

Guide to Sexuality and Reproductive Health

*For adults with
spinal cord injury,
brain injury
or stroke*

Froedtert

&

**MEDICAL
COLLEGE of
WISCONSIN**

Using this Guide

Living with an injury to the spinal cord or brain is difficult because it affects so many areas of everyday life. At first, we might not think about the real problems nervous system injuries cause with physical and emotional intimacy, relationships, and parenting. Because some of these areas can be hard to discuss even with people we trust, problems can go unaddressed. This guide will not answer every question you have, but it is a good place to begin looking for more information or starting a helpful conversation.

Sexuality, relationships, and parenting are very connected to our values and beliefs. Froedtert & the Medical College of Wisconsin health network will respect your identity, spirituality, and decisions within the bounds of what we are able to do. Froedtert & MCW health network works hard to create an inclusive environment where diversity is embraced to not only provide the you best care possible, but also to help people feel welcomed and accepted. The focus is on your recovery. Our goal is to give you a positive experience.

Before participating in **sexual activity**, you should talk with your doctor or other healthcare team member about any restrictions (i.e. bracing, positioning or weight bearing restrictions, etc.) you may have because of your spinal cord injury, brain injury or stroke.

Highlighted/bold words throughout this guide have definitions listed in the glossary. Please take the time to look these up if you need to have a clearer understanding of them.

Contacting Froedtert & MCW Neurologic Rehabilitation

We are here for you even after your hospital stay. Check back with us, talk to your medical providers, speak with people dealing with similar problems, or look online for even more information. New resources are always becoming available and existing ones are being updated.

Here is how to contact us during regular business hours:

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Sexuality

Sexuality is part of who we are, how we think, and what we need. It is a larger concept than just having sex because it involves physical, mental, social, emotional and moral aspects. It is unique for each person and continues to evolve throughout our lives.

After a spinal cord injury, **stroke**, or brain injury feeling anxious about sex and relationships is common. There are many **stereotypes** about what people with a disability can or should do. One way to begin developing more confidence and a positive view of yourself is to confront some common myths.

Myths about Disability and Sex

<p>MYTH</p> <p>Individuals with disability are no longer sexual beings</p>	<p>MYTH</p> <p>Don't discuss sex with healthcare providers</p>	<p>MYTH</p> <p>Good sex always means having an orgasm</p>	<p>MYTH</p> <p>You should not try new sexual things if you have a disability</p>	<p>MYTH</p> <p>People with disabilities have more important needs than sex</p>	<p>MYTH</p> <p>Those with a disability aren't sexually attractive</p>
<p>FACT</p> <p>Disability can change sexual functions, but it does not erase the ability or desire for sex</p>	<p>FACT</p> <p>Sex and sexuality are health issues and should be discussed with healthcare providers</p>	<p>FACT</p> <p>Disabilities around experiencing orgasms do not equal the inability to please or be pleased</p>	<p>FACT</p> <p>Trying new things is strongly encouraged, especially after changes in a person's body</p>	<p>FACT</p> <p>Sexuality is a fundamental aspect of being human whether or not you have some type of disability</p>	<p>FACT</p> <p>Many people enter relationships after an injury. They date, get married, and have kids</p>

HOW YOUR
BODY WORKS

How Your Body Works

Central Nervous System

The central nervous system has two parts: the brain and spinal cord. The brain controls almost everything. It produces thoughts, feelings, and actions. It manages how your body works physically. You can think of the spinal cord as the main connection between the brain and body. It has millions of **nerves** that let the brain and body talk to each other. You need both systems to work well. Problems with either of them can significantly change how your mind and body work together.

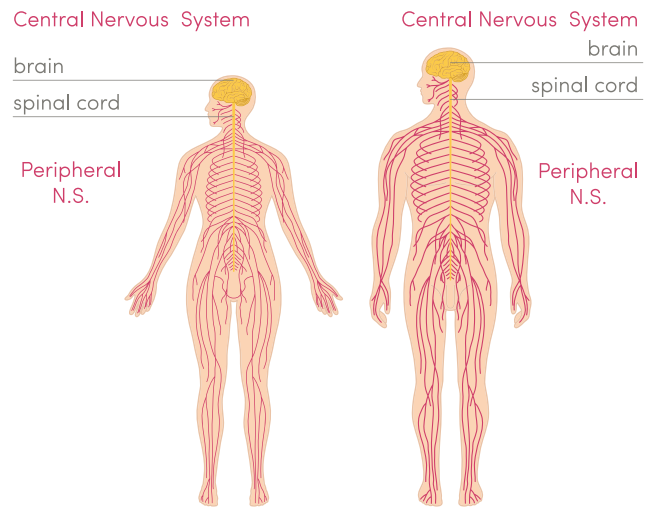
Peripheral Nervous System

The peripheral nervous system is made up of all the nerves outside of the central nervous system. These nerves branch out from the brain and spinal cord. They go out to other parts of the body, such as muscles and organs.

Sexual Functioning

There is usually some change to sexual functioning after a central nervous system injury, such as brain injury, spinal cord injury or stroke. Sexual functioning is mental, emotional and physical. These often change after an injury. Relationships can and do adapt to sexual changes that may have occurred. Good communication and an open mind will help make those adjustments when needed. You can speak with your doctor, nurse, or any other **rehabilitation** team member at any time.

It is not possible to know exactly how your body will work after an injury. Function can change over time, as the body will go through changes. Those changes right after an injury can be different from what may happen later. Different body parts can become more or less sensitive. Because of this, it is important to become familiar with how your body has changed. Paying attention to all five of your senses—sight, sound, smell, taste, and touch—will help you understand what feels right.



NERVOUS SYSTEM

Spinal Cord Injury

- » Your brain and body now have problems talking to each other.
- » Your type and level of spinal cord injury will affect different muscles and feelings.
- » Some sexual functions may still work and others may not.
- » Mental and physical arousal, sensation, and **orgasm** could be different or missing
- » Spinal cord injuries often produce “weird” physical sensations; they can also cause **spasms** or tightness that impacts sexual sensation and performance
- » **Autonomic dysreflexia** can happen during sex

Stroke/Brain Injury

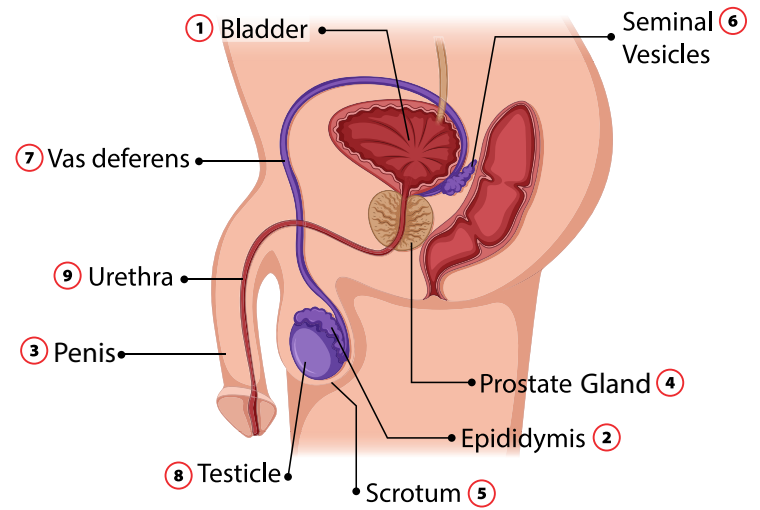
- » There may be changes in thoughts, actions, or body functions around sex
- » The mind and the body may not work as well together
- » You could feel more or less desire
- » It may be hard for your body to get sexually excited or to have an orgasm
- » Problems with movement might make it harder to have sex
- » Troubles with memory, talking, and emotions could make it harder to be with other people
- » People can become more impulsive after a stroke or brain injury, both in what they say and what they do

Sexual Functioning

The Male Reproductive System

The male reproductive system includes the following parts:

1. The **bladder** is an organ that collects and stores urine.
2. The **epididymis** is an organ that holds sperm, as well as allows them to gain the ability to swim, while they mature. It connects the testicle to the vas deferens.
3. The **penis** has three major functions:
 - ▶ **Urination.** The penis allows urine to pass from the bladder out of the body.
 - ▶ **Sexual Activity.** It is a man's main sexual organ for masturbation or intercourse.
 - ▶ **Reproduction.** It allows **semen** and sperm to pass out of the body. Semen is a greyish white bodily fluid secreted by the gonads of male animals. It carries sperm to facilitate successful fertilization.



