so, is it OK if your partner helps, or would it be better for a personal attendant to help?
- If you want to make love somewhere other than home, such as your partner's home or a hotel or motel room, have you checked in advance to find out if the building, room, and bathroom are accessible?
- What hygienic activities (e.g., bowel or bladder management, or washing) do you want to perform prior to making love so that you will feel comfortable being sexual with your partner?
- What supplies (e.g., tape, catheter, condoms) do you need to carry with you?

Spasticity and Spasms

Spasticity can be both a help and a hindrance. It can lead to contractures and make certain positions difficult. Arm or leg spasms can occur unexpectedly and interrupt the flow of lovemaking. Some people find they are more likely to have spasms when they are sexually excited. If spasticity limits your range of motion or ability to assume certain positions comfortably, communicating this to your partner will help ensure that both of you have the most enjoyable experience possible. When an unwanted spasm occurs during sex, it can sometimes be eliminated by having your partner put some weight on the area where the spasm is, or by changing position.

At times, spasms can help heighten sexual experience. For some men, spasms improve their erections, allow them to maintain certain sexual positions, or create movements of vibration or thrusting that can increase pleasure.

In general, a good, regular regimen of stretching and range of motion exercises are helpful in maintaining range of motion of your hips. A physical therapist can help you work out positions that are most comfortable for your body. Once an exercise or range of motion plan is established, you can practice on your own or with the help of a personal attendant or family member. There are also some medications that help control spasms.

Pain

Many people experience chronic or intermittent pain. Reactions to pain vary widely between individuals. Each person must decide for him or herself how much pain is manageable for a particular activity, including sex.

Fortunately, the medical world is slowly waking up to the fact that under-treatment of pain serves no beneficial purpose and that people who are truly in pain hardly ever develop addictions to pain medications. If you are in so much pain that most activities, including sex, are limited because of it, then you are probably not receiving the pain management you need. Many medical centers now have professionals who specialize in pain reduction. If the health professionals you are currently seeing are unresponsive to your needs in this area, look for someone who is. The American Pain Society (see References) can provide a list of pain treatment centers.

The Effects of Drugs and Medications

Both legal and illegal drugs can affect the sexual abilities and health of men and women. Nicotine can restrict blood flow, which can have a negative impact on a man's ability to have an erection and the response of a woman's erectile tissue (e.g., her clitoris) as well. In small amounts, alcohol can relax a person. However, alcohol can also depress both a person's mood and sexual abilities. In addition, it can have unpleasant interactions with other drugs in the body. Narcotics such as PCP and cocaine can affect personality and sexual expression, and decrease communication and honesty between partners.

Many prescribed medications can also negatively affect sexual feeling and function. These include some antidepressants, anticonvulsants, anti-hypertensives, and muscle relaxants. If you are taking medications, it is a good idea to speak with a doctor or pharmacist about their possible effects on sexual function. Sometimes the dosage may be lowered or another medication may be substituted. In some cases, an oral medication such as Viagra can help combat the sexual side effects of other medications such as SSRIs (a category of antidepressants).

Positioning

Since no two bodies and no two pairs of lovers are the same, everyone has to experiment to find the best positioning for them. Pillows or other padding can help relieve weight on joints or other areas of the body. Doctors and physical or occupational therapists may be able to suggest helpful resources. A sex book that has pictures of different positions may also be fun. A variety of such books can be found in most large bookstores.

As you experiment to find a comfortable position with your partner, move slowly to prevent injury. Finding the most comfortable and/or exciting positions for sex can become yet another reason to explore and communicate with your partner.

Working with an Attendant

Many people with SCI require a personal assistant to help with some or many aspects of daily living. If you need assistance in areas such as personal hygiene, dressing and undressing, transfer, and positioning, there will be a number of choices to make about who will provide this help when you would like to have sex with your partner. Some couples say that sex can lose its appeal when a sexual partner is also responsible for personal care activities such as personal hygiene and catheterization. Asking a personal assistant to take care of these things before and after sex presents its own challenges. It means the attendant will know details about your sexual life that you would much rather keep private. Depending on your or your attendant's attitudes about sex and privacy, this situation can be either embarrassing or fairly comfortable.

Unfortunately, there is no easy answer to this challenge because each situation is unique. The key to the situation remains communication. How do you feel about the details of your personal care when you want to have sex? How does your partner feel? Do you have an attendant you can trust with the some of the details of your private life? Is the attendant comfortable with the situation? If not, would it be worthwhile to look for someone who is? Instead of having sexual intercourse or having sex in bed at all, would you be content with more subtle forms of sexual expression such as kissing or sharing fantasies? No answer is right or wrong, and you can always change your mind as time passes and your needs and opinions change. It can be very helpful to speak with a therapist or counselor who is familiar with issues of sexuality and spinal cord injury, or to speak with other people who have experienced similar situations.

Conclusion

We hope this booklet has answered or at least *begun* to address some of the questions you may have about different aspects of sexuality and spinal cord injury. No matter what a person's level of physical ability is, we are all sexual beings. Spinal cord injury almost always changes at least some aspects of a person's sexuality, and these changes can be dramatic. Although finding a practical, comfortable, and joyful way of expressing sexuality after spinal cord injury can be difficult and frightening, especially at first, it can also lead you on an exciting and worthwhile journey.

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Organizations

- The American Pain Society. 4700 W. Lake Avenue, Glenview, IL 66025. Phone: 847-375-4715. Web address: www.ampainsoc.org/
- Coalition on Sexuality and Disability, Inc. 122 East 23rd Street, New York, NY 10010. Phone: 212-242-3900.
- The National Spinal Cord Injury Association Resource Center (NSCIRC). Hotline: 1-800-962-9629. Web address: www.spinalcord.org/resource/resource.htm

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