

Living with Spinal Cord Injury

A Guide for the Newly Injured



**United Spinal
Association**

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Anyone seeking specific medical advice or highly technical questions should
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Table of Contents

The Nervous System and How it Works	6-9
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Your Rehabilitation

• In the Hospital	10
• Exercise	11
• Dealing with Spasticity	12
• Pressure Ulcers	13-14
• Burn Prevention	15
• Bowel Care	15
• Bladder Care	16
• Urinary Tract Infections	16
• Catheters	17
• Intermittent Catheterization	17
• Techniques of Intermittent Catheterization	17-18
• Male External Catheters	18
• Other Types of Catheters	19

Returning to Everyday Life

• Your Overall Health	20-21
• Your Emotions	22
• Sexuality & Intimacy	23
• Travel	24
• Driving	25

Closing Advice	26
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• Research about Spinal Cord Injury	27
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The most common causes of spinal cord injury:

Motor vehicle accidents

Falls

Acts of violence

Recreational sporting activities

If you have a new spinal cord injury, or you are close to someone who does, you may have many questions and concerns. You might be wondering how this injury will change your life and how you can begin to adjust to these changes.

It's important to know you are NOT alone. Each year in the United States there are about 17,700 people who sustain spinal cord injuries. The number of people living with spinal cord injury in the United States is thought to be roughly 284,000 (National Spinal Cord Injury Statistical Center, 2018).

This book is designed to help answer some common questions, as well as provide insight and encouragement from people who have experienced spinal cord injury. The message is one of understanding and hope. When you are ready to learn more, please read on.

This book is possible because many people took time to share their stories and provide insight about adapting to life with a spinal cord injury. We appreciate their contributions, candor, and expertise.

Nick- Nick has been living with T10 paraplegia for 18 years.

Bill- Bill has been living with T 7 paraplegia for 15 years.

Daniela- Daniela has been living with C4-5 tetraplegia for 18 years.

Ian- Ian has been living with C5 tetraplegia for 17 years.

John- John has been living with C3 quadriplegia for 18 months



The Nervous System and How it Works

In order to understand your injury, it helps to first review the way a healthy nervous system functions. The critical components of the nervous system are the brain, the spinal cord, and the nerves. These parts communicate with each other and work together to help you move your body, feel pressure, and control body functions like breathing, bowels, bladder, and blood pressure. Figure 1 on page 8 shows the vertebral column, the bony structure that surrounds and protects your spinal cord, and the different sections of the spinal cord.



“Rehab was tough, and it introduced me to a whole new world I had never imagined, but it felt ‘safe’ and structured. Returning home was exciting, yet frightening at the same time. Time turned out to be the ‘great healer’ though as things DO get better once you are home a while.”

Bill, living with T-7 paraplegia 15 years

Paraplegia

Paralysis affecting the legs and lower part of the body. Usually occurs as a result of injuries at T2 or below.

Tetraplegia

Paralysis affecting levels below the neck involving both the arms and legs. Usually occurs as a result of injuries at T1 or above.

The Spinal Cord

The spinal cord is the largest nerve in the body. It is about 18 inches, and extends from the base of the brain down the middle of the back to the waist. Nerves are cord-like structures made up of nerve fibers. Nerve fibers are responsible for the communication of impulses to muscles and organs throughout the body. Spinal nerves branch from the left and right sides of the spinal cord, at each level of the spine. The spinal nerves deliver sensory information (feeling) to the brain and motor (movement) signals from the brain to the muscles.



“In my experience, the public does one of two things. Either they try their hardest to pretend you’re not there or they’re very helpful. I’ve found that smiling and saying “hi” puts people at ease and makes them realize that you’re no different than them.”

John, living with C3 quadriplegia for 18 months.

When the spinal cord is injured, the nervous system can’t communicate properly. The nerves above the injury work fine, but the ones at and below the injury can’t receive or send messages properly. Sometimes all the messages stop, so there is no movement or sensation (feeling) below the level of the injury.