4. The **prostate gland** is shaped like a walnut and is below the bladder. It releases fluid that helps make semen liquid as it comes out during ejaculation. The urethra passes through it.
5. The **scrotum** is a sack that houses and protects the testes.
6. The **seminal vesicles** are glands that secrete fluid that makes up semen.
7. The **vas deferens** are the tubes that transport sperm from the testicles to the urethra.
8. The **testicles** are egg-shaped organs housed in the scrotum. They produce sperm and **testosterone**.
9. The **urethra** is a passageway that allows urine and sperm to exit the body.

Male Sexual Functioning

After spinal cord injuries, brain injuries and stroke, some men can have problems with getting an **erection**, feeling sexual pleasure, or having an **orgasm**. It will take time to figure out what is happening and how you will adjust. Your health care team can answer your questions.

Erection

There are three ways that men get an erection: physical stimulation, mental excitement, or both.

- **Reflex Reaction:** Physical stimulation to the penis or other sensitive parts of the body. Brain does not control this – it is a reflex.
- **Psychological Erection:** Mental excitement. Only occurs when the brain is thinking about something sexual.
- **Combined Erection:** Erection can be caused by both mental excitement and physical sensations.

Strokes and brain injuries can limit a man's ability to become mentally interested in sex or can even cause physical changes that make erections difficult to have. The medicine you may be taking can also cause

problems with getting an **erection**. Do not stop or start taking any medication, including **over-the-counter** medication, until you talk with your health care provider.

Spinal cord injuries damage the **nerves** that carry feeling from the body to the brain, often causing problems with erections. Some men will have trouble getting erect. Some men can only get partial erections. Other men might be able to get erect, but they cannot keep the erection for enough time to have sex. There is no way to tell if these will be problems until you try things out. The ability to get and stay erect can change during your recovery time. The health care team can answer your questions.

Erection	Spinal Cord Injury
	» The level of injury and whether or not the injury is complete are important
	» Complete injury above T12: You may get erect when your penis is touched, even when this is not sexual; sexual thoughts or feelings typically will not cause an erection
	» Complete injury below T12: Touching on or around your penis usually will not lead to an erection; however, you may be able to have an erection from thoughts or fantasies
	» Incomplete injury at any level: When there is some movement and/or sensation below your injury, erection may be possible from thought, touch, or both
	Stroke/Brain Injury
» Strokes can sometimes change your emotions and thoughts; these changes might affect your sexual feelings which can change your ability to become erect	
» Movement and physical sensation are often different after a stroke; changes in these areas can affect whether or not an erection happens or how long it lasts	
» People with brain injury or strokes can feel either more or less sexual desire which is different from what they had beforehand	

If you have problems getting and keeping an erection, you can try several things. It will take time and practice. Like anything, each of these options has pros and cons to see what method works best for you. Discuss them with your health care provider. They can help find the best option.

- **Kegel Exercises:** Exercises to tighten the muscles in the groin area, specifically the vagina and anus. This technique might help with maintaining an erection and increasing pleasure for both partners.
- **Medications:** Can help get an erection, make an erection stronger, and help it last longer. These medicines come in the form of pills or shots. Talk with your health care provider; do not get them from anyone else. A few problems can sometimes happen: an erection that does not go away within four hours, pain because blood has stayed in the penis for too long, or infection if you use the shots.
- **“Stuffing” Method:** Works best for vaginal intercourse and oral sex; does not work well for anal sex. Easier to do with the man on top with the woman's legs drawn up.
- **“Vibrators” and Sex Toys:** Toys can be an easy, fun, and economical, and can also add some spice and even humor to your sex life. Usually safe and easy to use. Of all the toys, **vibrators** and **vacuum pumps** are often most helpful for men who want to get or stay hard. Vibrators are the best for men who want to increase the chances of ejaculation.
- **Electric Stimulation:** A small electric current can help the penis become erect and increase the time a man can stay erect. Pads that connect to a control box are placed on or near the penis. You must be taught how to use it safely. Do not try electric stimulation on your own.

- **Penis Implant:** Molded plastic, silicone, or metal material that is surgically put into your **penis** to make it hard. Most now have a pump to inflate the implant so that a man gets an **erection** only when he wants. Implants may also help to keep a **condom** catheter on and make **intermittent catheterization** easier. Some problems men can have with implants are infection after the surgery, the implant coming through the skin of the penis, failure of the pump, and trouble with urinating or catheterization.

Sensation

Some areas of the body can become more or less sensitive than before a spinal cord, brain injury or stroke. Men need to find out what feelings have gone away or changed; and which have stayed the same. Even if a man does not have feeling in his penis, he probably does have feeling in other areas. Remember that all the senses can provide pleasure, not just touch. Sexual thoughts and fantasies can help by allowing the mind and body to work together.

Sensation	Spinal Cord Injury
	» When areas above an injury are touched, the body may react with changes in heart rate or breathing, nipple stiffness, etc.
	» If the injury is at T6 or higher, men can be at risk of autonomic dysreflexia during sexual activity
	Incomplete injury:
	» A man may or may not feel sexual pleasure when genital area is touched. » Try gently pulling on pubic hairs, stroking the penis, or using a vibrator to give extra stimulation can help make up for what feeling may have been lost
Complete injury:	
» The message between the brain and penis is completely blocked » Men will not feel sexual pleasure when the penis is touched	
Stroke/Brain Injury	
» Sexual thoughts and fantasies that happen with intense pleasure may be different, this might change how sex feels to the person with a stroke or brain injury » Sensations may also be different or missing which can cause problems with having an orgasm	

Orgasm

Most men with strokes and brain injuries will be able to have **orgasms** unless sensation in the **penis** has been lost. Spinal cord injuries frequently cause problems with having an orgasm because of lost feeling as well as with difficulties in the **nerves** that control muscles related to ejaculating. Experimenting is the best way to find out what works.

Sensation	Spinal Cord Injury
	» Autonomic dysreflexia can happen during orgasms in people with injuries at or above T6
	» Pleasurable feelings felt in the genital area may not occur after spinal cord injury
	» Some men may feel pleasure and intense feelings or climax from touching areas above the level of their injury, even if their injury is complete and they cannot feel their penis
	» Complete injury: men will probably not experience a normal orgasm
	» Incomplete injury: some men might be able to ejaculate , but will need to experiment
	» Spasms of stomach, hips, and legs may also occur during orgasms
	Stroke/Brain Injury
	» Sexual thoughts and fantasies that happen with intense pleasure may be different, this might change how sex feels to the person with a stroke or brain injury
	» Sensations may also be different or missing which can cause problems with having an orgasm

Fathering Children

A spinal cord injury often causes physical changes that affect the ability to father children. Men with strokes and brain injuries usually do not have these problems unless their ability to have an orgasm has been impaired. A doctor to see if you can father children checks two things: (1) ability to ejaculate and (2) number and quality of sperm. In other words, the doctor will see if sperm can get out of the body and into the female partner, and if there are enough healthy sperm to father a child.

Ejaculation Assistance

Several options are available if a man cannot ejaculate normally.

