Sexuality for Women with Spinal Cord Injury

Sexuality =

Sexuality is an expression of one's self as a woman or man. It is intimate in nature, which means it is personal and private. Sexuality is commonly expressed through physical and emotional closeness. Most people consider sexual activity as a means to express physical intimacy. However, physical intimacy is more than sexual intercourse. Holding hands, hugging and kissing are good examples of ways to express physical intimacy. Likewise, emotional intimacy is more than feelings that result from physical contact. Emotional intimacy can be a connection with one's self that results in feelings of self-satisfaction, confidence and self-worth. It may also be a feeling of trust in another person and an openness to share private thoughts and feelings.

After Spinal Cord Injury _____

As a woman with spinal cord injury (SCI), you will discover that sexuality is still an important part of your life. It may take some time for a newly injured woman to become comfortable with her body and resume natural feelings of sexuality. Healthy adjustment begins with knowing the facts about the impact of SCI on sexual issues.

Sexual Function

In actuality, there are few physiological changes after injury that prevent women from engaging in sexual activity. Some women have decreased vaginal lubrication. This problem is likely the result of the interruption in normal nerve signals from the brain to the genital area.

Typically, lubrication occurs as a mental and physical reflex response to something sexually stimulating or arousing. Lubrication is a sign of sexual arousal and generally results in easier vaginal penetration and more pleasurable sexual activity. While most women with SCI maintain some degree of lubrication, those who wish can utilize a water-based lubricant (never use oil based lubricants), such as K-Y Jelly, to facilitate sexual activity.

Depending on your level and completeness of injury, you may experience a change in surface sensation and ability to contract your muscles. This may lead you to try sexual positions or activities different from those prior to your injury. Talking to your partner about your need and/or desire for these new activities and positions is also a way to improve your relationship.

One of the changes that you may notice after SCI is that it takes longer for an orgasm to occur and/or it feels different. While the majority of women with SCI are able to experience orgasm, it may take more stimulation than prior to injury. Also, many of the medications that women take can make it more difficult to achieve orgasm.

If you are having difficulties, the use of a vibrator may help women with an injury below the T6 level. It may also be helpful to speak with your physician to see if your medications could be adjusted to minimize their impact on your sexual responses.

Fertility

It is normal for most women to experience a brief pause in their menstrual cycle after SCI. This pause may last as long as six months after the injury. However, a study from the UAB Model SCI System (Jackson, 1999) showed that the ability of women to have children is not usually affected once their period resumes. If your period does not resume, talk to a doctor about possible options for treatment.

Sexual Adjustment

Women who know the facts about living with SCI understand that the loss of movement or sensation does not mean a loss of pleasure. Women with SCI can, and do, resume active, enjoyable sex lives after injury.

Issues with body image can be a primary area of concern (see Table 1). It is important because how you feel about yourself will influence your desire to engage in sexual activity, and your partners desire as well. A positive attitude and a little humor will naturally attract others to you and will help you feel





good about yourself.

One of the main keys to adjustment is learning to manage impairment related issues of everyday life. All women have doubts, concerns and questions, so it is normal for women with SCI to feel the same way. However, the facts are simple. Women with SCI:

- are desirable;
- have the opportunity to meet people, fall in love, and marry;
- are sexual beings;
- have sexual desires;
- have the ability to give and receive pleasure;
- can, and do, enjoy active sex lives; and
- can become pregnant and have children.

Women who accept these facts as true will find it easier to achieve a satisfying and happy sexual relationship.

You and Your Partner

Many women worry about whether or not they can maintain a relationship after injury. In reality, it is impossible to predict the success of any relationship. Lasting relationships depend on a number of factors such as personal likes and dislikes, common interests and long-term compatibility. All relationships take hard work, dedication and commitment.

Women with SCI need to help their partners understand the issues of spinal cord injury and the areas of concern. Communicate clearly and work together to solve problems. This is a great way to build physical and emotional intimacy.

Areas of Concern ____

Table 1 ranks ten common areas of concern for women with SCI. While these concerns may be more common right after injury, these are life long issues that may always need special attention. The best way to feel good about these concerns are to discuss them with your partner ahead of time, be aware of what could happen and be prepared to deal with any problems that arise. In time, you and your partner will become more at ease in dealing with these issues.

