Sexuality

Much progress has been made in improving the general health and life expectancy of people with spinal cord injuries. The emphasis is now on improving the quality of life, an area that includes sexuality. Adjusting to a spinal cord injury can be very challenging. Every system in your body is affected by your spinal cord injury, including sexuality both physically and emotionally. A person's sexual identity need not be destroyed by a spinal cord injury. However, a lack of information and understanding surrounding sexuality is more of a handicap than any physical change that may have occurred.

Discussing sexuality can be a difficult subject because it is considered private. Sharing your concerns about sexuality and sexual function may help you adjust. Even though sex is an important part of sexuality, it isn't the whole picture. Certainly one part of sexuality includes the functional and physiologic part normally associated with sex, like erections, intercourse, and pregnancy. More importantly, how you feel about yourself will affect your sexuality. In other words, who you are as a person, and what is acceptable and important to you. If you don't feel good about whom you are, it's very difficult to grow in your own sexuality.

There are events in the course of our lives that have influenced us and make us who we are. Whether we are a man or woman greatly influences how we are treated at home, school, and work. Other influences include our religious and cultural background. The point is that all of us are very different. Our level of sexual function, our self-concept and values, and the influences shaping our lives have made us truly unique individuals.

Right now, because of your injury, you may feel as though you've been stripped of your sexuality. Sweat suits, TED stockings, and halo devices just don't do much to make you feel attractive or "sexy." As hard as it may seem to you right now, you have to believe that you have not been robbed of your sexuality. You are still the same person you were before your accident, and it's important that you recognize that fact.

Your rehabilitation program helps you to relearn how to do all those things you could do before your injury. Learning how to be comfortable with your sexuality is no different. Remember, your sex life is definitely not over. You will, however, need to explore new ways of doing things.

So, what issues are important in dealing with your sexuality? Basically the same ones that are important for non-disabled people. Communication with your partner, foreplay to set the mood, relaxed atmosphere, and experimentation and exploration all play an important role in realizing your full sexuality.

You'll find that certain erogenous zones above your level of injury -- your face, ears, neck, shoulders, inner arms, chest and nipples become highly sensitive. You need to let your partner know just what it is that arouses you.

The feeling of physical relief from orgasm (whether caused by mental or physical stimulation) you had prior to your injury will probably not seem the same. But, an orgasmic like release can still be

felt. Some areas of your body, like those at or above the level of injury, may become more sensitive. It's up to you to experiment and communicate with your partner until you achieve satisfaction.

Another important consideration is bowel and bladder function. Naturally you want to avoid embarrassing accidents. A good working bowel program helps avoid bowel accidents during intercourse. Also, it's best to catheterize yourself just before beginning intercourse.

You may find that, because of your injury, the traditional "missionary" position just doesn't work for you. This is the time for you and your partner to be creative. Men may find for example, that it's best for their partner to be on top while others prefer the side lying position. Some people find having sex while sitting in a chair is best for them because balance can be maintained and the hands are left free for touching one another.

If spasms interfere with your sexual activity, you should take your anti-spasm medication just before beginning intercourse. Some people have fewer problems with spasms in a warm atmosphere, so you may want to increase the room temperature or wear warm stockings on your legs.

If your injury is above the level of T6 you may find that sexual activity brings on an episode of autonomic hyperreflexia. This does not mean that you will never be able to have sex again. It does mean that you will have to try a different position and elevate the head of your bed. You need to stop and rest for a moment. Don't assume that the autonomic hyperreflexia was caused by having sex. It could be a problem relating to your bowel or bladder.

We can't over emphasize the importance of good communication with your partner. Both you and your partner must be comfortable with your disability - both in terms of what your injury is and what it means in the way of sexuality.

In some cases your partner may be both lover and caretaker. This is an issue that you should discuss and resolve. Some couples cannot handle one person serving both roles. If that describes your situation, don't feel that you or your partner are abnormal. You may want to arrange for attendant care to look after your needs for physical assistance.