Figure 2 (page 8) depicts the innervation of major muscle groups by spinal segment. Figure 3 (page 9) depicts the level of sensation by spinal segment. A complete injury means there is no sensory or motor function preserved in S4-S5. In this case there is no feeling in the anal area and no ability to voluntarily contract the anus. If the injury is incomplete, some sensory and/or motor function is still present in or through S4-S5. Your healthcare provider will do physical examinations to find out whether your injury is complete or incomplete. You will be tested several times in both inpatient and outpatient settings because the completeness of your injury may change over time.

As the body grows, the vertebral column grows more in length than the spinal cord. Because of this, there is often a discrepancy between the skeletal level of vertebral fracture and the neurologic level of spinal cord injury. The neurological level of injury refers to the lowest level of the spinal cord that still has normal sensory and motor function after injury.

The Nervous System and How it Works *(Cont'd)*

Figure 1: Spinal Anatomy

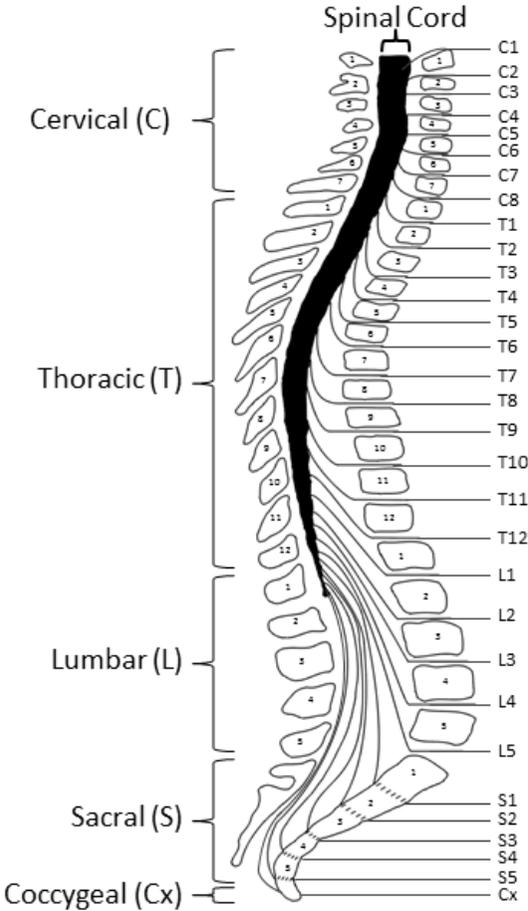
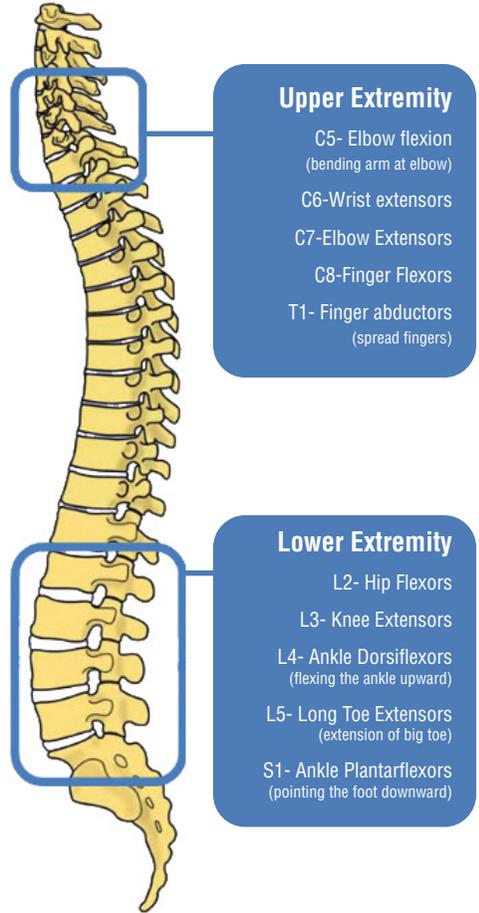


