LIVING WITH PARALYSIS

# Sexuality & Reproductive Health After Paralysis

CHRISTOPHER & DANA REEVE FOUNDATION

TODAY'S CARE. TOMORROW'S CURE.®

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# Sexuality & Reproductive Health After Paralysis

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**Sex doesn't end when you have a spinal cord injury – but it will change as some adaptations will be needed.**

Sexual satisfaction can be an important factor in overall well-being and quality of life, whether you're living with paralysis or not. For individuals with spinal cord injury, recovering sexual function is consistently rated among the highest priorities for improving quality of life.

> **My first question of the doctor after I woke up after my injury was: Can I have kids?"**
> *– Alan, C-5/C-6 incomplete injury in 1988*

For some, sex is at the top of their mind after the acute phase of a spinal cord injury: they may wonder whether they can still have sex or orgasms. For others, a return to sexual activity may be the last thing on their mind. Similarly, the capacity to have children may or may not be a huge concern, depending on the stage of one's life and one's desire to reproduce. There is no "right" way to be or feel. Accepting where you are right now, and recognizing that feelings can change at any time, is enough.

Navigating the physical, emotional, and psychological issues that come up around sexual well-being and reproductive health after paralysis can be challenging. Talking about the issues and confronting any questions you have around the topic can help remove the unknowns and clear up misconceptions.

**This pamphlet is meant as a guide, offering an overview of what to expect and pointing you to reliable sources where you can learn more about individual topics according to your own needs.**

## STRAIGHT TALK ON SEX

Let's set the record straight: people living with paralysis can anticipate having an active, satisfying sex life, even if it most likely looks different than the one they had before, or the one they imagined having if the injury occurred prior to sexual maturity. Having a child is also within reach for many people living with paralysis. These principles are really universal, applying equally regardless of one's gender identity or sexual orientation. Adjusting one's expectations along with one's behaviors and being willing to explore new ways to achieve sexual pleasure are critical.

> ***Nurse Linda Says…*** ***"It is absolutely possible to have a fulfilling and active sex life with paralysis."***

Your healthcare team should be initiating a discussion about sexual and reproductive health and should be willing and able to talk about your concerns and answer your questions. But let's be clear: this is not always the case. Not all clinicians are comfortable talking with their patients about sex, and not all are skilled in the nuances of positive sexuality. It may be that you need to take the initiative and broach the subject with your medical team. Think about the questions you have and request plain, direct answers – recognizing that there may not be simple or "right" answers. If your questions are not answered to your satisfaction, ask to be referred to someone with more experience dealing with the sexual issues of paralysis. You may want to seek out the advice of a licensed sex therapist or counselor specializing in sexuality issues.

Some people find it helpful to talk with another person living with paralysis; peer counseling and peer mentoring services can connect you with someone who has had the same experiences. The Reeve Foundation offers a peer mentoring program for support – call 800-539-7309 to reach the Reeve Foundation's Peer & Family Support Program.

> **Find someone through peer mentoring programs. It's better than a psychiatrist. Talk with someone who has been through it, who has real experience."**
>
> *– Alan, C-5/C-6 incomplete injury in 1988*

Regardless of the status of their genital function after an injury, many people find that, sooner or later, sexual desire returns. If it doesn't, it's possible something may be affecting it. Physical conditions such as a urinary tract infection, hormone deficiency, or side effects of medications could be at the root and should be addressed with your medical team. Certain medications, including antispasmodics, pain killers (especially opioids), and antidepressants, are known to be associated with increased risks of sexual dysfunction.

## SEXUAL FUNCTION POST INJURY

Human sexuality is complex and goes well beyond having a functional vagina or penis. It encompasses physical as well as emotional elements; cultural, religious, and generational conditioning; body image and self-esteem; relationship dynamics; psychological status; how we perceive ourselves sexually; sexual history (including any past trauma);

gender identity regardless of physical appearance; and any number of other factors. These are factors that affect all people, not just those with paralysis. For people living with paralysis, concerns specific to their injury are layered onto these other factors. There may be physical issues related to the capacity for sexual arousal or to spasticity, incontinence, or medication side effects as well as psychosocial concerns related to the injury and the ongoing adaption to a "new normal."