Another part of living with your spinal cord injury is decreased spontaneity in lovemaking. You may find yourself in a situation where you now need your partner to help you into bed and undress you . Where you have been accustomed to being the aggressor you may now find yourself relying more upon your partner for doing those things you once took for granted. Be creative. Work the preparation time into your foreplay. Use plenty of verbal stimulation.

Be aware of your attitudes about the traditional sexual roles of men and women. Discuss them with your partner openly and honestly. It's vital that you have a good opinion of yourself. This is important in every part of your life, particularly in meeting others and entering into relationships with them. If you don't feel good about yourself you cannot be a good love-maker.

The Male Spinal Cord Injured Person

Let's begin this section by reviewing the male anatomy. The scrotum, a pouch of skin between your thighs, contains two testicles, the male sex glands. The testicle's functions are to produce hormones responsible for male sexual characteristics, like facial hair and a deep voice, and to produce sperm.

Sperm is stored in the epididymus, a series of tightly coiled tubes contained within the scrotum. Because the scrotum is located outside the body, the temperature of the sperm can be maintained at a temperature lower than 98.6 degrees F. This is an important fact affecting the ability of sperm to stay alive. During sexual activity, sperm pass from the epididymus through another tube called the vas deferens and out through the urethra which passes through the penis. Along the way sperm mixes with lubricants and secretions from several glands to combine into the whitish fluid called semen that is expelled during ejaculation.

The most commonly asked question is "Will I still be able to have sex?" Your sexual organs remain unchanged by your injury, and they continue to produce sperm and hormones. There are, however, some definite changes that do take place. You will usually know within one to two months after your injury whether you can have an erection. Erections can be classified as one of two types: reflexogenic and psychogenic. Reflexogenic erections result from direct physical stimulation (foreplay, touching, masturbation) or indirect stimulation (a full bladder, muscle spasms, or body movement). This is a pure reflex; your brain is not involved in this type of erection.

Psychogenic erections occur with mental stimulation caused by pictures, fantasies, even certain odors. In this example, the brain has sent a message down your spinal cord.

Men who have had a spinal cord injury can usually have one or both types of erections. Once again, it will depend on the level of injury and whether it is classified as complete or incomplete.

Complete injuries above the twelfth thoracic and first lumbar (T12, L1) vertebrae usually have reflexogenic erections. Men with complete injuries at T12-L1 or below may have psychogenic erections. Those with incomplete injuries can have both types of erections. Just because you don't see a spontaneous erection doesn't mean that your mental reactions are not the same. It's just that the nerve impulses are not getting through. This can be very frustrating to you, and it's something that you and your partner need to discuss. Most of the time reflex erections will allow you to have intercourse but sometimes it is a fleeting erection and cannot be maintained. If this is the case you may want of consider several options.

Vacuum pump - This device uses suction to allow blood to flow into the penis. It's maintained by using soft rubber rings at the base of the penis. The erection is maintained until the rings are removed. This can be purchased from several different companies and must be prescribed by your doctor.

Caverjet - This is a medication injected directly into the side of the penis. This medication causes the veins to fill with blood causing an erection. The erection can be maintained for a length of time determined by the amount of medication used and by your body's reaction to the drug. Reports from men using this drug are very encouraging. Unless they have a very high injury they are able to inject the drug themselves. Some reported side effects are persistent erections lasting several days and scar formation from the repeated injections. This drug needs to be prescribed by your doctor and instructions given on proper dosage, administration, and side effects.

Muse (alprostadil) - This is a urethral suppository inserted into the urethra which relaxes smooth muscle and allows blood to flow into the arteries causing an erection. The erection can be maintained for a length of time determined by the amount of medication used and how your body reacts to the drug. Muse is easier to use than injected medications and is reported to be well tolerated by patients. Complications experienced by some men were prononged erections, and

penile or urethral pain. Vaginal burning was reported in about 6% of partners of patients using Muse. This medication must be prescribed by your doctor and instructions given on proper dosage, administration, and side effects.