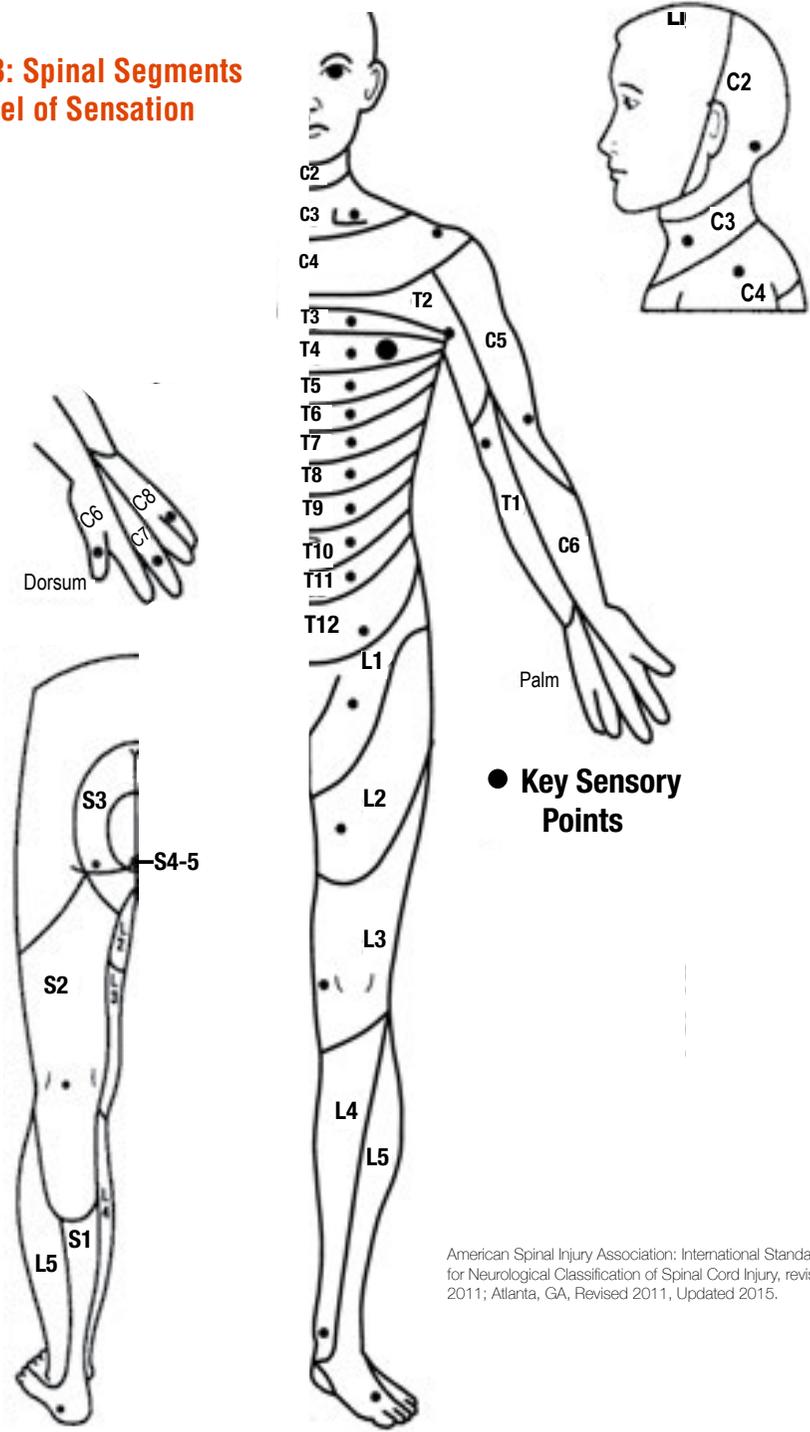
Figure 2: Key Muscles and Spinal Cord Level of Innervation



Model Systems Knowledge Translation Center Factsheet, 2015. Understanding Spinal Cord Injury: Part 1 - The Body Before and After Injury. Used with permission.

From International Standards Training e-Learning Program (InStEP), American Spinal Injury Association, 2016, Richmond, VA. Adapted with permission.