**Sexual functioning post injury requires a holistic approach that doesn't overlook the range of factors that influence one's sexual life and satisfaction.**

Engaging in sexual activity is consistently rated as a top quality-of-life priority among people living with paralysis. As a result, rehabilitative medicine is paying closer attention to the idea of sexual rehabilitation. There is a growing recognition that best practices in rehabilitative care include integrating sexuality education and counseling with other health-related care services right away. Improvement of sexual life in men and women with spinal cord injury can be possible if rehabilitation specialists educate them and their partner in sexual skills and understanding.

## SEX EDUCATION, REVISITED

Remember those sex ed classes they forced you to take in junior high? This time is different.

Sexual rehabilitation encompasses a wide range of topics related to sex and sexuality. Here are some of the issues you'll want to cover with your healthcare team:

- personal values and attitudes regarding sexuality before and after spinal cord injury
- how sexual behaviors and expectations might need to be rethought after injury
- a review of the sexual response cycle
- the effects of your spinal cord injury on sexual function and response and the treatments available to compensate for these changes
- findings from research about pleasure and orgasm in people with spinal cord injury
- factors that facilitate the process of sexual self-discovery
- suggestions about how to improve sexual responsiveness, which may include things like improving the romantic aspect of the environment (soft music, low lighting, candles, flowers, and pleasant smells)
- using oils or lubricants to enhance pleasure (water-based ones are preferred to reduce the risk of complications such as urinary tract infections)
- genital hygiene issues, especially related to bladder and bowel issues (e.g., importance of catheterization and bowel programs prior to sexual activity to avoid accidents)
- strategies related to mobility challenges and positioning

## HAVING 'THE TALK' — AGAIN & AGAIN

While some people have no problem having the "sex talk," not everyone is at ease talking about sex or sexuality, even with their intimate partner. Yet communication is key to navigating the questions and challenges that may arise around sexual health and well-being.

### Communicating about sexuality is not a one-off affair. It is an ongoing dynamic process.

Whether you've just met someone or you've been married for decades, clear and honest communication about needs, desires, hopes and fears is essential at every step of the rehabilitation and reintegration continuum. This can lay the groundwork for a mutually compassionate exploration of sexual intimacy. You and your partner can decide how, when, and what to talk about, and do it at a pace that feels right for you. If this is difficult for you or your partner, seek the advice of someone you can be comfortable with and whom you can trust to speak frankly, be it a counselor, minister, or peer advisor. Couples' counseling may be helpful for you and your partner to work through these issues.

## DATING WHILE PARALYZED

The trite saying you may have heard too many times is that "Dating is hard enough!" Adding the challenges of living with paralysis to the dating game certainly does add a layer of complexity, as anyone who has done it will attest. Dating horror stories — as well as some very funny anecdotes — abound. But just as common are success stories — people who have met, dated, fallen in love, married or partnered up, and lived happily ever after (or divorced and did it all over again), all while one or more of the partners was living with paralysis.

> **"Humor helps. Humor breaks everything down. Being up front and honest doesn't mean you have to be serious all the time. Lighten up!"**
> *– Alan, C-5/C-6 incomplete injury in 1988*

### Finding love is not only for the able-bodied.

Everyone who has dated while paralyzed emphasizes the need to be open and honest with your date or potential date. People will have questions; some people will ask bluntly and others won't. One of the most common questions that comes up in a budding relationship — or sometimes even in initial conversations — is whether or not you can still have sex. Being prepared for the question and knowing what you will say can help ease the awkwardness around these issues.

If you're feeling daunted by dating, or even the idea of it, seek out others who have been there. A great place to start is the Reeve Foundation's Online Paralysis Community called Reeve Connect at https://community.christopherreeve.org where you can jump into an ongoing discussion or

**The most important thing is not to lose confidence or focus. I was 21 in a wheelchair when I met my husband at a bar. We've been together 17 years and we have two children."**

*– Emily, C-7 incomplete injury in 2001*

you can ask your own question in the community forum and gather wisdom from people who get it.

**RESOURCE TIP:** Online dating can open up a world of possibilities for people living with paralysis. In addition to the old standbys like Tinder, Match.com, eHarmony, and OKCupid are a growing brood of disability-specific dating sites, including www.dating4disabled.com and www.soulfulencounters.com.

## PSYCHOLOGICAL ADJUSTMENT

Emotional issues can impact one's sexuality directly and indirectly. Depression, anxiety, loss of self-esteem, body image, stress, medications and changes in interpersonal relationships can all impact sexual desire and function. These issues can be complex to sort out.