- **Vibrators:** A vibrator placed on the penis can cause **erection** and ejaculation. It is placed on the penis for 1 to 5 minutes at a time. This process may be repeated several times until ejaculation occurs. This method may not work in the first 6 months after injury. It can also cause autonomic dysreflexia for people whose injuries are at T6 or above.
- **Injections:** Injection must be done in the hospital or a doctor's office. A medication (neostigmine) is injected through the joints of spinal bones near the spinal cord. Ejaculation of sperm then occurs. Sometimes, the sperm may not flow out through the penis but may flow into the **bladder**. This drug is not often used because of side effects that can include vomiting, autonomic dysreflexia, and infection.
- **Electroejaculation:** A device is placed into the rectum that electrically causes ejaculation. A doctor who has experience with the procedure must do this. Sperm usually starts to come out after this has been done several times. However, this method may not work for the first 6-12 months after an injury. The electric shock can also be painful if a man has feeling in the rectal area. Spasms in the stomach, hips, and legs can occur during the procedure.

Sperm

There are some reasons why sperm may not be healthy enough to father children after a spinal cord injury, stroke, or brain injury.

Reasons why sperm may not be healthy enough to father children:				
Body temperature becomes too high for healthy sperm	Sperm go into the bladder during ejaculation rather than out of the body	Frequent urinary tract infections can kill them	Some medications make sperm die off or lead to unhealthy sperm	Sperm stay inside the body for too long making them less able to fertilize the egg

Ejaculating more frequently improves the health of sperm. Younger, more active sperm replace the old sperm when it leaves the body.

If you want to father children, there are several options for what to do with the sperm once they have been collected. You or a doctor can place the ejaculation fluid into your partner's vagina. This is usually more successful if you have a doctor help you, but some couples have become pregnant doing it themselves. Sperm can also be frozen at a sperm bank until you would like to try to have children. In this case, the sperm are collected in a medical office.

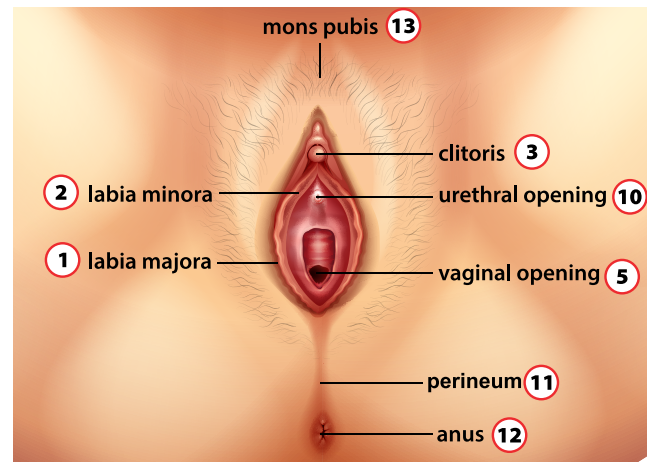
NOTES

The Female Reproductive System

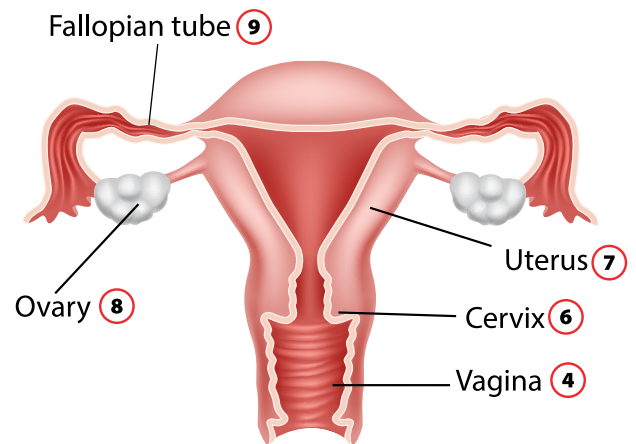
The parts of the female reproductive system are:

1. The **labia majora** (“large lips”) are skin folds surrounding the vagina. They provide protection to the vaginal area.
2. The **labia minora** (“small lips”) are smaller skin folds that sit inside the larger ones. They are right next to the vaginal opening.
3. The **clitoris** is set above the urethra (the hole from which women urinate). It is a very sensitive area. Most female **orgasms** come from pleasuring the clitoris.
4. The **vagina** is a tube from the labia to the womb. It is between the urethra and the anus. The vagina allows the **penis** to enter during sexual intercourse and allows a baby to pass through during birth.
5. The **vaginal opening** is between the urethra and the anus.
6. The **cervix** is an opening between the womb and vagina. Sperm go from the vagina into the womb and then further up where they fertilize the egg.
7. The **uterus** is inside the lower abdomen (belly area). It is thick and muscular in order to carry and nurture an unborn baby.
8. The **ovary** is a small organ found on each side of the uterus. Ovaries hold a woman’s eggs and produce female hormones like estrogen.
9. The **fallopian tubes** attach the ovaries to the womb. They carry the egg from the ovary to the womb. The sperm in these tubes fertilizes most eggs.
10. The **urethral opening** is the opening of the urethra.
11. The **perineum** is the space between the anus and the vaginal opening in the female.
12. The **anus** is the external opening of the digestive tract.
13. The **mons pubis** is the rounded mass of fatty tissue lying over the joint of the pubic bones.

Anatomy of Female Genitalia



FEMALE REPRODUCTIVE SYSTEM



Female Sexual Functioning

Vaginal Lubrication

When a woman is aroused, her body prepares for sex by making its own natural **lubrication**. It makes intercourse easier and more enjoyable. After a spinal cord injury, lubrication lessens. Sometimes it may not occur at all. Also, as women get older the amount of lubrication usually decreases. This is especially true after menopause, which leads many women to experience vaginal dryness. Such dryness can happen with hormone changes from brain or

spinal cord problems too. The level of a spinal cord injury will affect vaginal **lubrication**. Some medications can also cause vaginal dryness. Talk with your health care provider if dryness becomes a problem.

Try using water based personal lubricants if the woman does not lubricate enough. These can be purchased without a prescription in any grocery or drug store. The package will say if it is water based. Do not use oil-based lubricants (such as hand lotion or Vaseline). These can lead to infection and they dissolve **condoms** when used during sex.

Vaginal Lubrication	Spinal Cord Injury
	Complete injury:
	<ul style="list-style-type: none"> » Above T12: Lubrication will occur when your vagina is touched » Below T12: Lubrication may occur due to sexual thoughts and emotions
	Incomplete injury:
	» Lubrication will probably happen
	Stroke/Brain Injury
	» Stroke/Brain Injury usually won't affect the physical ability to lubricate
	» Stroke/Brain Injury can cause problems with lubrication if the ability to sense touch is affected or if emotional changes have occurred

Sensation

Experimenting with touch is a helpful way to find out what still feels good and what may not. What feels good and bad can change, affecting where and how you like to be touched. Remember that in spite of any changes, each of your senses can provide pleasure. Sight, sound, touch, taste, smell, and temperature are all able to make you feel good. Fantasies, arousing thoughts, and creative ideas also help people explore by allowing the mind and body to work together. Try to discover what feels best now that some sensations might be different.

Sensation	Spinal Cord Injury
	Complete injury:
	» Women will not feel anything when their vagina is touched
	Incomplete injury:
	» Women may be able to get ready for sex by gently pulling their pubic hairs, stroking the vagina, or using a vibrator
	» Touching might feel different; the areas a woman likes to have touched could change
	Stroke/Brain Injury
	» Stroke/Brain Injury can cause changes in how touching feels in different parts of the body
	» Any changes will depend on which specific parts of the brain have been damaged

Orgasm

Women who have had a stroke or brain injury can usually have an **orgasm**. Spinal cord injuries often prevent women from having an orgasm, especially if the injury has broken communication between the brain and genitals. The only way to know is to experiment, and to do so for a while after the injuries happen. Sometimes sensation will improve over time, but not always.

Menstruation

A woman's period is called **menstruation**. Injuries to the nervous system can cause changes in a period. Some medications may also cause changes.