Figure 3: Spinal Segments and Level of Sensation



American Spinal Injury Association: International Standards for Neurological Classification of Spinal Cord Injury, revised 2011; Atlanta, GA, Revised 2011, Updated 2015.

Your Rehabilitation



In the Hospital

The first days following a spinal cord injury are filled with physical examinations and diagnostic tests. Medications may be given to reduce the inflammation of the spinal cord, and to prevent blood clots. Health monitoring in an intensive care unit for a period of time is not unusual. The X-rays and scans help the doctors determine the level of injury and whether damage was sustained to any other part of the body. If the vertebral column is fractured or compressing the spinal cord, surgery may be required to stabilize it or a brace may be necessary.

“After nearly four months in the hospital I was ready to go home. I couldn’t wait for a night without alarms and flashing lights. Surround yourself with those who are positive and care for you. Remember what you learned in rehab and apply it, trust yourself and apply your knowledge.”

John, living with C3 quadriplegia for 18 months.

The higher and more extensive the injury, the more equipment and assistive devices will be needed for daily living. The injury level will also dictate whether a power or manual wheelchair is needed. Help with daily living activities (bowel and bladder care, positioning, transfers, dressing, and bathing) may also be necessary.

A team of healthcare providers will be involved during hospitalization and rehabilitation to maximize learning how to manage a spinal cord injury.



Exercise

Exercise is essential for good cardiovascular health. Exercise will help you maintain your physical strength and help make daily living activities easier. Exercise provides other benefits as well, including increased flexibility, improved muscle tone, increased stamina and energy, and stress management.

“Exercise has helped me to remain fit and allows me to release stress. There are many different types of exercises that can be done by people with SCI/D; the trick is finding the ones that make you feel like you are really getting the benefit from that particular exercise.”

Nick, living with T 10 paraplegia 18 years

Initially, your exercise program will be designed to increase your strength so you can accomplish a number of new activities like pushing a wheelchair, transferring your body, and moving in bed. Learning the proper technique to perform these activities is important to help maintain your safety. You will have a program tailored to your specific needs.

Many of the people who have spinal cord injuries continue to enjoy athletics and team sports. If you enjoyed participating in sports or exercise before your injury, you may wish to continue.



Here are some management options for spasms:

- Identify and eliminate the possible cause such as a pressure ulcer or a bladder infection
- Stretch and work out your muscles, exercise and apply pressure to the limb when it spasms, if appropriate
- Medications
- Nerve blocks
- Surgery and interventions such as infusion pumps.

If spasms occur, be sure to discuss the available treatments with your healthcare team.

Dealing with Spasticity

Spasticity is a sudden involuntary contraction of muscles. Many people with spinal cord injuries or certain diseases (such as multiple sclerosis) have problems with uncontrolled spasms of their arms or legs. A certain amount of spasms can be good because they help to maintain muscle tone and to increase blood circulation to the legs. However, too many spasms can be painful and make daily living activities difficult for you and your caregiver.

Pain

Following your injury it is not unusual to experience pain. Two common types of pain are neuropathic and musculoskeletal. Neuropathic pain is often described as burning, pins and needles, electric or cold sensation, and it is felt at or below the level of your injury. Musculoskeletal pain is often in the back, shoulders or wrists, and is usually the result of physical stress and exertion from lifting, moving, and exercising. While often normal, pain symptoms may be an indicator of an injury or infection. If you are experiencing pain you should consult with your healthcare professional for diagnosis and treatment.