A willingness to explore alternative or new-to-you ways to express sexuality can help a person with paralysis (and his or her partner) achieve a level of sexual satisfaction equal to or exceeding their pre-injury level. Cultural, religious, and generational attitudes about sex can sometimes be barriers to a full exploration of sexual intimacy; examining how such beliefs and conditionings might be impeding one's progress in achieving a fulfilling sexual life may be worthwhile.

### Love Your Body

Research investigating how body image impacts sexual functioning demonstrates that body image concerns influence sexual thoughts, attitudes, and behaviors. Positive body image correlates with higher self-esteem and sexual functioning in general.

**To be comfortable in an intimate relationship, you have to be comfortable with yourself first. You're in charge of you."**

*– Alan, C-5/C-6 incomplete injury in 1988*

The same principles apply regardless of sexual orientation or gender identity. Many people struggle with body image issues and paralysis can compound these issues.

Learn to appreciate your body and cultivate acceptance of your

post-injury body through self-care practices that address physical, emotional, and psychological well-being. Focus on your positive attributes and engage in activities that make you feel good. Get to know your body through self-exploration, which will help you to understand how different physical sensations contribute to arousal.

> ***Nurse Linda Says...*** *"Your body may have changed, but you are still an attractive, vital person."*

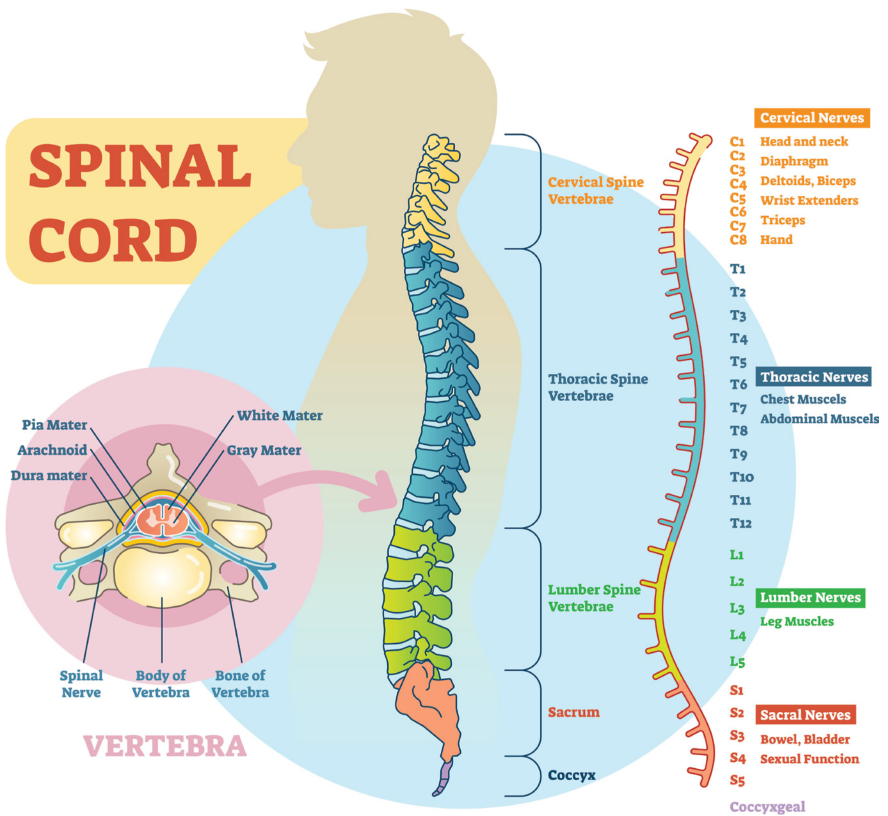
## SEX & THE BRAIN

The brain, it has been said, is the largest sex organ. The brain both receives sensory signals from the body and sends messages to the penis or vagina via nerves that travel along the spinal cord. Damage to these nerves can affect how the messages are relayed. The human brain can also generate sexual thoughts independent of sensory perception that can drive physical arousal through mental imagery.

