

# Living Your Life

## Love, Sex, and Becoming a Mother

*Information for women living  
with mobility issues and  
bladder dysfunction*



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Attention to Detail. Attention to Life.

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People often want a fulfilling sexual relationship with a partner as part of a satisfying and productive life. If you have a spinal cord injury (SCI) – whether the source is an accident or a medical condition – it can create challenges in your desire to be physically close to another person. SCI affects almost every part of life. It is tempting to imagine that your physical condition creates too many barriers to enjoying a happy and satisfying sex life. Further, you may want to have a child and are wondering if and how that dream can ever become a reality.

We created this booklet to provide information that may help you enjoy sexual activity and to help with pregnancy and childbirth if you so desire. Each person’s medical situation is unique, and you should speak with your doctors and nurses about your reproductive capabilities. Besides giving you basic information, this booklet can help you plan what you want to ask and talk about with your medical professionals.

**Please consult a medical professional before using this product if any of the following conditions are present:** Severed urethra, unexplained urethral bleeding, pronounced stricture, false passage, urethritis – inflammation of the urethra.

Self-catheterization should only be carried out after medical advice and only in accordance with the instructions provided. Always follow the care plan and advice given by your healthcare professional. For urethral intermittent self-catheterization (ISC), it is typical to catheterize at least 4 times a day at intervals of 6 to 8 hours. If you are unsure about your catheterization, please contact your regular healthcare professional.

## Adapt to Your Circumstances

Everyone in your situation – regardless of the injury’s origin and whether they are male or female – must adapt to the physical limitations caused by their injury. Achieving an active and satisfying sexual relationship with SCI is a challenge but it is one you can meet, just as you are meeting challenges in other parts of your life.

Expressing sexuality can be difficult, even for people without physical limitations. It is natural to feel uncertain about sexual expression. The first step is to express your concerns. Don’t remain alone with your questions, fears, or doubts. Be sure to speak openly with your partner.

Many people with paraplegia are able to live in a happy, intimate partnership or even start a family. The process will take time but as you gain confidence your sexuality can be a liberating and joyful experience. (Hammond and Burns, 104, 113; Maddox, 125)

You have many other resources to help you make the most of your abilities. Talk with a medical professional who can help you solve practical issues. A psychologist or counselor provides support in learning how to manage your emotional concerns, and possibly those of your partner as well. And finally, you can look to others with similar medical situations, people who have already successfully overcome many of the challenges that you face. (Kroll and Klein, 49)

Look around, and you will find a strong support system.

*“Since I was in a committed relationship at the time of my accident, I very soon thought about the topic of sexuality: ‘How will the first time be? How does my partner come to terms with the situation?’ In the rehabilitation department in the hospital there was a nice psychologist to whom you could bring such intimate questions and who could answer them well.”*

*Stephanie, 32*



## Take the First Step with Fresh Thinking

The first and possibly most important step to take as you move toward a more vibrant sex life is to confront your situation and work towards accepting it. Talk with your healthcare provider about your concerns and ask for appropriate referrals.

Especially if you have just experienced an injury, it is natural to focus on what no longer “functions” in your body. If you dwell on the downside, you can lose sight of the present and the opportunities for the future. If you find that you cannot shake the idea that you are unattractive or cannot imagine that a person with your disability could ever be attractive again, consider seeking help from a psychologist or counselor.

You will want to be open-minded and ready to learn new approaches – both with the physical side to sex and in the way you communicate with your partner. Many options are still available to you, and completely new possibilities are waiting to be discovered.

*“My advice to others who are impacted is to allow yourself to come to your new situation in as unbiased a way as possible. Just try it, what is pleasant and what is not, what is comfortable and what is not, and it is very important to give it time. In no case should you load gigantic expectations to pressure you with the first attempts. The higher the expectation, the greater the disappointment. Good feeling comes mostly with increasing practice and positive experiences.”*

*Kathy, 37*

## Find Courage to Try New Things

Just because something is different, it does not mean that it will be less exciting or less enjoyable.

With or without SCI, women may or may not associate the sexual experience directly related to the genitals.