Bladder management is a concern for most women with SCI. There are a number of ways to reduce the chance of urinary accidents during sexual activities. First, women might limit fluid intake if they are planning a sexual encounter. Drinking too much fluid increases urine output and causes the bladder to fill more quickly. Women who use intermittent

Table 1

Areas of Concern about Sexual Activity

- Urinary Accidents
- Bowel Accidents
- Not satisfying a partner
- Feeling sexually unattractive
- Others viewing me as sexually unattractive
- Not getting enough personal satisfaction
- Preparation too much trouble
- Hurting self
- Loss of interest
- Not liking methods for satisfaction

catheterization for bladder management can empty their bladder before engaging in sexual activity. Women who use a Suprapubic or Foley catheter may have concerns about the tubing. The Foley can be left in during sexual intercourse because the urethra (urinary opening) is separate from the vagina. If the catheter tube is carefully taped to the thigh or abdomen so that it will not kink or pop out, it should not interfere with intercourse. Women also have the option of removing the Foley catheter before sexual activities, but the catheter needs to be properly reinserted following sexual activities.

Bowel management is another concern for women with SCI. The best way to avoid accidents is to establish a consistent bowel management program. Once a routine is established, an accident is much less likely to occur. For added confidence, empty your bowel and avoid eating before sexual activity.

Sexual satisfaction may be an issue for some women who wonder whether or not they can be sexually satisfied or satisfy a partner. Talking to your partner, experimenting with new ideas and working together will help you find mutual satisfaction.

Sexual exploration can also help couples enhance their physical pleasure. The goal is to find sexual activities that are interesting, enjoyable and mutually pleasurable. As couples work together, it may help to try different methods of giving and receiving physical pleasure. Some couples may find that methods for gaining sexual satisfaction are the same as before injury. However, those "old" methods may not be satisfying. Sexual exploration can help you and your partner enhance your physical pleasure. The goal is for both you and your partner to gain mutual satisfaction. Hopefully, you will then find that sexual activity is interesting and enjoyable.

It may also be necessary for some couples to explore

a variety of sexual positions to find comfort during sexual intercourse. This exploration may be needed especially if *spastic hypertonia* (muscle spasms or contractures) or pain occurs during sexual activities. If spastic hypertonia or pain is a problem, it is recommended that you talk to a doctor for advice on treatment.

Sexual arousal is the emotional and physical process of stimulating excitement and readiness for sexual activity. Emotionally, you will likely find that you are still aroused by the same things as before your injury. These emotionally stimulating activities might include dressing up, a romantic dinner, showering together or an erotic film. This is another opportunity for sexual exploration. It may help to know what other women with SCI find physically arousing. Also, it is often helpful to "explore" your body and see what works before being sexually active with a partner. Women have reported they can achieve arousal through their mouth and lips, neck and shoulder, clitoris, stomach, vagina, thigh, breasts, buttocks, ears and feet.

Other Potential Problems

Autonomic Dysreflexia (AD) is a life-threatening condition for women at the level of T-6 injury and above. Although sexual activity normally results in a rise in blood pressure, which is one sign of AD, women at risk and their partners should be watchful for other signs such as irregular heart beat, flushing in the face, headaches, nasal congestion, chills, fever, blurred vision, and/or sweating above the level of injury. While AD has not been noted in lab studies of sexual response in women with SCI, if you experience multiple signs of AD during sexual activity stop immediately. If symptoms continue after stopping, it is crucial to contact a doctor immediately for advice.

Verbal and physical abuse is an unfortunate reality in some relationships. Women who are in an abusive relationship can talk to friends, family, doctors or clergy to find local agencies that help women escape abusive relationships. Seek help from the agency of your choice. However, if needed, the National Domestic Violence Hotline is 1-800-799-SAFE (7233) or TTY 1-800-787-3224.

Sexual Dysfunction in women is gaining interest in the medical community. For women with SCI, dysfunction is most often a lack of desire to participate in sexual activities or a failure to achieve satisfaction. There are treatment options available, so talk to your doctor if you think sexual dysfunction might be

impacting the quality of your sex life.

Aging can impact sexuality. Many women have a decline in sexual interest and a decrease in vaginal lubrication after menopause. It is worthwhile to discuss these issues with your doctor because in some cases medications may be prescribed to assist with these problems. Although it is natural to experience some changes in sexuality over time, there is no reason why you cannot continue to enjoy an active sex life as you age.

Conclusion ———

Sexuality does not have to change after spinal cord injury. Women with SCI can still express sexuality both physically and emotionally. However, it is important for women to learn how their injury may have changed their mind and body. When you prevent potential problems and properly manage areas of concern, you will feel comfortable in exploring, expressing, and enjoying all aspects of sexuality regardless of your level of injury.