The degree of sexual reflexes one retains after a spinal cord injury varies significantly among individuals and depends on the level and the severity of injury. To understand why, it's helpful to know how arousal works in the nervous system. Sexual arousal is attained via one or both of two pathways: a psychogenic (mental) path driven by sexual thoughts or visualizations and a reflexogenic path driven by reflexive response to touch in the penis or vagina. Each path relies on discrete areas of the spinal cord. Psychogenic arousal occurs when afferent nerve signals generated by sexual thoughts travel from the brain down the spinal cord to the T10-L2 spinal segment. From there, nerves branch off to convey messages to the genital area that induces arousal – penile erection in men and vaginal lubrication in women. Reflexogenic arousal arises when efferent nerve signals responding to sensations in the external genitals and buttocks are sent to the corresponding section of the sacral spinal cord (S3-5), triggering the physical signs of genital arousal.

## HOW SEX CHANGES AFTER INJURY

In men and women, psychogenic arousal (which results from sexual thoughts or hearing or seeing something sexually stimulating) is typically lost after complete spinal cord injury above the lumbosacral spinal




cord center (usually above T10). Reflexogenic arousal (which results from direct physical contact), on the other hand, is often preserved in injuries above T10. These should be seen as general guidelines, as men and women with varying injury levels and degrees of incompleteness will experience various capacities to utilize their psychogenic or reflexogenic arousal pathways.

It's important to remember that "arousal" and "genital arousal" are two different things. Everyone can feel sexually aroused even if the penis or vagina is not responding to arousal. A man can be aroused without exhibiting an erection; a woman can be aroused even if vaginal lubrication doesn't occur. You can still get piloerection (erection of hair), nipple arousal, etc. above the level of injury. Sex involves more than the penis or vagina.

Even when paralysis results in loss of sensation and/or decreased function in sexual organs, sensations above the level of the injury are unaffected. This presents an opportunity for exploring previously unrecognized or underappreciated erogenous zones that can drive

sexual arousal, particularly in the torso, neck and head. Sexual exploration can lead to development of new areas for sexual arousal, especially areas of your body which are ticklish, the under arm, inside of the elbow and other places you will find that are unique to you.

Mobility and positioning issues may present logistical challenges during sex. Finding positions that work for you and your partner may take time and experimentation. Pillows, cushions, or other props can be incorporated strategically to assist with positioning. Illustrated guides or videos demonstrating various sexual positions appropriate for people with paralysis are available (see Resources p. 19-20). Use your imagination. Playful exploration of positioning that affords comfort and safety are the best ways to find what works for you and your partner.

> ***Nurse Linda Says…*** *"People always ask: 'Which position is best?' The answer is that there is no position that is best for every person living with paralysis (or without). It's different for everyone."*

## AROUSAL VS ORGASM & EJACULATION

Paralysis may affect an individual's response of genital arousal, which for women means less vaginal lubrication and for men means difficulties with achieving and sustaining an erection and with ejaculation. Psychogenic or the mental stimulation of the sexual response is still present. Some people believe genital sexual response is sex; however, the mental part of sexual response is far greater. The mind has to be stimulated and responding before the mechanical aspect of genital response occurs.

Orgasm, defined as a pleasurable release of sexual tension associated with involuntary contractions and, often, with ejaculation of sexual fluids, is a distinct neurological event that is controlled at the S3-5 level. If messages from the brain are unable to reach this spinal cord segment, penile or vaginal response may be elusive. In practice, both men and women with paralysis may experience difficulty achieving genital orgasm and it may require longer periods of sexual stimulation. However, psychogenic orgasm is possible.

The psychological state of euphoria associated with orgasm is a brain-based phenomenon. Orgasm can still be achieved by both men and women living with paralysis; however, the sensation may be altered.

In men, ejaculation of seminal fluids may or may not occur depending on the type of spinal cord injury. Retrograde ejaculation, when semen travels backwards toward the bladder rather than out the tip of the penis, might occur in men. Sometimes called a “dry orgasm,” retrograde ejaculation is not harmful but is problematic if the goal of sex is insemination (see Fertility section).

## SEXUAL DIFFICULTIES AFFECT MEN & WOMEN DIFFERENTLY

### For Women

For women with paralysis, decreased lubrication and difficulty in reaching physical orgasm are the most common physiological obstacles to greater sexual satisfaction. Compared to men, there are fewer medical options for assisting women experiencing a reduced capacity for sexual arousal. Sildafenal, the active ingredient in Viagra, has been studied in able-bodied women with sexual dysfunction with disappointing results; still, some doctors may prescribe it “off-label” for women on a “let’s see if it works” basis. Using your newly discovered or developed erogenous zones may help with mental orgasm.