Menstruation	Spinal Cord Injury
	» How often a period occurs may change; some women do not have their periods for three to six months after an injury – please contact a doctor if the period does not return or if there are other questions or concerns
	» Women can get pregnant before their period returns if they were able to before
	» Women may still have headaches, irritability, mood swings, and bloating even without a period
	» Tampons and sanitary pads can still be used; both should be changed at least every four hours
	» Skin around the vagina should be inspected to watch for pressure sores and other problems
	» People with injuries above T6 may experience autonomic dysreflexia before and/or during a period or if you use a tampon
	Stroke/Brain Injury
	» Stroke/Brain Injury can cause significant changes in a woman's period including when it occurs
	» Many women experience a significant delay in their period after a stroke or brain injury
» If your period does not return, or if you have questions or concerns, please contact your doctor	

Menopause

Menopause is normal and happens to all women. Each woman is unique. Changes during menopause will be different for everyone. The more people know about menopause the better prepared they will be.

Women usually experience menopause between the ages of 45 and 55. Disabilities sometimes change the age at which women experience menopause. Menopause in women who have injuries to the spinal cord and brain has not been well studied.

What can I expect?

The word menopause means to “stop having periods.” Before menopause, there is a time called pre-menopause when the ovaries make less and less of the female hormone estrogen. You can still get pregnant until menopause is completely finished. This may take up to one year without a period.

What can I do about menopause symptoms?

It is important to talk with your health care provider about problems during menopause. The management of menopause depends greatly on the specific symptom you are having. For example, estrogen therapy can help with hot flashes and vaginal dryness, as well as minimize bone loss of osteoporosis. However, many women will have contraindications to estrogen therapy. Other treatments can be of benefit for some other problems. Many of the symptoms women experience prior to and during menopause can gradually ease after menopause. Pregnancy is not possible for women after menopause. You should continue to use birth control until your doctor tells you that you have completed menopause. Even after menopause, you should practice “safe sex” to prevent sexually transmitted infections (STIs).

SEXUAL
SAFETY

Sexual Safety with a Disability

I am more concerned about sexual assault. What should I do?

Safety is very important. Discuss your concerns about safety openly and honestly. Many people worry more about assault now because they feel more vulnerable. You can effectively reduce risk and increase safety by taking specific actions about specific problems.

The more you know the safer you are...	Always have a charged cell phone with you
	Avoid being alone in isolated or dark places
	Check out locations before going somewhere new
	Get a cell phone charger for your vehicle
	Use locks and install peepholes in doors at wheelchair level
	Identify accessible doors and routes
	Keep your car in good repair and full of gas
	Learn how to say "no" and to feel comfortable doing so
	Tell someone where you are going and when you will be back

You may want to talk this over with a close friend or a member of the **rehabilitation** team for more ideas. You can also ask the local police or sheriff's department to complete a safety inspection for your home or apartment.

What if someone touches me in a sexual way when he/she is providing personal cares and I do not want them to?

Professional care workers are forbidden to touch their clients sexually. No personal care worker has the right to push your limits or to make you feel uncomfortable with sexual jokes or comments. If anything like this happens, **you have the right to tell that person to stop**. You also have the right to call the agency or police. Telling someone to stop is not always easy. You may be afraid of losing someone to do your cares or putting stress on a personal relationship. Some people worry that a worker will hurt them or do a bad job. Getting advice and talking with someone you trust can be a good way to start dealing with this type of problem.

What should I do if I am providing cares to someone and he/she asks me to touch them in a sexual way?

Different types of relationships have different rules for sexual touching, but the most basic rule is that touching should never occur unless you want it to happen—whether or not a disability is involved. Paid care workers may never touch their clients sexually. Other caregivers may sexually touch someone if appropriate and desired for all concerned. If you do not wish to bring sex into a relationship with someone in your care, the best approach is to clearly and directly tell that person about your feelings. Let them know what you think about their request so that they understand the limits of what you are willing to do and discuss.

Relationships

Will I still be attractive?

A big part of looking good is feeling good. What do you think about yourself and your body? Do you believe others will be attracted to you? A positive attitude is attractive to other people regardless of what has happened physically. It is the first step.

It takes time to get used to all of these changes and how they might affect your appearance or behavior. You will gain confidence as you learn more about how your body works. Over time, you will begin to feel better about yourself. Your self-confidence will grow. It might even become better than before. Self-confidence is very attractive.

If You are in a Relationship

Many people will be in a marriage or relationship when they have a spinal cord injury, stroke, or brain injury. These types of major health problems do change relationships, but often for the better!

How will a new disability affect my relationship?

New disabilities provide both challenges and opportunities to a relationship. They cause changes, which can lead to stress but also to new opportunities for getting closer. New disabilities have a way of magnifying the strengths and the weaknesses already present in relationships.

Couples who do well after a disability are flexible, patient, and willing to learn. The couple tends to communicate well with each other. They solve problems together. In addition, they know when to give each other support, but also back off, when needed. Because changes caused by a disability can be frustrating and worrying, there is more tension in a relationship for a while—even if it is under the surface.

Successful couples realize that the situation is difficult and that the other person is trying to cope. However, some couples take out the worry, extra work, and frustration out on each other. In either case, tension and disagreements let people know where the problems are so that they can work to address them. Disagreements tell you what to think about as a couple.

Research with couples consistently shows there are clear do's and don'ts for communicating with your partner, whether the person has a disability or not.

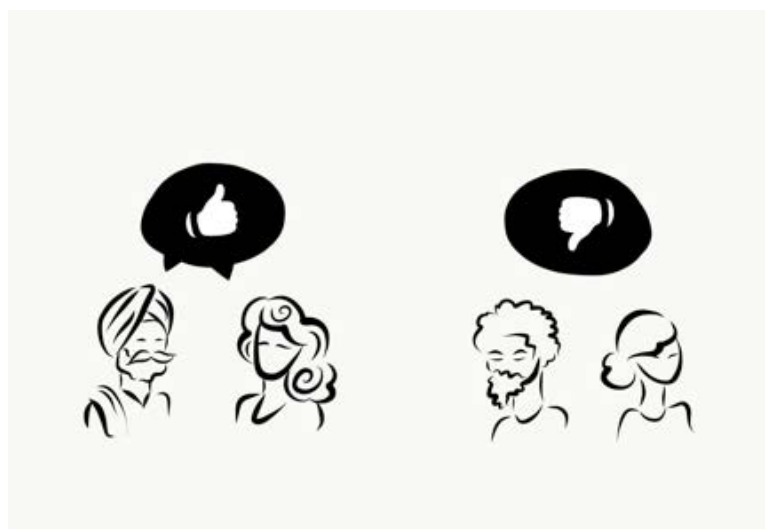


Do's and Don'ts of Talking with Partners

Adapted from the work of Dr. John Gottman

DO: GET CLOSER AND SOLVE PROBLEMS	DON'T: GET MORE DISTANT AND RESENTFUL
<p>✓ RESPECT & LISTEN This is someone you love. Follow the Golden Rule. Talk with your partner in the way that you want them to talk with you, even when they do not.</p> <p>✓ FOCUS Talk about one thing at a time, instead of a long list of problems. If we handle one thing at a time, the discussion stays calmer and the long list gets shorter.</p> <p>✓ COOPERATE Stay with the discussion. Take time if away if you need to cool down, but always come back to the discussion. Tell your partner that you will come back.</p>	<p>× ATTACK Calling names, tearing down, using sarcasm and the like make someone too hurt and angry. It kills trust, shuts down cooperation, and drives people away.</p> <p>× DEFEND Justifying actions or shifting the blame is not listening to what is being said. We are not hearing the problems and are missing a chance to understand.</p> <p>× EXAGGERATE We cannot work on what is really happening when someone blows things out of proportion, or rants about every problem and hurt that has ever happened.</p> <p>× IGNORE Problems build up, we get hurt, and trust ends when couples will not talk to each other, leave discussions unfinished, or do not pay attention to what is said.</p>

We all make some of the mistakes. However, if the mistakes become a regular part of your relationship then things are going to be hard. If you stay with the better ways of communicating then people can often work it out together even when life gets difficult.