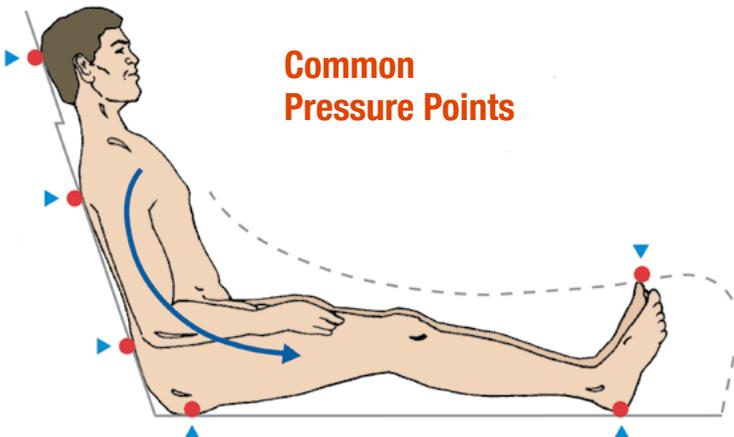
Pressure Injuries

After a spinal cord injury, you are at risk for developing pressure ulcers. A pressure ulcer is any wound due to unrelieved pressure in a particular area. A pressure ulcer results in damage to underlying tissue. Other names for pressure ulcers are bedsores, pressure injuries, and decubitus ulcers.

Following spinal cord injury, you are supporting your weight differently than you did before and you may not feel the need to shift your weight due to decreased sensation. This change puts your skin and the underlying tissue at risk for injury. Dragging your body across a flat or inclined surface, or allowing your skin to be wet for prolonged periods of time can also increase the risk of pressure ulcers.

One of the first signs of a problem may be a red spot, an area of hardness, or discoloration on an area of your skin that supports your body weight. Check your pressure points at least twice a day, or have someone else do this for you.

Your healthcare team will help you obtain a wheelchair cushion and other equipment which can help reduce your risk. You will also learn how to do pressure releases, or have someone else help you do them. Pressure releases take all the pressure off for a short period of time and should be done at least every twenty minutes when you are in your chair. It is essential that you maintain your wheelchair cushion in good condition and replace it when necessary.



Your Rehabilitation *(Cont'd)*



Pressure Injury Prevention Tips

- Do pressure releases every 15 to 20 minutes
- Check your skin twice a day using a mirror
- Change your position in bed and in the chair frequently
- Learn transfer techniques to avoid dragging your skin across surfaces
- Be careful to avoid bumping and scraping
- Keep your skin conditioned and clean, and do not expose your skin to urine and stool
- Avoid prolonged sitting on wet clothes or moist surfaces
- Eat a nutritious diet and drink adequate fluids
- Properly maintain and check your cushions
- Maintain a healthy weight; avoid poor nutrition, or becoming underweight or overweight
- Wear shoes that are one size larger than you wore prior to your injury. This will help prevent blisters and pressure on your feet and toes
- Don't massage reddened areas. Do not use heat lamps or try to dry out pressure ulcers

If you think you're developing a pressure ulcer, contact your healthcare provider and stay off the area. Pressure ulcers are treated differently than other types of injuries or skin problems. An examination will help determine how much damage there is, and whether infection is present. You may need to restrict your activity and use special bandages that will help protect the area while it heals. In severe cases, surgery, hospitalization, medications, and skin grafts may be needed.

Burn Prevention

Because there are now areas of your body without sensation, you need to be aware of how your body is positioned, and carefully watch what it comes into contact with. Many people with spinal cord injuries have burned themselves severely on hot grills, heating pads, spilled coffee, dropped cigarettes, and in the tub or shower, because they did not feel the temperature against their skin. Even the floor board of a car or the cement around a pool can become very hot, causing severe burns to your feet or legs without you noticing. Check your skin often and be aware of hot or extremely cold surfaces. Extremes in temperature can produce deep skin damage that can take months to heal and puts you at risk for severe infection.

Things to consider for bowel care

- Think about your bowel program.
- Follow your bowel routine every day.
- Eat a balanced diet that includes fruit and vegetables, and drink plenty of fluids each day. This helps prevent constipation.
- Take medications as directed.
- Completely empty your bowels before leaving the toilet.

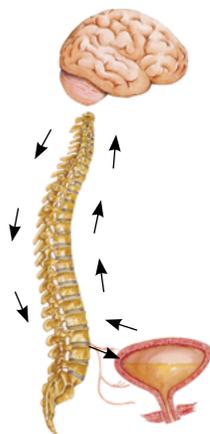
Bowel Care

After spinal cord injury, your bowels may function differently. During rehabilitation you will learn a bowel program which will involve proper diet, exercise, medication, and regularly scheduled bowel care. The goal of the program is to maintain health by having regular bowel movements and avoid having bowel accidents.