**In short, there is no “magic pill” to address women’s sexual issues.**

Recommendations for therapy focus on self-exploration and experimentation through masturbation and partner foreplay, with or without sexual aids such as vibrators or stimulators. Direct clitoral stimulation through manual or oral contact, or with a vibrator or suction device, may induce lubrication in some women. Water-based lubricants may be used to facilitate intercourse when natural lubrication is lacking. Oil-based lubricants such as petroleum jelly are not recommended as they increase the risk of infection and are messy and hard to remove.

### For Men

Men with spinal cord injury may have difficulty achieving or maintaining an erection or with ejaculation and orgasm. Depending on the level of injury and whether it is complete or not, natural erections may still occur via either psychogenic or reflexogenic pathways. Reflexive erections may not be sustained long enough for intercourse, and men with sacral injuries who are reliant on psychogenic arousal may experience premature ejaculation and loss of erection due to concurrent activation of sympathetic nerve pathways.

### Erectile Dysfunction (ED)

Talk with your doctor for appropriate interventions for ED. Questions to consider and understand are: Can you attain a full or partial erection? How long does it last? Is premature ejaculation an issue?

Depending on the answers to these types of questions, treatment might include the following:

- **Nonmedical approaches and devices** may be used to attain arousal (such as vacuum pumps, penile rings, vibrators). Nonmedical approaches should be tried before medications or invasive treatments. Adaptive equipment such as penile rings, flexible bands that fit snugly around the base of the penis, may be a first line of treatment to prolong an erection. Vacuum pumps are very popular with some people. Rings should only be used for a limited time as they can cause problems if left on too long or forgotten.
- **ED drugs including injectable drugs** that help achieve and/or maintain an erection may be an option in some cases. While oral ED drugs are widely used and are mostly safe and well-tolerated, they are not without side effects, including prolonged erection, which can be especially problematic in paralysis and may raise the risk for autonomic dysreflexia. If testosterone deficiency is identified as a potential cause of ED, testosterone replacement therapy may be prescribed.
- **Penile implants** made of semi-rigid flexible silicone or inflatable devices may be recommended when other options fail. Implants are a last resort because they require surgery on the penis.

## SEXUAL PLEASURE POST INJURY

Sexual satisfaction is not solely limited to orgasm. Emotional bonds, intimacy and fulfillment in our interpersonal relationship can be important components of sexual satisfaction. Intimacy is expressed in myriad ways that go beyond sexual touch. These facets of sexuality may remain intact after a spinal cord injury.

Difficulties achieving genital arousal and/or orgasm do not equate to a loss of sexuality, loss of desire, or loss of ability to give or receive sexual pleasure. While spinal cord injury may make certain areas of the body less responsive to sensation, other areas may be even more sensitive, opening opportunities to discover and explore new erogenous zones.

For many people, a "transition zone" of skin adjacent to the area that retains pre-injury levels of sensation may have altered sensation that is perceived by the brain as erotic. Exploring this zone and focusing stimulation there can be arousing for both partners. It's also important to recognize that even in those areas directly affected by the injury, sensual touch may, with time and practice to determine the optimal technique and pressure, elicit pleasurable sensations.

**Emotional intimacy is not intercourse-dependent or dependent on genital sensation or arousal.** Sensual exploration can take intimacy to new levels that can be deeply satisfying. Think beyond intercourse: experiment with "making love" to your partner without penile penetration. Explore each other's body playfully, with loving reverence and respect. Have fun discovering new ways to increase intimacy and pleasure.

**Get creative. Don't be afraid to experiment. Be honest with your partner; be proactive, and be willing to try new positions."**

*– Alan, C-5/C-6 incomplete injury in 1988*

Use your imagination! Mental arousal via thoughts, past memories, fantasies, role-playing, or visual stimulation can enhance sexual well-being and satisfaction. Explore how all available senses — sight, smell, taste, hearing, as well as touch — can be incorporated into sexual interactions. Make friends with sex toys: be open to experimenting with sexual aids such as vibrators or stimulators in conjunction with water-based lubricants. Try different body part combinations such as mouth, armpit, inner elbow.

Sexual pleasure is individual; no hard and fast rules exist for what feels best for any one person. Cultural, religious and generational beliefs and conditioning can profoundly impact our attitudes about sexuality and what is appropriate. It's up to each of us to figure out what works for our particular situation with our partner. If sexual closeness is important to you, it's worth the effort.