If You are Not in a Relationship

Not everyone wants to be in a relationship, but if someone does there are often many questions and worries about finding someone after a brain injury, stroke, or spinal cord injury. Most often, our patients who want to find a good relationship end up doing so.

How do I meet people?

We can meet people in the same way and in the same types of places as before. People tend to date others where there is physical attraction and when there are common interests, values, and goals. People with disabilities might have more trouble getting to places or doing what they did before, but over time, people find ways around these types of roadblocks. New activities developed after an injury can also provide outlets for meeting others who might be interesting.

Former patients suggest meeting someone through friends, going out in a group, using online dating sites, and doing activities outside the home. Talking with other people who have similar disabilities is another good way to get ideas for how to find others. Do not assume that someone interesting is going to look down on you because of a disability. Many people will not. However, you will not find them by staying away from people you do not know.

Are people interested in dating someone with a disability?

People dating someone with a disability might need to be more open-minded, emotionally mature, and giving depending on how much the disability affects self-care ability, appearance, speech, or movement. You will be much more desirable to someone else if others believe that you have a life that they find interesting, enjoyable, and meaningful regardless of challenges that a disability might bring.

NOTES

GETTING READY
TO HAVE SEX



Getting Ready to Have Sex

Worries about Sex with a Disability

Not everyone wants to resume his or her sex life right away after a spinal cord injury, brain injury or stroke. Many people rediscover a satisfying sex life once they navigate changes that disabilities can bring. Even though a spinal cord injury, brain injury or stroke can change how sex happens, physical pleasure and emotional connection are more than possible. Many people will have some concerns. Successfully beginning a good sex life after a spinal cord injury, brain injury or stroke requires communication.

Talking about sex

Talking about sex is probably the best way to share what is physically possible, what needs to change, what does not need to change, and what feels good. These discussions are good whether your partner(s) is new or someone you have been with for a while. Talking about sex can be uncomfortable. However, the other person needs answers if they have questions or worries. He or she may have incorrect information or concerns that need to be clarified. It is also helpful to talk about thoughts and feelings about sex with a disability. It can be hard to know what to bring up or how to do it. Here are some tips on how to begin that conversation.

How to start the discussion

- **TIMING:** Pick the right moment. Be together when you will not be rushed. Try to be physically close to your partner. Hold hands or cuddle. This makes difficult topics easier. If your partner starts the conversation, try to go with it and talk.
- **WHAT TO SAY:** It is usually best to be up front. Tell your partner you would like to talk about sex. Begin by letting them go first. Ask them what they think or if they have any thoughts or concerns. Encourage honesty.
- **LISTEN:** Really listen to what your partner has to say. Do not offer comments until they have a chance to express a whole thought. Summarize what they talk about and be sure you heard correctly. Think about what they are saying instead of what you want to tell them.



- **ACCEPT:** Relax. Your partner will have his or her own reactions. Not all of these may be pleasant to hear. Do not take what they say personally. People might not always be able to say things in the best way. Many people get nervous talking about sex, which increases the chance of mistakes.
- **PATIENCE:** You will probably need a few conversations, some of which may need to happen even once you start having sex. Not everything can be gone over in just one discussion. It is okay to have several, to stop and start again later.

People usually get nervous when talking about sex. They can become defensive or choose the wrong words. You both may be worried about someone leaving a conversation with hurt feelings. You will not know until you try. Here are some topics people often want to talk about.

SOME TOPICS YOU MIGHT DISCUSS	Starting Sex	I want to have sex (again). Are you ready? Is it okay if I kiss/touch you? Could you kiss/touch me here?
	Worries	I am worried that sex will be different from before. Are you? Are you worried about hurting me if we have sex? How worried are you that something will go wrong if we have sex? Is there anything that bothers you about my body?
	Changes	Some of the things we do will change. What will or will not change? I have trouble feeling parts of my body. How will that affect us? Why do we want to have sex? Pleasure? Closeness? Emotions? Kids?
	Experimenting	Let us try out some new things to see what feels good. Should we use sex toys to get around what the disability makes difficult? How much do we want to try some new things?
	Kids	Can we have kids? Do we want (more) kids? Should we use birth control? If so, which types? What challenge will the disability cause if we do have kids?

My partner says it is a chore to have sex with me

If one partner helps you a lot with bathing, dressing, feeding, and bowel or **bladder** care, he or she may find it hard to change from being a caregiver to a lover. The best way to deal with these feelings is to talk things over. Come up with a plan to lower the level of stress that you and your partner may be feeling. Think of other people who might also be able to help. Maybe there are also ways you can make doing personal cares more fun or more sensual.

I am just not interested in sex

Not everyone wants to have sex, especially when going through a major medical problem. Sometimes people have never really felt sexual, even before the disability. Pain, fatigue, medication, a down mood, and worry can all change how you feel about yourself and others, including whether or not you want to have sex again. These things can also sap a lot of time and energy. Feeling sexual when you are going through a hard time takes a while. There is no right way to feel about having sex. If you do, you do. If you do not, you do not. However, professional help may be useful if low sexual desire makes you feel bad or causes problems, such as in a relationship.

What You Will Need Before Sex

People with disabilities related to movement, sensation, and personal care may need to prepare for having sex. These preparations can now include checking the **bladder** and bowel, disconnecting drainage tubes and bags, transferring to a new location, reducing the risk of pressure sores, or shifting positions.

You and your partner(s) can work together to manage a wheelchair or other equipment during sex, get undressed, or to assist with catheters and transfers. A partner of someone who has a spinal cord injury, brain injury or stroke needs to learn about physical and mental changes that the disability has caused so that sex is safe and enjoyable.

Sex with a disability gets easier over time. People understand what to do and how it will feel. At first, think ahead. Anticipate. Here are some things to consider when you first start. Some of these areas may be more or less important depending on the type of disability.

Bladder Management

Sex can increase pressure on the bladder or trigger a bladder reflex. Both can cause urine to leak during sex. Empty your bladder close to the time you are having sex. If you can use the toilet on your own this is a good time to do it. If you use a straight catheter then it is a good idea to do it before sex even if this might not be your normal time.

If you have an **indwelling catheter** such as a Foley or **suprapubic catheter**, ask your doctor if it can be removed for sex. Ensure there is someone who knows how to put the catheter back in if you are not able to do it yourself.

Both men and women can often have intercourse with an indwelling catheter. Women can leave in the catheter. Many women tape it out of their way onto their stomach or thigh. Men sometimes fold the catheter over their **penis** or put a **condom** on over the catheter and penis. Use water-based jelly to lubricate the catheter or condom. Be sure to ask your health care providers if you have questions.

Bowel Management

As with bladder management, sex can trigger a bowel reflex and lead to a bowel movement at the wrong time. You may want to have sex when your bowel is empty. A good time would be soon after completing a bowel program or having a bowel movement.

Cleaning

Clean your genital area with mild soap and water before sex. Keeping your genital area clean will help prevent skin breakdown and infection. Skin breaks down quickly. Body fluids can irritate skin. Lotions or creams used during sex can also irritate skin. Be sure to clean up right away after sex.

Quick Tips Before Sex

BOWEL & BLADDER:

Empty before sex or have sex just after you go. Be prepared in case you have an accident.

COMMUNICATION:

Talking to your partner(s) about what you would like to do, how you would like to do it, and what the effect of the disability will be on your sex life.

POSITIONING:

Experiment with different positions before you have sex rather than once you start to have sex.

SUPPLIES:

Absorbent pads, bandage tape, catheter equipment (if needed), clean medical gloves, towel, water-based lubricants, wipes, etc.

Drainage Bags

Empty drainage bags. Put them securely out of the way to prevent damage.

Medications

Some medications can make having sex more difficult. Many medications can cause drowsiness, lead to a weaker **erection**, reduce your body's **lubrication**, reduce sex drive, or make it harder to have an **orgasm**. Ask your doctor about which of your medications might interfere with sex.