If needed, women with SCI should not hesitate to get professional advice if they experience problems related to sexuality. For example, a professional counselor can help resolve problems with self-adjustment and relationship issues. A physiatrist (doctor who specializes in rehabilitation medicine) can be an educational resource for women and help them manage medical issues. Plus, a physiatrist can likely recommend a urologist and gynecologist knowledgeable on issues related to sexual and reproductive health for women with spinal cord injury.

References =

- -Masters WH, Johnson VE. *Human Sexual Response*. Boston, Mass: Little, Brown and Co Inc, 1966.
- -Bors E, Comarr EE. Neurological disturbances of sexual function with special reference to 529 patients with spinal cord injury. *Urol Surv.* 1960;110:191-221.
- -Sipski ML, Alexander CJ, Rosen RC. Sexual arousal and orgasm in women: effects of spinal cord injury. *Ann Neurol.* 2001;49:35-44.
- -Sipski, ML, Alexander, CJ. Sexual activities, response and satisfaction in women pre- and post-spinal cord injury. Arch Phys Med Rehabil, 1993;74:1025-1029.
- -Jackson AB, Wadley V. A multicenter study of women's self-reported reproductive health after spinal cord injury. Arch Phys Med & Rehab 1999;80(11):1420-1428.
- -McClure, S. Female sexuality and spinal cord injury. Arkansas Spinal Cord Injury Association Fact Sheet #8, 1992
- -Charlifue SW, Gerhart KA, Menter RR, et al. Sexual issues of women with spinal cord injuries. *Paraplegia*. 1992;30:192-199
- -White, MJ, Rintala DH, Hart KA, Fuhrer MJ. Sexual activities, concerns and interests of women with spinal cord injury living in the community. Am J Phys Med Rehabil, 1993;72(6):372-378.
- -Benevento BT, Sipski ML. Neurogenic bladder, neurogenic bowel, and sexual dysfunction in people with spinal cord injury. *Physical Therapy*, 2002;82(6):601-612. Review.

Resources

Secondary Conditions of Spinal Cord Impairment Health Education Video Series -Sexuality and Sexual Function (2006)

Free video download from the University of Alabama at Birmingham Model SCI System. Online at:

http://www.spinalcord.uab.edu/show.asp?durki=97417

A 3 DVD series, sold only as a set, is available by mail. Total cost is \$30. Make check payable and send to:

UAB Office of Research Services
619 19th St S, SRC 529,

Birmingham, AL 35249-7330
(205)934-3283

Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities (and the People who Care About Them)

By Ken Kroll and Erica Levy Klein, book, approx 220 pages, available for purchase online, \$15.95 plus S&H: https://www.newmobility.com/bookstore-romance.cfm?type=REG&order_id=new
Or contact No Limits Communications, Inc. at (888)850-0344

SexualHealth.com

This website provides information about the ways in which different kinds of spinal cord injuries can affect sexual relationships and functioning.

http://www.sexualhealth.com/

channel.php?Action=view sub&channel=3&topic=11

Spinal Cord Injury Manual

A free online publication from the Thomas Jefferson University Regional Spinal Cord Injury Center of Delaware Valley (includes a section on Sexuality). Available online at:

http://www.spinalcordcenter.org/manual/index.html To inquire about mail service call (215) 955-6579

Spinal Cord Injury: Sexuality

Article from the Rehabilitation Institute of Chicago LIFE Center, reviewed November 2006.

Available free online at:

http://lifecenter.ric.org/content/2560/

?topic=3&subtopic=163#pagetop

Or contact (312) 238-LIFE (5433)

Sexuality Reborn

Video available for purchase from Kessler Medical Rehabilitation Research & Education Center. Online order form at:

http://www.kmrrec.org/nnjscis/consumer.php?cnav=5 Or call (973) 243-6812

Through the Looking Glass

A nationally recognized center that has pioneered research, training and services for families in which a child, parent or grandparent has a disability or medical issue.

http://lookingglass.org

2198 Sixth Street, Suite 100, Berkeley, CA 94710-2204 1-800-644-2666 (VOICE)

The National Domestic Violence Hotline

http://www.ndvh.org

If something about your relationship with your partner scares you and you need to talk, call the National Domestic Violence Hotline at:

1-800-799-SAFE (7233) or 1-800-787-3224 (TTY)

Dating & Relationships after SCI

Free online SCI Forum Report from the University of Washington NW Regional SCI System.

Available online at:

http://sci.washington.edu/info/forums/reports/dating.asp Or contact (206) 685-3999

Visit the Spinal Cord Injury Information Network at www.spinalcord.uab.edu

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