A sex therapist or counselor experienced in dealing with sexual issues can help you and your partner discover a deeper sexual relationship. The quality of interpersonal relations with one's partner can profoundly affect the ability to be sexually intimate; a skilled counselor can help unearth issues that may impede a more satisfying sex life for both of you.

**RESOURCE TIP:** You can locate a sexual health practitioner through professional organizations such as the American Association of Sexuality Educators, Counselors and Therapists (AASECT) at www.aasect.com or the Society for Sex Therapy and Research (SSTAR) at www.sstarnet.org.

## PHYSICAL & PRACTICAL CONSIDERATIONS

### Autonomic Dysreflexia (AD)

Individuals with spinal cord injuries at the level of T6 or above are at risk for autonomic dysreflexia (AD), a sudden and sharp increase in blood pressure that has can have serious consequences. Symptoms and signs of AD include very high blood pressure, slowed heart rate, pounding headache, flushing, sweating or paleness, nasal congestion, blurred vision, and piloerection (body hair standing up). Though less common, elevated blood pressure can also occur in the absence of symptoms.

Sexual activity, especially orgasm or ejaculation, can trigger AD and worsen its symptoms. In the event of AD onset during sexual activity, the activity should stop immediately, and the individual should sit up while AD treatment is given.

Emerging scientific research suggests that mild to moderate signs of AD are not necessarily medically dangerous and may in fact be a sign of impending or incomplete orgasm rather than a concerning event. Ask your health care team if you are at risk of AD before having sex for the first time after injury. They should be able to tell you how to manage your AD and how to treat it. Severe AD should always be avoided and treated whenever it occurs. Please note that if you are taking erectile dysfunction (ED) drugs, you should check with your physician on how to handle an AD episode. The standard treatment for AD can't be used with ED drugs.

## Bladder & Bowel Issues

Fear of bladder or bowel incontinence can be a significant source of anxiety during sexual activity and may interfere with intimacy or the ability to attain orgasm. Honest, open communication with one's partner in concert with prudent pre-sex precautions can ease concerns of having an accident during sexual intimacy. Emptying one's bladder before sex can help but some men find that an erection is easier to attain with a full bladder, so these issues must be sorted out on an individual basis.

Catheters pose a challenge during sex. Individuals using indwelling catheters need to take care that the catheter doesn't become dislodged during sex or contaminated. Removing the catheter during sex is one option. Some men have found success in folding the tubing down the shaft of the penis or clamping the end of the catheter and placing a condom over it (and the penis); however this can also be problematic if the balloon port is damaged, which raises the specter of bladder distention and associated medical complications. External catheters obviate these concerns and may be more conducive to sexual activity. Catheters and their insertion sites should be cleaned before and after sex.

Sexual activity can lead to urinary tract infections for both men and women due to lack of lubrication or aggressive stimulation. Women can develop vaginal discharges from lack of air circulation due to sitting on non-breathable cushions or urine containment systems.

## Protecting Limbs & Joints

Spasticity is involuntary contractions of muscles or increased muscle tone that can't be controlled. It can cause loss of flexibility and range of motion, is common among individuals living with paralysis, and sometimes can interfere with sexual activity. Supporting your limbs with cushions or bolsters during sexual activity can help prevent injury.

Arousal and orgasm can affect the degree of spasticity – stimulation may increase it and orgasm or ejaculation may reduce it. Be aware of how sexual activity affects your own limbs and joints and take necessary precautions.

## Skin Care

Friction, pressure, shearing, or repetitive motion during sexual activity can increase the risk of skin breakdowns, and decreased sensation can make it difficult to recognize potential problems as they are happening. It's important to carefully inspect skin surfaces, including the penis and testicles or vagina and the buttocks, immediately after sex to identify any evidence of skin problems. Any existing pressure ulcers, while not

necessarily precluding sexual activity, should be carefully protected to avoid exacerbation of the wound or disruption to bandages or dressings.

### Sexually Transmitted Diseases (STDs)

The risk of acquiring a sexually transmitted disease does not disappear after a spinal cord injury. Individuals with paralysis need to protect themselves from STDs (as well as unwanted pregnancy). Condoms are the best choice for safe sex. Sexually transmitted diseases can occur at any time to anyone. You might not feel the usual symptoms of burning or itching. Be sure to be tested for STDs.

### Birth Control

Pregnancy is always a possibility as the result of sex. Men might leak sperm without ejaculation. Sperm can be in men's urine as a result of spinal cord injury. After a spinal cord injury, women can become pregnant even without the resumption of menstruation. If you do not desire pregnancy, birth control must be used.