Even though you are able to have reflex erections, keep in mind that ejaculation is possible in only a small percentage of spinal cord injured men. It usually occurs only in men who have an incomplete injury. Of course, without ejaculation the likelihood of your partner becoming pregnant is low. Even for spinal cord injured men who do ejaculate, sperm motility and quality is reduced. The reason for this is not clear, but some urologists believe that because you are sitting most of the time the scrotum is kept warmer than normal resulting in fewer live sperm. Your urologist can do a sperm count and advise you of the likelihood of fathering children.

New research is showing promising success with **vibrator stimulation** used on the penis to stimulate ejaculation. Literature is supporting some success with vibrator induced ejaculate and home inseminations. Bonnie Simms, Head of the Fertility Education Service at Craig Hospital in Colorado, did a survey which showed that 50% of the men could get an ejaculation at home and has reported several pregnancies from vibromassage. Your partner will need to chart her cycle for ovulation and stay lying for thirty minutes with her hips on a pillow.

Another method used to produce ejaculate is **electroejaculation**. Your urologist will insert a rectal probe that electrically stimulates an ejaculation from which your partner can be artificially inseminated. If you have retrograde ejaculations they will extract the semen, treat it, and then inseminate your partner. Sometimes the quality and motility of the sperm increase with more frequent ejaculations.

Today there are many ways to **artificially inseminate**, from the simple home technique, to intrauterine, to very sophisticated techniques involving surgery. The more complex the greater the expense, which can sometimes cost as much as $5,000 to $10,000.

Infertility is frustrating and devastating to most people. Overcoming it takes time, patience, and money. Talk to your urologist and infertility specialists. Sometimes it is helpful to attend a support group that deals with infertility, like the nationally known group called Resolve.

If you and your partner desire to have a child, consider all your options. In addition to the many new procedures now available you can also consider adoption. You cannot be discriminated against because you are disabled.

The success of a parent, whether biologic or adoptive, disabled or able-bodied, truly depends on the individual. What are you willing to give? A heart full of love is more evident to a child than any disability.

Ten Fertility Factoids

1. Electroejaculattion (EEJ) to produce sperm has been used in animal husbandry since 1936. The first sucess (meaning that a baby was born) with (EEJ) and paraplegia was in 1977 in France. The first U.S. EEJ babies were born to paraplegic dads in 1987.

2. A reasonable estimate is that about 300 babies have been born in the United States to spinal cord injured fathers using EEJ. That's not exactly a baby boom, but it's 300 more little people than would be alive without the newer techniques.

3. More than 90 percent of SCI males can produce an ejaculate. Start with a vibrator before moving to the electric probe. Vibratory stimulation usually works best on men with T8 lesions and above. Getting sperm isn't the problem: getting good sperm is.

4. Even after many cycles and many tries, only 35 percent to 40 percent of couples eventually get pregnant. Why? There appear to be functional abnormalities of the sperm. Sperm obtained by EEJ have low viability, poor survival, impaired mucous penetration and poor fertilizing capability. Moreover, EEJ sperm are two-thirds less motile (able to swim) after 24 hours than normal sperm.

5. It doesn't seem to matter when sperm are obtained in relation to onset of injury. Some doctors recommend obtaining a specimen for freezing soon after injury. But studies show that even 30 plus years since injury, sperm quality is often good enough for intrauterine pregnancy. For some reason, sperm obtained early on after injury may not be as good as that obtained two or three years post-injury.

6. Heat and current from the EEJ probe do not seem to impair sperm quality. There is a slight risk of rectal tissue damage from the probe.

7. Best results from EEJ are achieved by men using intermittent catheterization. Generally, the levels of bacterial are lower than with indwelling catheters.

8. People with thoracic injuries ejaculate better than those with cervical or lumbar injuries. Complete injuries do better than those with incomplete injuries. Incompletes may feel discomfort.