Positioning

If you are a man with decreased mobility, it may be easier to lie on your back. For intercourse, having your partner sit on top can give more comfort, mobility, and stimulation. Many people like wheelchair sex. Your partner faces either forward or backward. Scooting forward in your chair and removing the armrests may help.

It may also be easier for women to lie on their backs. You can also lie on your side with one or both of your knees pulled up, letting your partner enter from behind. As with men, people often enjoy wheelchair sex. For intercourse scoot forward, remove the armrests, and have your partner kneel or squat in front.

There are devices available to help position people during **sexual activity** who may have decreased mobility. You have to be careful of pressure sores. Doing pressure reliefs is just as important during sex.

Spasms

Sometimes **spasms** make it hard to be in a certain position or to stay in that position. However, not all spasms are bad. A number of people find that spasms can cause movements that make sex more enjoyable and even help the **penis** to stay erect longer. Women who have leg spasms sometimes find relief if they put a pillow under their knees.

Tracheostomy

Finding the right position to allow for easy breathing is extremely important for an enjoyable experience. If you use a ventilator, consider the placement of tubes and the ventilator itself during sex. Some tubes may disconnect. Be sure someone is around who can reattach them quickly if this happens. Anyone with breathing problems or on a ventilator should avoid putting pressure on their chest.

Definition

Autonomic dyreflexia is a potentially life-threatening medical condition that many people with spinal cord injury (SCI) experience when there is a pain or discomfort below their level of injury, even if the pain or discomfort cannot be felt.

It may cause the following symptoms:

- › rise in blood pressure
- › pounding headache
- › sweating above the level of injury
- › goose bumps
- › blurred vision
- › restlessness
- › skin redness or flushing
- › nasal congestion
- › chills without fever
- › cold and clammy skin below the level of injury
- › low pulse (although rare, a fast pulse can occur)

Spinal Cord Injury

- » If you are a person with an injury at T6 or above, **autonomic dysreflexia** (dangerously high blood pressure) can occur during sex
- » Bowel, **bladder**, skin and positioning issues may contribute to autonomic dysreflexia during sex
- » Water-soluble lubrication before sex can decrease risk for autonomic dysreflexia and spasms
- » Your doctor may be able to give you medications to prevent blood pressure problems during sex

What You Will Need After Sex

Cleaning

Protect your skin by cleaning up sex fluids and bowel or **bladder** accidents. Use soap and warm water or use wipes to clean your skin. Dry off completely. Make sure that your bed linens and/or seat are also dry. Damp spots can harm your skin. People often like to clean each other up as part of “afterplay” when they have sex.

Communication

Talk about how sex went and be sure to offer verbal affection. By talking about how things went, the enjoyment can linger and you can make sex even better next time.

Positioning

Just as you think about the best position during sex, you should also think about the best position for after sex to keep you comfortable and reduce pressure on your skin. This is especially true if you fall asleep after sex. Staying in one position for a long time can cause skin breakdown.



Reproduction

Women who can get pregnant will usually be able to do so even after a spinal cord injury, brain injury or stroke. Likewise, men with a brain injury or stroke can usually father children. Some men with spinal cord injuries will experience physical changes that reduce or take away the ability to become a father, especially as the years go by. Medical tests are the only way to know for sure. Assume that you can still have children unless your doctor has told you otherwise.

Types of Birth Control

Many people want to delay or prevent pregnancy. For them, birth control may be a good option. Birth control takes many forms. Birth control can interfere with the release of the woman's egg, prevent egg and sperm from meeting, or reduce the chance that a fertilized egg will implant itself in the womb. Medications and medical devices require a prescription. Other methods like **condoms** and many gels do not. Incorrect use of birth control significantly increases the chances of pregnancy. Sometimes pregnancy happens even when birth control methods are used correctly. Not having vaginal sex is the only 100% effective birth control method for a woman able to have children.

Devices

Most devices prevent a pregnancy by keeping the sperm and egg apart. Some of those require a doctor's order. Those devices include the diaphragm, **cervical cap**, and **intrauterine device (IUD)**. Many of the birth control devices that do not require a doctor's order (i.e., over the counter) can be bought in stores where you buy health care products. These include condoms, **contraceptive sponges**, foams, creams, jellies, and vaginal suppositories.

Hormone Medications

Oral contraceptives (birth control pills) are the most common kind of birth control medication. Some women have a capsule placed just under the skin to deliver these drugs or use a patch instead of taking a pill. These different methods work by giving low doses of female hormones which stops the release of an egg during a woman's monthly cycle. These medications also cause mucus at the opening of the womb to become thicker, making it difficult for sperm to reach the egg.

Many doctors hesitate to prescribe hormone contraceptives for people with nervous system injuries because of increased health risks. Many of these medications can increase the risk for blood clots and strokes. You may already be at risk for developing a blood clot or having another stroke due to decreased mobility and other problems caused by a spinal cord injury, brain injury or stroke.

Techniques

Birth control techniques include sexual activities other than vaginal intercourse, especially during the woman's fertile period. The Rhythm Method means having sex only during the time of the month when a woman is less likely to get pregnant. However, there is a 30% chance of getting pregnant when the Rhythm Method is the only birth control used.

Surgery

Surgical procedures are available to permanently prevent pregnancies. Sterilization in men is called a **vasectomy** and sterilization in women is called a tubal ligation.

Concerns for Women

Spinal Cord Injury

- » Changes in your sensations may limit the feeling you get from your genitals and abdomen, making it hard to know if you have an infection should something go wrong with surgery or an IUD
- » The Rhythm Method requires that you check your temperature daily; this may not work well after your injury because of the way your body now regulates temperature

Talk to your provider about different birth control methods to make sure which ones are safe and effective for you.

A Woman's Period

Many women become concerned when they do not have a period after their injury or stroke. However, it is common for women to go 3 to 6 months without a period after this type of traumatic event. Periods will usually restart over time and once again begin their cycle. Sometimes, medicines that you now take or changes to your hormone system can change your periods. If you are concerned about what is happening with your period, please talk to your health care provider. It is better to ask than not know. **You may still become pregnant even if you are not getting your period.**

Pregnancy

Pregnancy and having healthy children are still possible for most women after a brain injury, stroke, or spinal cord injury. While there may be challenges, pregnancy can be the beginning of a wonderful journey. Here are some areas that deserve extra attention.

Knowing that you are pregnant

Women often suspect they may be pregnant due to changes in their bodies and lack of period. Noticing these signs can be more difficult when a spinal cord injury, brain injury or stroke has made sensation different or thrown off the normal cycle of your periods. You will probably need to be a little more watchful. Talk with your health care providers to know if this applies to you.

What might change during pregnancy?

Find a gynecologist or obstetrician who knows about the needs of women with your type of disability in order to help you through the pregnancy. You will find out which medications are safe for you and your baby. Your body may also have different nutritional needs other physical changes that only a specialist will know how to manage. Find a physician who is willing to listen and who is open to your suggestions. **You may be the best teacher about your body.**

Occupational and physical therapists are also great resources. Ask your doctor for therapy orders as soon as you find out you are pregnant. They can help you learn how to stay mobile, keep your independence, and teach you skills to take care of the baby. Our therapists at Froedtert have helped women successfully navigate pregnancy and learn about childcare. You can work with them to help you get the confidence you need as a mother after a spinal cord injury, brain injury or stroke.