Diaphragms, intrauterine devices, condoms and birth control pills are the popular options for birth control. Some may not be optimal if your paralysis causes dexterity issues or limited hand function. The pill may cause increased risk of deep vein thrombosis, a potentially life-threatening blood clot. People living with paralysis may already be at risk for blood clots so please discuss the options and risks with your doctor.

## REPRODUCTIVE HEALTH: FERTILITY & FAMILY PLANNING

Paralysis impacts reproductive health in varying ways, and it can be helpful to know what to expect. While a full exploration of the issues surrounding fertility, pregnancy, childbirth and parenting are beyond the scope of this booklet, many resources are available that address these issues in depth. It is important to note that pregnancy is always a possibility for women living with paralysis.

See the Resources section for a listing of verified sources where you can learn more about these topics.

## Menstruation

Women may experience a pause in menstruation following spinal cord injury, but menstrual periods typically return within a few or several months of the injury. Please be aware that pregnancy can occur even if your period has not returned. A low body mass index, which is not uncommon after spinal cord injury, may affect the regularity of menstrual cycles. Women should consult their physician if their periods do not return, especially if it has been more than six months.

**My advice to people living with paralysis who would like to start a family is: Just do it. As long as you're medically fit to do so, do it. People have so many questions: 'How can I be a good parent? I can't even be on the floor with my child.' The physical things are not the main issues. Everybody can read to their child. Everybody can hold their child. Everybody can be present for their child. Of course, it will be challenging. But don't talk yourself out of it. Just know that you will figure it out."**

*Emily, C-7 incomplete injury in 2001, mother of two*

## Parenting Decisions

Men and women with paralysis can be parents if they want to be, regardless of the level of injury. The same rules apply to parenting decisions after an injury that apply to all people contemplating starting a family.

Parenting with a disability can be rewarding and challenging; it's important to understand the challenges as well as the rewards. Gather information, talk to other people who have done it, and seek out trusted resources (see Resources section p. 19-20).

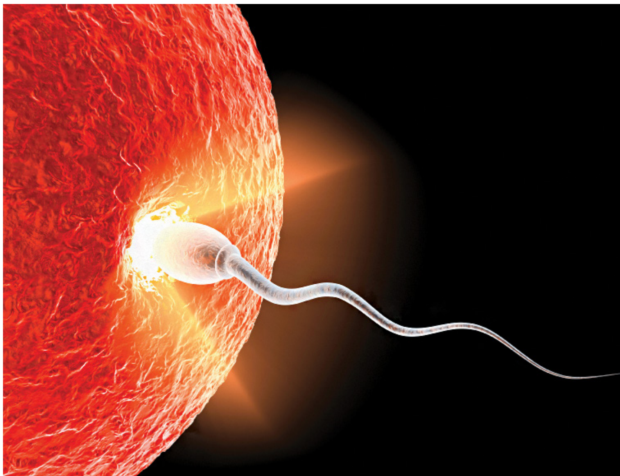
## Male Fertility After Paralysis

Men's fertility may be affected by an inability to ejaculate, or by the reduced motility (slower movement) of sperm, which makes it more difficult for them to fertilize the woman's egg. A number of options are available to overcome these challenges, including in-home insemination procedures and medically assisted fertilization such as intrauterine insemination (IUI), in vitro fertilization (IVF), and electroejaculation.

Retrograde ejaculation is sometimes associated with paralysis. Normal ejaculation occurs in part because the bladder neck closes, allowing semen to flow out the urethra. If the bladder neck remains open, semen can travel retrograde, back into the bladder rather than out the penis. Retrograde ejaculation reduces a man's fertility potential, because fewer sperm are expelled. If you think this could be happening to you, ask your physician about medications that can address it.

## Pregnancy and Childbirth

It may be difficult to imagine being pregnant, giving birth, and caring for a baby after a spinal cord injury, but it is both possible and potentially life-changing. Sure, paralysis will present unique challenges at



every stage, but if you've always dreamed of having a child of your own, there should be nothing to hold you back from doing so after an injury. Successful pregnancies tend to be more common in women who are of a younger age at the time of injury and at the time of pregnancy. Marital status, motor function, mobility, and occupational health also correlate with successful pregnancy.