9. Men with injuries above T5 or with a history of autonomic dysreflexia are usually premedicated with nifedipine, a fast-acting, short-lasting drug to control blood pressure.

10. The new high-tech fertility method called intracytoplasmic sperm injection (ICSI) will greatly improve chances of fertility because sperm doesn't have to be motile. Because it is manually inserted into the egg, a sperm doesn't have to know how to swim. The downside: ICSI is expensive, it may not be covered by insurance, and it doesn't work 70 percent of the time.

Excerpt from: New Mobility, Sam Maddox, *Medical News Ten Fertility Factoids* July August 1995, pg. 20. For information on New Mobility, or to subscribe, call 800 543-4116.

Your primary nurse can also provide articles on specific topics related to sexuality. You may also want to speak to a urologist or staff member with whom you feel comfortable.

The Female Spinal Cord Injured Person

"Will I still be able to have sex?", "Will I enjoy sex?", "Can I still satisfy my partner?", and "Can I still have a baby?" are all questions that women with a spinal cord injury ask. The answer to all of these questions is simple - Yes! Your anatomy has not changed and everything works as it did prior to your injury. A woman with a spinal cord injury continues to have a normal reproductive cycle. The ovaries, fallopian tubes, uterus and vagina remain unchanged. Hormones remain unchanged, and if you are an adolescent you will continue to develop and grow normally.

Sometimes due to the shock of your injury your menstrual cycle may be absent or irregular. Usually your menstrual period should return within six months after your injury. If your period is irregular for more than six months you should contact your doctor for a check-up. During menstruation, you can use tampons or pads as you did pre-injury.

You can have sex and enjoy a sexually satisfying relationship. Depending on your injury, your position and the way you move will be different. Skin sensation below your level of injury may be decreased or missing.

Being sexually active allows you to give and receive pleasure. Use all of your senses - sight, hearing, touch, and smell - to heighten your pleasure. Communication with your partner, foreplay, mood setting, and stimulating erogenous zones such as your neck, ears, lips, breasts all contribute to your sexual stimulation. Sometimes women experience vaginal dryness during sex and may need to use a water soluble lubricant, such as KY Jelly.

Remember, communicating, experimenting, positioning are all very important in a fulfilling sexual relationship. Your ability to have orgasms as you did before your injury may be different. How much sensation you have depends on your injury but, many women report a sensation that can be equated with an orgasm.

One of our former patients commented, "The most important thing is to learn to be open and creative. Just because you can't move certain parts of your body doesn't mean you can't be exciting. A lot of orgasms come from the excitement of the act of intercourse, not just the physical feeling." Another patient said, "I believe that sex is so different - you really have to try different ways until you find what satisfies you. Every person has their own sexuality and they will have to learn what they need."

Pregnancy

Yes, you can have a baby! You can have a normal pregnancy and, in most cases, have a normal vaginal delivery. Even though paralyzed, you will go into labor normally and the uterus will continue to contract until you deliver.

Choosing to become pregnant is something many women look forward to and is a "right" of becoming an adult. Comments like "Oh, you *can* have sex?" and "Will the baby be disabled too?" show the misconceptions people still have. You will need to educate your family, friends and sometimes healthcare professionals about your specific needs. In most cases your own obstetrician/gynecologist will be able to handle your care, but if you feel you

are not being listened to or feel uncomfortable, then shop around for a physician that will work with you and has a positive attitude. .

Certain precautions must be followed during pregnancy and labor, particularly with quadriplegic women. Although all women share many of these problems, you will have to be especially observant during your pregnancy. It's important to be closely followed by your obstetrician and the spinal cord injury team. We recommend that a urologist follow your pregnancy as well. In addition, we also recommend that your obstetrician contact the spinal cord injury team so that we can make them aware of the complicaions which can arise due to your injury.

If your injury is above the level of T6, labor and delivery may cause autonomic hyperreflexia (A.H.) This is a serious complication that causes a very high blood pressure. Inform your obstetrician if you have an injury above T6 so he can have medication on hand to counteract the effects of A.H.