For example, many women have discovered erogenous feelings are strengthened in parts of their bodies which are not affected by the injury. Other women report that they experience completely new “hot spots” on their body. For them, touch is a more intense experience than ever before.

As you interact and communicate with your partner, you can explore your body in a new way and have sensations that you didn’t have before. (Kroll and Klein, 35-74)

Cuddling, kissing, tenderness, a sensual and romantic atmosphere, and a deep inner feeling of familiarity are all part of a healthy sex life. These feelings remain with you even after the injury — and over time they can change and adapt too.

*“In comparison with my experiences ‘before’ my sex life is different now — of course — but despite the limitations on both sides, it is entirely satisfactory. At first it seemed more difficult than it actually was. Sex is a very important part of my relationship. It simply belongs to it.”*

*Sandra, 33*



## Communicate with Your Partner

Sexuality is an important part of life. If you want to enjoy the best possible sex life, that is a good thing! It is a sign of a positive attitude toward life in general.

To support an enduring relationship, it is important that you be open with your partner as you share your feelings, desires, and needs, as well as your fears or doubts. Your partner, too, needs time to adjust and be open with you. Ultimately it is about the future of your partnership – and you both need to participate. Such discussions are not easy for anyone, but honest communication and mutual trust are essential. This would be true even if neither partner had a disability.

Here are a few suggestions for ways to strengthen your communication:

Don't wait until you are just about to have sex! Take time for a real conversation when you can explore the topic, not just when you have a few minutes. Ideally, you will be in a comfortable, neutral place – riding together in a car, or relaxing at home.

In fact, because an unexpected conversation on this sensitive topic might create stress for one of you, it can help to plan a time and place in advance.

Planning will also help you avoid stressful distractions. If one of you is under time pressure, or is hungry or tired, it is more challenging to reach a common understanding.

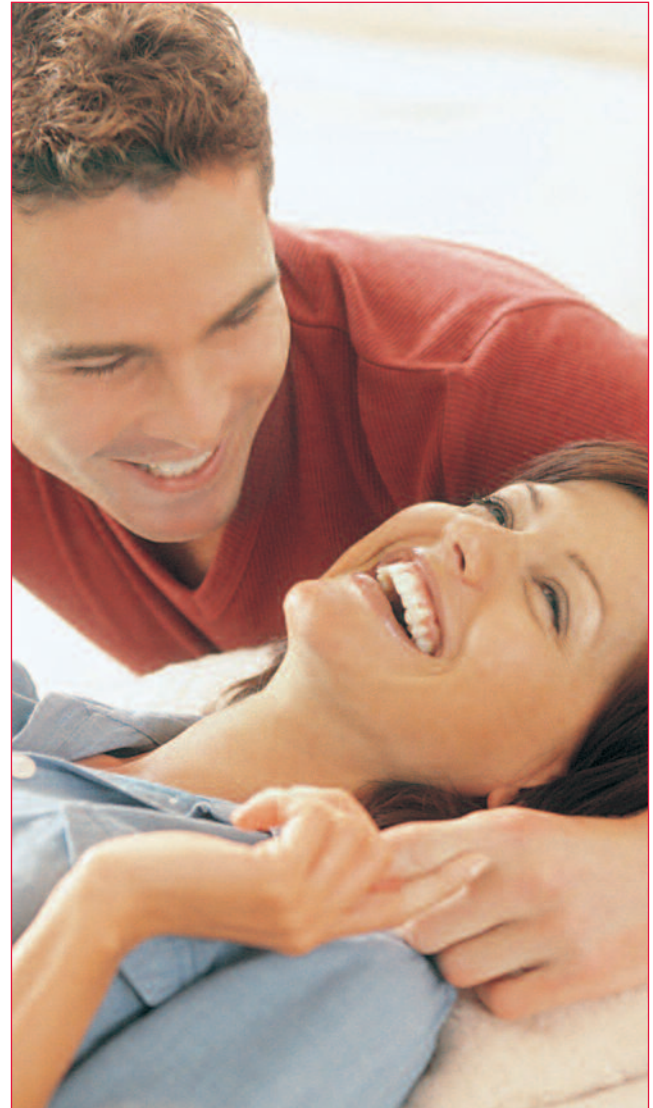
Be informed. If you and your partner want to learn about possible new ways to have sex, it can help if you read books or explore information about the subject on the Internet.