Understanding what to expect and how to prevent or manage complications is key. The risk of secondary complications is increased during

pregnancy, including blood clots, urinary tract infections (UTIs), and pressure sores. Autonomic dysreflexia is a particular concern during pregnancy as well as labor. Prior to labor, discuss pain management during delivery with your physician. Your body will respond to childbirth even if you can't feel it – thus childbirth may trigger AD. There is also an increased risk for premature labor and delivery.

The bottom line is that women with spinal cord injury are typically able to carry a pregnancy to full term and deliver a baby. Labor and delivery may require adjustments depending on one's level of injury and associated disability. Finding an OB/GYN who has experience working with women with paralysis can make navigating pregnancy, labor, and delivery less risky and less anxiety-producing.

> **Being a parent – having a child and raising them – is one of the most rewarding things you can do. I encourage everybody with a disability to consider it, to not write it off. Having a child is a great reason to stay healthy and get out of bed. What better incentive to take care of one's mental and physical well-being than to want to be around as your child grows into adulthood?"**
>
> *Emily, C-7 incomplete injury in 2001, mother of two*

Adoption and surrogates are other options for people with SCI who want to have a family.

## IN CLOSING...

Sexuality is an important aspect of life satisfaction and well-being; living with paralysis doesn't change that fact. A return to sexual activity is consistently rated as a top priority for individuals living with paralysis – for both men and women. As the recognition of this fact grows, the importance of incorporating sexual rehabilitation into post-injury healthcare and rehabilitative protocols has increased.

Sex doesn't end with a spinal cord injury. But it will be different. Being equipped with clear, accurate information, knowing what to expect, and taking steps to explore new-to-you aspects of sex and sexuality without judgment or undue anxiety will help you successfully navigate the journey of sexuality post-injury and sustain your sexual and reproductive well-being.

## RESOURCES

If you are looking for more information on sexual health and reproduction or have a specific question, Reeve Foundation Information Specialists are available Monday through Friday, toll-free at 800-539-7309 from 9 am to 5 pm EST.

The Reeve Foundation maintains a fact sheet on sexual resources. Please also see our repository of fact sheets on hundreds of topics ranging from state resources to secondary complications of paralysis.

Below are some additional resources on sexual health and reproduction:

**Craig Hospital: Sexual Health and Fertility with SCI**
https://craighospital.org/spinal-cord-injury-resource-library?q=&topics=14807

**Disabilities Health Research Network:**
**PleasureABLE Sexual Device Manual for People with Disabilities**
http://sci-bc-database.ca/wp-content/uploads/PleasureABLE-Sexual-Device-Manual-for-PWD.pdf

**Model Systems Knowledge Translation Center:**
**Sexuality and Sexual Functioning After Spinal Cord Injury fact sheet**
www.msktc.org/lib/docs/Factsheets/SCI_Sexuality.pdf

**Paralyzed Veterans of America:**
**Sexuality and Reproductive Health in Adults with Spinal Cord Injury**
www.pva.org

**Sexual Health Network: The Sex and Paralysis Video Series**
www.drmitchelltepper.com/sex_and_paralysis_video_series

### FOR MEN

**"Is Fred Dead?: A Manual on Sexuality for Men with Spinal Cord Injuries"**
A book by Robert W. Baer, Psy.D. Dorrance Publishing Co. 2004

**"A Guide and Resource Directory to Male Fertility Following Spinal Cord Injury/Dysfunction"**
A booklet from the Miami Project to Cure Paralysis

## FOR WOMEN

**Shepherd Center: Empowering Women with Spinal Cord Injury**
www.shepherd.org/more/resources-patients/women-sci-resource-videos

**Series includes videos on:**

- **Pregnancy**
- **Labor and Delivery**
- **Intimacy**
- **Dating**
- **Sex Positions**
- **Parenting**

## PREGNANCY & CHILDBIRTH

**Model Systems Knowledge Translation Center:**
**Pregnancy and Women with Spinal Cord Injury**
https://msktc.org/sci/factsheets/Pregnancy

**University of Alabama at Birmingham School of Medicine:**
**Reproductive Health for Women with Spinal Cord Injury video series**
www.uab.edu/medicine/sci/uab-scims-information/
reproductive-health-for-women-with-spinal-cord-injury-video-series

## PARENTING

**Through the Looking Glass**
www.lookingglass.org

**Parents with Disabilities Online**
www.disabledparents.net

**SCI Parenting**
http://sciparenting.com/info/

## We're here to help.

Learn more today!

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