Many spinal cord injured women report problems with wetness between cathing due to increased pressure on the bladder. Some women have used a Foley catheter throughout the later months of pregnancy. Other women report difficulty catheterizing themselves because their abdomen is so large.

Urinary tract infections affect even able-bodied pregnant women. But because of your injury you are at an even greater risk for this problem. It's also very important to check the medications that you are normally using for your bladder to make sure they are safe for use during pregnancy. Many antibiotics and Ditropan are contraindicated in the first trimester. Try drinking more cranberry juice and fluids to reduce urinary tract infections.

Constipation is another common problem experienced by women during pregnancy. You may find that some additional measures are necessary to maintain an effective bowel program, such as increasing the amount of stool softeners used.

Your pregnancy may place you at a greater risk of forming blood clots in your legs because of your immobility and the pressure of the growing fetus. Check your leg mesasurements around the calf and thighs to see if they are both the same size. If they are unequal call your physician.

As your pregnancy progresses and your weight increases and it becomes more difficult to shift your weight, your skin is more prone to developing pressure sores. Take extra care to do good weight shifts, check your skin, and do not sit on red skin areas. Just follow good skin care principles.

You should be aware that labor can be premature and painless. Most women report an awareness of onset of labor. They report sensations like "chills" or an "internal sensation." Still others say they can see of feel the contractions with their hands. Some doctors may admit you to the hospital a short time before your due date for observation.

It would be advisable to check out the hospital where you plan to deliver for accessibility and to prepare the staff for your special needs.

Perhaps the most important thing to recognize is that you are still able to give birth to a child, and even more importantly, you are able to be a good and loving mother.

Breast feeding versus bottle feeding is a decision that you will have to make. Some mothers feel that breast feeding their infants is easier and helps the bonding process. If you have high quadriplegia you may need some assistance with positioning the baby. Some mothers find bottle feeding works better for them. You should choose what is right for you and your baby.

Birth Control

Your ability to bear children will continue until menopause, so if you don't want to become pregnant you will need to use some type of birth control.

Several methods of birth control are available to you.

- **rhythm method** - the safest but least reliable method. Timing is the key. It involves counting days between menstrual periods to find the most probable time of ovulation. Intercourse must be avoided at this time or protection used. We recommend that you talk to your primary nurse or family planning counselor before using this method.
- **diaphragm with spermacidal jelly** - an effective method if used properly. The diaphragm may be hard to insert if you have decreased sensation or limited hand function. You could have your partner insert it as part of foreplay.
- **IUD (intrauterine device)** - a wire is placed in the uterus which prevents a fertilized egg from attaching to the uterine wall. A problem can result if the wire is displaced and could not be felt as a result of decreased sensation.
- **condom** - effective if used correctly by your partner. Condoms should be used with a spermacidal jelly.
- **the "pill"**- effective, but it increases the risk of blood clots forming, a risk already present with a spinal cord injury.
- **tubal ligation (women)/vasectomy (men)** - a surgical procedure providing permanent birth control.

Parenting

Whether you are a Mom or Dad in a wheelchair, you can still be a successful parent. A spinal cord injury changes how you go about being a parent but, it cannot change the relationship between you and your child. Parenting conjures up many pictures in our mind - holding a baby, throwing a ball, taking a walk or riding bikes together. Parenting is so much more than that. It is caring, loving, sharing, listening, supporting, encouraging, teaching, directing, and setting examples. A disabled parent can do all of these.

You will struggle with all of the same issues that any parent does. You will make some right choices and some wrong choices. The bottom line is LOVE. Each child is unique and you will grow and learn together as all families do.

Some tips from other spinal cord injured parents

When pushing your wheelchair and holding your baby, alternate holding the baby with one arm and push the wheelchair with the other. To free up both hands use a pleat seat or a sling with a pillow, a front baby carrier, a

bassinet on wheels, or a stroller. As the baby grows he learns to hold on - to not wiggle or fall off. In fact you may find that as your child grows older they enjoy spending time on your lap.