Spinal Cord Injury

- » Anemia (low blood count)
- » **Autonomic dysreflexia** is more likely
- » Breathing problems
- » Changes in bowel and **bladder** routines and schedules
- » Difficulty moving and transferring toward the end of the pregnancy
- » Early labor (before the 36th week)
- » Fatigue above and beyond what already happens during pregnancy
- » Greater risk of pressure sores because of weight gain and less mobility
- » Higher chance of blood clots in legs
- » Increased **spasms**
- » Pre-eclampsia is more likely
- » Premature or low birth weight babies
- » Swelling of hands, legs and feet
- » Trouble with self-cares due to weight change and body shape changes
- » Urinary tract infections or accidents from the baby pressing on your bladder
- » Increased back pain

Stroke/Brain Injury

- » Anemia (low blood count)
- » Breathing problems
- » Changes in bowel and bladder routines and schedules
- » Difficulty moving and transferring toward the end of the pregnancy
- » Early labor (before the 36th week)
- » Fatigue above and beyond what already happens during pregnancy
- » Greater risk of pressure sores because of weight gain and less mobility
- » Higher chance of blood clots in legs
- » Increased spasms
- » Pre-eclampsia is more likely
- » Premature or low birth weight babies
- » Swelling of hands, legs and feet
- » Trouble with self-cares due to weight change and body shape changes
- » Urinary tract infections or accidents from the baby pressing on your bladder
- » Increased back pain
- » Difficulty with new learning

Possible solutions for pregnancy issues

- Get to know your typical blood pressure
- Know signs and symptoms of autonomic dysreflexia
- Educate your healthcare provider about autonomic dysreflexia
- Think about different positions or set-up you could use for bowel and bladder care
- Consider need for extra help with bowel and bladder routine
- Consider use of an indwelling catheter if cathing becomes too difficult
- Consider temporary change in seating to assist with pressure reliefs and make room for weight gain
- Break up tasks to help with fatigue
- Use equipment for checking your skin (i.e., use of phone camera or inspection mirror)
- Consider use of compression stockings to prevent blood clots and reduce swelling
- Use adaptive equipment or change in the position you complete self-cares to help with dressing and bathing (i.e., reacher, sock-aid)
- Consider getting assistance with self-cares towards the end of your pregnancy
- Consider changes to seating to help with back pain
- Sleep on a wedge or multiple pillows to make it easier to breathe
- Use adaptive equipment to ease difficulty with clean up
- Use a toileting schedule to decrease risk for accidents due to urgency
- Consider the use of devices such as walker, cane, or slide board for transfers towards the end of your pregnancy
- Request extra written materials including pictures and simple instructions to help with new learning
- Have family be present during any teaching activities

What might be different during labor and delivery?

The stresses and strains of childbirth can lead to more problems for people with brain injuries, strokes, and spinal cord injuries. Not all of these difficulties are physical. Some are more emotional in nature.



Labor and Delivery

Spinal Cord Injury

- » **Autonomic dysreflexia** and breathing problems are more likely
- » Injury below T10: You will be able to feel contractions during labor
- » Injury above T10: You may not feel contractions, but touching your abdomen over the uterus can help you know when contractions are happening
- » Mobility and sensation limitations can make labor and delivery more challenging
- » Natural childbirth is possible if you have quadriplegia or high paraplegia. However, paralysis of the trunk muscles may affect how you push during delivery
- » Many women with spinal cord injuries will deliver by Caesarian section

Stroke/Brain Injury

- » Delivery itself can happen normally
- » Depression or other emotional problems may impact your labor and delivery experience
- » Difficulty moving or communicating may cause challenges when working with the delivery team
- » Problem solving and memory deficits can make it hard to know what to do during labor and delivery

These problems can often be prevented or managed. With this knowledge, you and your medical team can create a successful plan.

Possible solutions for labor and delivery issues

- Make sure your doctor is aware of problems that can occur during labor and delivery due to your spinal cord injury, brain injury or stroke.
- Work with your doctor to write up a plan with a list of possible problems that could happen on the day of delivery and how to deal with these problems in case your doctor cannot be at your labor and delivery.
- Keep your written plans at the doctor’s office, with your spouse or partner, in your purse, and in your car in case you have an unplanned delivery without your medical team there to assist you.
- Plan for how to continue pressure reliefs during labor; labor can be long, and you can develop a sore if you are not prepared.
- Monitor your blood pressure and watch for other signs of autonomic dysreflexia during labor and delivery.

Breast Feeding

Women with disabilities can breast-feed their babies. As is true for any mother, women with a spinal cord injury, brain injury or stroke should know that some medicines can get into the breast milk and that some of these medications can hurt the baby. Your medical team will know and can answer questions.

Women with spinal cord injuries below the T6 level will usually produce less milk after 6 weeks. If the injury is above T6 then **autonomic dysreflexia** can happen when the baby breast-feeds or when you pump. Women with spinal cord injuries who want to breast feed should work with an experienced occupational therapist to learn positioning, clean up, safety, and equipment skills.

People with strokes and brain injuries will often have depression and other difficulties such as impulsivity and rigid thinking. Strokes and brain injuries can affect memory and problem solving skills. Working with occupational and speech therapy can improve your ability to successfully breast feed your new child.

Possible solutions for breastfeeding issues

- Consider using a horseshoe shaped pillow (such as a Boppy®) around your stomach to help support and hold the baby close to you.
- Make sure the fasteners on breastfeeding bras and tank tops are easy to use or have them adapted with Velcro®.
- Make sure the on/off buttons on breast pumps are easy to manipulate or ask your therapist to help you adapt them.
- Look for breast pumps that are easier to clean up.
- Create a written breastfeeding schedule if you have memory issues.
- Monitor your blood pressure and watch for other signs of autonomic dysreflexia when you start breastfeeding.



Parenting

People with a disability often worry about their ability to raise children. An aunt, uncle, grandparent, or family friend who has a spinal cord injury, brain injury or stroke will also have concerns about meeting a child's needs. The good news is that people with these disabilities are usually able to successfully interact with and parent children.

Questions people with disabilities have about caring for children	What do I or will I enjoy about being a parent or caregiver for this child?
	What is most important to me about being a good parent or caregiver?
	What is my greatest fear about what could go wrong now that I have a disability?
	How does my disability affect my ability to meet my child's physical needs (e.g., dressing, bathing, etc.)? If I can't help my child with these needs, is there someone who can?
	What kind of adaptive equipment will I need so I can take care of my child? Where can I get this equipment?
	How can I meet my child's safety needs?
	Will I have enough energy to take care of myself and my child?
	How did I discipline my child before my injury? What will be different now?

Getting Physically Ready

There are things you can do to prepare your body and brain to get ready for parenting with an injury, whether you are the mother or the father. You may want to ask your health care provider for therapy orders. Your therapist can help make an exercise program that will fit your needs.

Preparation will help you in the following areas:

- Increase strength to help you lift and carry your baby.
- Increase balance and ability to reach away from your wheelchair in order to lift and carry your baby; it is helpful to practice using a weighted baby doll in your therapy sessions prior to having your baby.
- Increase your fine and gross motor skills within the limits of your level of injury in order to get your body ready to handle childcare equipment. Some of these items may include syringes, bottles, clothing, toys, diapers, car seats and swings.
- Practice situations that may require problem solving and memory when taking care of your child.
- Talk with your health care team and family to help decide how much supervision you will need to safely provide child care if needed.



Setting up the Environment

Taking the steps to make changes to your environment can greatly increase safety and independence with taking care of your child.

Furniture

Choosing the right furniture or modifying items you already have will make things easier.

- Changes to a crib may include raising the height, providing a side-opening rail, and changing the locking device.
- Practice reaching from different heights to make the right choices with baby furniture (i.e. a bassinette versus a pack and play).
- Consider different options for your positioning and placement of furniture while changing the baby's diaper (i.e. a desk you can roll under, couch, bed, or using your lap with the legs strapped together).
- If you have balance problems, get sturdier furniture that you can steady yourself on while caring for your child.
- You may want to have a chair nearby so you can sit while caring for your child.



Choosing equipment

As with furniture, using the right types of equipment makes a big difference. You can modify what you have or get special equipment to make things easier.

- Choose bottles, grooming items, clothing, etc. that match what you are able to do with your hands and your level of function. Your therapist can adapt many of these items.
- Items that you might find helpful when parenting from a wheelchair level include Boppy®, Moby® wrap, infant travel harness, use of wheelchair seat belt for toddlers, and clothing with easier fasteners such as zippers, Velcro® and overalls.
- If you have memory problems, keep a checklist of what equipment you need for different activities.