Successful conversations between couples usually include these practices:

- Speak in the I-form. That is, don't say, "You don't think I'm attractive anymore." Instead, state your point of view: "I am unsure and worried that you don't find me attractive anymore." That way, it doesn't sound as if you are making an accusation, only stating a concern

- State your wishes as suggestions: "I would like to try a new position that I have read about. Would that be okay for you?" That soft approach can keep your partner open to ideas

If you continue to struggle with communicating about this sensitive issue, be ready to turn to a professional to help you over the rough spots.



## Manage Physical Issues

There are several physical ways that a spinal cord injury will impact your sexuality. A loss of sensitivity can occur, as well as vaginal dryness, spasticity, and incontinence. While these symptoms can be unpleasant and distracting, there are ways to counteract their effects.

**Dryness.** When a SCI means nerves are not transmitting stimulation, a woman's vagina may not become lubricated as it did before the injury. There are many commercial lubricants on the market which are available without a prescription. Water-soluble lubricants will also help reduce irritation. (Hammond and Burns, 117-118)

**Spasticity.** While you cannot completely eliminate spasticity, there are several ways to reduce it. Be sure to take your anti-spastic medications around the time you expect sexual activity. In addition, there are many ways to reduce spasticity – including a supportive environment and certain positions during intercourse. For example, you can use cushions that are arranged to support your body. A warm room can also help to suppress spasticity. (Kroll and Klein, 41-42; Shapiro, 133)

A massage will reduce muscle tension and is harmonious with foreplay. Ask your partner to pay special attention to the inner thighs, back, and abdominal muscles. (Kroll and Klein, 53, 59)

In addition, some positions are less physically demanding for the woman than for the man. Positions where the affected partner lies underneath, or leans on a seat allows more support for the body; this relaxes your body and helps to reduce spasticity. The classic missionary position – male on top, female underneath – is a good example, and it allows the woman to part her legs without incurring spasticity. (Kroll and Klein, 41-42)

**Incontinence.** Incontinence during or after orgasm is a realistic concern. It is important to talk about this possibility with your partner. The best time to talk about an incontinent episode is before you find yourself in a sexual situation; choose a time when it is easiest for you both to talk and listen.

A sense of physical trust may have to be redeveloped even if you have been in an intimate relationship prior to your injury. Bathing together or washing each other may help establish a trusting atmosphere.

In addition, the bladder should be emptied before you are intimate, especially with intercourse. (Shapiro, 133; Maddox, 126)

*“The joy of sex life should not be dominated from accompanying events from my injury, such as incontinence, for example. Handling incontinence requires a certain degree of planning — and fortunately I have not experienced such an incident. I always catheterize myself just before we are intimate. And of course I let my partner know that something might happen. And if it should happen, it is reassuring that we have absorbent towels readily available, discreetly stored under the bed. This gives me security.”*

*Amy, 35*



## Having a Baby: Children and Pregnancy

An injured spinal cord does not mean you cannot have children. In fact, your ability to have children is fundamentally untouched by an injury to the spinal cord. However, there may be physical reasons why a woman with a disability would find pregnancy inadvisable. (Kroll and Klein, 68)

If your injury is recent, your menstrual period may be temporarily suspended for a few months. If you do not want children, it is important to avoid sexual intercourse during this period unless you use preventive measures. In principle, the probability of pregnancy is as great as it was before the injury.

If you decide to take birth control pills, talk with your doctor about risks. Be aware that they can increase the risk of thrombosis and embolism (blockage of blood vessels). (Kroll and Klein, 71-72)

If a pregnancy does occur, the usual screening tests should be conducted. Make sure that you and your doctor review the drugs you are taking for your SCI so they are suitable for a pregnant woman.