In the nursery, use a sturdy table or other surface you can roll under as a changing table. When your baby is small a lap board can be used for changing diapers. You can use a regular crib but when the siderail is down you will need to place your wheelchair along side the crib. Other cribs are available or can be adapted so the side rails open out like a door, fold down at the upper third, or open in the middle and swing out. Shop around and find the one that will suit your needs the best. Playpens provide a great safe area while you are busy or if you are fearful that the baby will crawl out of your reach. When your spouse is at home or when you have visitors the baby can be allowed to crawl on the floor.

Managing the baby, diaper bag, bottles, car seat, and stroller can be a challenge when traveling with young infants. You may want to consider going with your spouse or another adult. A wrist strap or harness is helpful when taking toddlers shopping and is worth the peace of mind. You may also want to consider fencing in the yard to combine freedom with safety. One parent suggested a car phone so you could get help if you had car trouble when traveling with children.

If you have high quadriplegia you may need to consider a nanny. Even though you may need assistance with the physical care of your child, remember, no one can take the place of mom and dad.

Parenting toddlers and older children require strict and consistent discipline for reasons of safety, and independence.

As children reach school age dealing with your children's friends is important. Get involved in your child's school and activities. This will help their friends become comfortable with your being in a wheelchair. Going into a classroom and talking about your disability and how you can do things from a wheelchair helps put their friends at ease. They grow up with this fact and don't see it as strange- rather, you are just their friend's mom or dad who happens to be in a wheelchair.

In general, spinal cord injured parents tell us:

- you don't need a lot of special equipment to care for an infant
- be on the lookout for ways to maximize safety for your child
- be organized
- be consistent in your discipline, particularly in matters of safety
- as with all children, you need to work to keep communication open, especially as the child grows older

Children are not disadvantaged because of your disability. They learn to do many things early in life and they are more independent than most children their age. Both parents must realize that problems with their children are not caused by their parents' disability.

You may find it helpful to talk to other parents who have had similar experiences. In a group with other disabled parents you can share experiences, tips for coping, and validation that you made the right choice to be a parent.

The most important advice other parents gave was to "love your baby"

Sexual Re-adjustment

Understanding sexual function is only a small part of sexual readjustment after a spinal cord injury. Weaving this knowledge of changes in sexual function into your own identity and attitudes is an important process. Sexual drives do not end after a spinal cord injury, and herein lies the challenge. A comfortable attitude about your body image becomes more apparent to a potential partner than a disability. Whether walking or wheeling, all people bring something to a relationship. You can contribute something that another can't.

So if your needs and drives are the same, what now? Consider the same factors you did before your injury. If dating is your priority, you first need to get out and be seen. Build relationships through work, school, church, and other social functions.

Now that you've met someone, what next? Communication and enjoying each others company is the main ingredient of any relationship. When you are ready for more sexual intimacy, let your partner know what you can and can't do. Don't make the mistake of thinking that he or she knows. Openly discuss your needs and share your concerns about an appliance, bowel and bladder function, and sexual positions. Your partner will appreciate not being surprised and may think of ways to help. If autonomic hyperreflexia is experienced during intercourse, you may need to stop and change positions.

Setting up a framework of trust and communication can prevent either partner from having unrealistic expectations. Both of you must tell each other your likes and needs. Use lots of foreplay and experiment. Remember, your erogenous zones may be different after your injury. One area that may become highly sensitive is where your level of sensation changes. Discover what is satisfying and exciting for both of you. Sexual activity must excite your mind as well as your body. Use your imagination - lights, music, body oil, or fragrance.

And remember, a relationship is a two-way street. Be sure that both your needs and those of your partner's are being met.

If you are presently married, finding a partner is not your first priority. But much of what else we've discussed remains important: the need for positive attitude, the importance of communication, imagination, and sensitivity. Your spouse needs to take an active role in the rehabilitation program, work through his or her feelings, and learn to adjust and adapt just as you must.