Safety

Childproofing your home is important for any parent. Persons with a spinal injury, brain cord injury or stroke may need to take extra time and preparation to provide safety for themselves and their children.

- Place gates near stairs to decrease the risk for falls.
- Place medicines and cleaning items out of reach unless you are able to manage safety locks on cabinets.
- Place protective padding on sharp corners, like coffee tables where babies, toddlers, parents and others with balance challenges could get hurt.
- Secure heavy items (like a television) to the stand and attach the stand or cabinet to the wall.



- Set water heater to 120° F or less to prevent someone from being burned.
- Use a different part of your body to test the temperature of milk or formula if you have loss of feeling. You can also use a thermometer to test the temperature.
- Select the changes that will allow you to manage your living space and keep your child safe.

Helping Children Understand Disabilities


Children do not always understand their feelings and are not always able to say what they need. You may see changes in their behavior after your disabling event. It is important that you help your child to understand their feelings and talk about their concerns.

These behavior changes may include:


- Being afraid to come near you, touch you, or be away from you
- Asking questions over and over again
- Increased “naughty” behavior
- Being demanding, especially of attention
- Acting immature for their age
- Bed-wetting
- Thumb-sucking
- New problems in school




Can you still take care of me?



Are you going to die?

Are you still my mommy/daddy?



Can you still do fun things with me?

They may really be asking:

Suggestions that may help your child’s behavior include:

- Continue to do fun things with your child
- Let your children know you love them
- Continue to be involved in family activities during your hospital stay and after you return home
- Include your children in your **rehabilitation** as much as possible
- Try to keep your child’s schedule as consistent as possible
- Encourage your child to ask questions
- Keep rules for behavior as consistent as possible

Can People with Disabilities Adopt?

Adoption is an option for becoming parents. Adoption agencies and programs can help you decide if it is the right choice for you. These programs can also inform you about legal procedures, and the different ways to adopt a child. An adoption agency cannot refuse to allow you to adopt a child because you have a disability. The adoption process can be difficult. You will need time, money, lots of energy, and patience to complete this process. Remember, your injury should not limit your options with adoption or the ability to be a parent.

NOTES

FINAL
THOUGHTS

Final Thoughts...

As you can see from this guide, people with a disability can find and keep relationships, enjoy healthy sex lives, and parent children. You may need to adapt your thoughts and techniques to match a new situation. However, our patients who have had time to adjust say that this is possible—especially if you keep an open mind and approach things as a manageable challenge. We hope this guide has answered many of your questions and has given you more confidence. You will probably have other questions as you go through this journey, so we encourage you to save the booklet as a reference and talk to your trusted medical team for support and information. **YOU CAN DO IT.**

NOTES

Glossary

A	Anus	The external opening of the digestive tract.
	Autonomic dysreflexia	A potentially life-threatening medical condition that many people with spinal cord injury (SCI) experience when there is a pain or discomfort below their level of injury, even if the pain or discomfort cannot be felt. It may cause the following symptoms: rise in blood pressure, pounding headache, sweating above the level of injury, slow pulse (although rare, a fast pulse can occur), goose bumps, skin redness or flushing, nasal congestion, chills without fever, blurred vision, restlessness, cold and clammy skin below the level of injury.
B	Bladder	An organ that collects and stores urine.
	Brain injury	Damage to the brain caused by and external physical force or due to prolonged lack of oxygen.
C	Cervical cap	A small, bowl-shaped latex or silicone cup that is inserted into the vagina and fits over the cervix. It is always used with spermicidal cream or gel.
	Contraceptive cream	A special cream inserted into the vagina. It stops sperm from reaching an egg. It is used to prevent pregnancy.
	Contraceptive foam	A special foam inserted into the vagina. It stops sperm from reaching an egg. It is used to prevent pregnancy.
	Contraceptive jelly	A special jelly inserted into the vagina. It stops sperm from reaching an egg. It is used to prevent pregnancy.
	Contraceptive sponge	A small, round birth control sponge made from soft, squishy plastic. It is placed deep inside the vagina before sex. It covers the cervix and contains spermicide (contraceptive cream, foam or jelly). It is used to prevent pregnancy.
	Contraceptive vaginal suppository	A special suppository inserted into the vagina. It stops sperm from reaching an egg. It is used to prevent pregnancy.
	Condom	A sheath-shaped barrier device, used during sexual intercourse to reduce the probability of pregnancy or a sexually transmitted infection.
D	Diaphragm muscle	The main muscle of breathing. It is found just underneath your lungs.
E	Ejaculate	The mechanism that allows semen to be discharged from a man's penis.
	Epididymis	An organ that holds sperm, as well as allows them to gain the ability to swim, while they mature. It connects the testicle to the vas deferens.
	Erection	The body's response to a man's desire for sex. This can happen through touching or by having sexual thoughts, sights, smells, or sounds that turn you on sexually.
I	Indwelling catheter	A small tube that goes through your urethra into the bladder. It drains urine from the body. (Also called a Foley catheter).
	Intermittent catheterization	A small tube, or catheter, is inserted into the bladder to drain urine from the bladder. It is removed when the urine has been drained.
	Intrauterine device (IUD)	A small birth control device that is inserted into a woman's uterus to prevent pregnancy. IUDs are one form of long-acting reversible birth control.
L	Lubrication	A naturally produced fluid that lubricates a woman's vagina. If there is not enough natural lubrication, sometimes artificial lubricants can be used.
M	Menstruation	The regular discharge of blood and mucosal tissue from the inner lining of the uterus through the vagina. It is also known as a "period".

N	Nerves	A cable-like bundle of fibers that let the brain and body talk to each other.
	Orgasm	The release of sexual tension after achieving a peak of sexual stimulation.
O	Over-the-counter medication	Medicines you can buy without a prescription from your doctor.
	Penis	A man's main sexual organ for masturbation or intercourse. It has 3 functions: urination, sexual activity and emission of semen.
P	Perineum	The space between the anus and the vaginal opening in the female.
	Prostate gland	A walnut shaped gland below the bladder. It releases fluid that helps make semen liquid as it comes out during ejaculation. The urethra passes through it.
	Rehabilitation	The process of doing away with, adapting to , or compensating for disabilities.
S	Scrotum	A sack that houses and protects the testes.
	Semen	A white-colored bodily fluid carries sperm. It is secreted from the seminal vesicles.
	Seminal vesicles	Glands that secrete fluid that makes up semen.
	Sexual activity	The way in which humans experience and express their sexuality. It can be expressed in many different ways.
	Spasms	A sudden, often uncontrolled, contraction of a muscle; a muscle jerk.
	Spinal cord injury	Any damage to the spinal cord that can lead to loss of movement and feeling. It can also affect how your brain controls your internal organs.
	Stereotypes	An over-generalized belief about a particular category of people.
	Stroke	A disease that affects the arteries leading to and within the brain. Part of the brain cannot get the blood (and oxygen) it needs, so it and brain cells die.
	Suprapubic catheter	A tube that drains urine from your bladder. It is inserted into your bladder through a small hole in your belly.
T	Testicles	Egg-shaped organs housed in the scrotum. They produce sperm and testosterone.
	Testosterone	The primary male sex hormone. Plays a key role in the development of male reproductive tissues such as the testis and prostate, as well as promoting secondary sexual characteristics such as increased muscle and bone mass, and the growth of body hair.
	Tubal ligation	A surgical procedure for sterilization, also called having "tubes tied". A woman's fallopian tubes are cut, which prevents pregnancy because the eggs cannot reach the uterus.
U	Urethra	A passageway that allows urine and sperm to exit the body.
	Urination	The penis allows urine to pass from the bladder out of the body.
V	Vacuum pumps	A device that produces an erection by creating a vacuum around the penis.
	Vas deferens	The tubes that transport sperm from the testicles to the urethra.
	Vasectomy	An operation that stops the man's sperm from being able to leave the testes. With no sperm entering the woman, she will not get pregnant.
	Vibrators	A device used for massage or sexual stimulation.

If you have any questions about any other terms, please ask your health care team.

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