If you are experiencing bowel difficulties consult your healthcare professional as you may need to change the routine you are following.

Your Rehabilitation *(Cont'd)*

The process of urination requires undisturbed communication between the bladder and the brain.



Bladder Care

Spinal cord injury can cause changes in the way your bladder works. Your bladder may empty too frequently, not frequently enough, or in an uncoordinated way. Your urinary sphincters may also work incorrectly. The way your bladder and sphincters behave depends on the location and extent of your injury.

You may have a neurogenic bladder, which typically does not empty by itself. The type of treatments most often used for neurogenic bladder problems include intermittent catheterization, male external catheters, and medications.

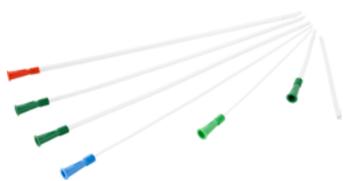
Urinary Tract Infections

If you have a neurogenic bladder disorder you may have occasional or frequent urinary tract infections (UTIs). These can occur when there is an increased amount of bacteria (or other microorganisms) in the tissues of the bladder, urethra, or kidneys. It is important to contact your healthcare provider at the first sign of a urinary tract infection. Not everyone develops these symptoms. If you are not feeling well or you suspect you have an infection, contact your healthcare provider. Your urine will be tested and medications will be prescribed if an infection is present. Be sure to take all the antibiotic prescribed, and to contact your healthcare provider if your symptoms return. If you experience frequent urinary tract infections, your healthcare provider may recommend additional tests or treatments.

You may experience these signs if you have a urinary tract infection:

- More frequent urination or need to catheterize more than normal
- Leakage of urine between normal voiding or catheterization
- Increased muscle spasms
- Fever
- Back pain
- Milky, cloudy, or darkly colored urine
- Foul smelling urine

Catheters



A catheter is a small hollow tube which is inserted into the bladder to drain urine when the bladder can't empty on its own. If the catheter is intended to stay in the bladder for hours, days, or longer, it is called an indwelling catheter. If the catheter is inserted to drain the bladder, and then removed, it is called an intermittent catheter.

Intermittent Catheterization

Intermittent catheterization is a way to empty the bladder completely. People who use intermittent catheterization as a method of emptying their bladder are taught by a professional to catheterize on regular intervals to prevent bladder overdistention. For some, this may require inserting a catheter four to six times each day. Supplies may be carried discreetly in a pocket or bag. To learn the procedure, you must learn where the catheter is inserted and how to use the product. You must also be able to reach your urethra (at the tip of the penis for men and in front of the vagina for women) and manipulate the catheter. You can drain the urine through the catheter and into the toilet or receptacle such as a urinal, or drain the urine into a disposable bag. Women can't always see their urethra and may learn to do the procedure by touch or by using a mirror. People of all ages can learn intermittent catheterization. The procedure can also be performed by a trained caregiver or family member if you are unable to perform the procedure yourself.

There are two main techniques of intermittent catheterization

- Clean technique
- Sterile technique

Your healthcare professional will help you choose the most appropriate method for you. It's important, regardless of the technique you use, to be fully trained by a healthcare professional.

The Mitrofanoff procedure can simplify the catheterization process for individuals who have difficulty accessing their urethra by eliminating the need to transfer from the wheelchair or undress. The Mitrofanoff Procedure (Mitrofanoff appendicovesicostomy) is a surgical procedure where the appendix or a piece of the small intestine is used to create a channel between an opening in the skin on the abdomen (called a stoma) and the bladder. The individual can then complete intermittent catheterization by inserting the catheter into the stoma.

Your Rehabilitation *(Cont'd)*



Intermittent catheterization can be done using two main methods. Your healthcare professional will help you choose the most appropriate method for you.

Clean Technique

Clean technique is performed using a single-use sterile catheter, good hand washing and soap and water cleansing of the urethral area with daily hygiene. Additional cleansing may be required if the area has been contaminated in some way, especially with stool.