Toward the end of the pregnancy you should have particularly close supervision. It is possible that your gynecologist may not have much experience with pregnancies in women with disabilities. It may make sense to you to ask your gynecologist to put you in touch with a physiatrist and/or neurologist so you can be informed about your specific needs.

You should be aware of special concerns relating to catheterization during pregnancy. The risk of urinary tract infections is increased during this time. It is important to be especially aware of hygiene and to use an appropriate catheter system. A closed intermittent catheter may be safer for use during pregnancy. (Creasy and Resnick, 1088)

Intermittent self-catheterization can become more difficult in the advanced stages of pregnancy. In the final weeks, it may be necessary to have assistance with intermittent catheterization.

During pregnancy, the growing uterus puts pressure on the bladder causing frequency of urination. This may mean increasing the frequency of catheterization. (Burroughs, 73)

*“If the desire to become a parent is present, then you should not have too much to worry about — just go with your wishes. Of course, my parents and some of my friends were concerned that I might be overwhelmed. But in retrospect, there was no situation where I had the feeling that I didn’t have my son well in hand. I have never regretted my decision at any time. I can only recommend to every woman to go with her internal feelings and have the courage to undergo it. Most importantly, if the desire is there — there’s always a solution for everything.”*

*Jill, 36*



## Delivering Your Baby

If you want to learn about pregnancy and childbirth, you will find that most general information applies to your situation, just as it would for a non-paraplegic. However, there are certain nuances that apply to your specific situation.

A “natural” childbirth is entirely possible. Childbirth can take place even without active “pushing” by the mother. In some cases, however, a caesarean or the use of a suction device may be necessary. This will occur slightly more frequently than with non-paraplegic women. (Maddox, 126; Creasy and Resnick, 1089)

*“I gave birth to my son in a general hospital. Because I could not feel the contractions, but rather only some abdominal pains, for safety’s sake I went to a hospital and was given a recording device 14 days before the expected date of birth. When it was apparent that the pains had risen sharply, the birth was then started. Since I could not actively push with the birth process, my son was taken out with forceps, a tool used for completion and/or acceleration of vaginal birth.”*

*Tracey, 33*

Special care should be taken with an injury above T-5 or T-6 during pregnancy and childbirth. For such women, doctors are concerned about the risk of an autonomic hyperreflexia/dysreflexia (increase in blood pressure and a decreased heart rate). Under certain circumstances this is the reason why some high-risk women undergo a prophylactic peridural catheter, which is a type of regional anesthesia for the temporary switching off of individual nerve segments. (Burroughs, 216-217)

*“I believe that children of disabled parents develop a different view of things. My son was very attentive and helpful from an early age. It was never a problem for him that his mother sits in a wheelchair, and he never exploited the situation. I believe that children can develop a sense for this particular situation and their behavior and personality develop accordingly.”*

*Kate, 34*



## Useful Resources

### **The American Urological Association**

www.auanet.org  
1.866.RING AUA (1.866.746.4282)

### **Christopher and Dana Reeve Foundation**

www.crfp.org  
1.800.225.0292

### **The Buoniconti Fund to Cure Paralysis**

www.thebuonicontifund.com  
1.888.STANDUP (782.6387)

### **The Miami Project to Cure Paralysis**

www.miamiproject.miami.edu  
1.800.STANDUP (782.6387)

### **National Association for Continece (NAFC)**

www.nafc.org  
1.800.BLADDER (252.3337)

### **National Rehabilitation Information Center**

www.naric.com  
1.800.346.2742

### **National Spinal Cord Injury Association**

www.spinalcord.org  
1.800.913.6370

### **Paralyzed Veterans of America**

www.pva.org  
1.800.555.9140

### **The Simon Foundation for Continece**

www.simonfoundation.org  
1.800.23SIMON (237.4666)

### **Spina Bifida Association**

www.sbaa.org  
1.800.621.3141

### **Spinal Cord Injury Information Network**

www.spinalcord.uab.edu  
1.205.934.3283

### **Us Too International, Inc.**

www.ustoo.org  
1.800.80.USTOO (1.800.808.7866)

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