Sterile Technique

Sterile technique is performed using a method that does not allow the hands to directly touch the catheter before or during catheterization. Hands are washed and the genital area is cleaned. Sterile gloves are used if using a standard straight catheter. Sterile technique may also be performed using a closed or “no touch” catheter system. Sterile “No Touch” hydrophilic catheters may have a protective tip and sleeve which helps provide the user with an easy to use catheter that also offers protection against contamination. Most offer an integrated collection bag to collect urine.



Male External Catheters

Men who have urine leakage from the penis may benefit from the use of a male external catheter. This device is like a condom, applied to the shaft of the penis. The male external catheter is worn discreetly under the clothing and connected to a leg bag or a bedside drainage collector.



Drainage Bag



Leg Bag

Other Types of Catheters

If you are unable to insert and remove a catheter to drain your bladder, you may need to use an indwelling catheter. This type of catheter is held in the bladder by an inflatable balloon and provides continuous drainage. Complications of indwelling catheters may include urinary tract infections, urethral injury, bladder stones, and/or blood in the urine (hematuria)*. Long-term indwelling catheters are replaced once a month or as recommended by your healthcare professional.

A suprapubic catheter is an alternative for individuals who have difficulty managing intermittent catheterization, such as those with paralysis of the arms or those for whom a urethral indwelling catheter is not an option. A suprapubic catheter is an indwelling catheter placed directly into the bladder through the skin above the pubic bone. This catheter must be placed by a urologist during outpatient surgery or an office procedure.

With indwelling catheters, a drainage bag is required. There are two main types of drainage bags. One type is a leg bag that attaches by straps to the leg. A leg bag is usually worn during the day since it fits discreetly under pants or skirts, and is easily emptied into the toilet. The other type of drainage bag is larger. It may be used during the night and is usually hung on the bed.

*Citation:

Hollingsworth JM, Rogers MA, Krein SL, et al. Determining the noninfectious complications of indwelling urethral catheters: a systematic review and meta-analysis. *Ann Intern Med.* 2013;159:401-410.

Returning to Everyday Life

Your rehabilitation will involve learning new skills. You will need equipment, such as a wheelchair, transfer tub bench, or shower chair. You may even need special equipment for bowel and bladder management. A very important part of your recovery involves setting goals to work toward. While each person's goals are different, the overall plan is to move toward resuming your life and getting back as best you can to the routines and activities you enjoyed prior to your injury.

Your Overall Health

It is important to maintain your general health in addition to managing your spinal cord injury. The type of examinations and tests needed vary according to your age, sex, and health history. A complete medical check-up and influenza (flu) vaccine is recommended once a year. Visit your urologist annually. Urodynamic tests (special studies of your bladder) may be recommended.

Some research has shown that spinal cord injury may be associated with an increased risk of heart disease and stroke. Maintaining normal body weight, regular exercise, healthy eating and not smoking are important aspects of maintaining your overall health.



There are certain medical complications that occur more commonly after spinal cord injury; some are listed below. Learn about these risks, and discuss ways of preventing them with your healthcare provider.

Fractures	Broken Bones
Osteopenia/ Osteoporosis	Chronic bone disease involving low bone mass and deterioration of bone; it can raise your risk of fractures.
Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)	Blood clots that form in a vein deep in the body can cause leg pain, swelling, and redness. If a clot travels through your bloodstream, it can lodge in your lung. This is called a pulmonary embolism, or PE. A PE is a medical emergency.
Orthostatic Hypotension	Sudden low blood pressure that occurs with position changes. It may cause fainting, profuse sweating, and a rapid heart rate.
Autonomic Dysreflexia (AD)	A risk for people with SCI level T6 and above. This is a medical emergency. Your blood pressure rises significantly, you may get a pounding headache, a slow heart rate, profuse sweating, goose bumps, flushed skin, blurred vision, and anxiety.
Septicemia	An infection that enters the bloodstream. Symptoms can include fever and chills, confusion, nausea and vomiting, increased heart rate, and low blood pressure.
Pneumonia	Infection involving the lungs. This can be caused by bacteria, viruses, or other organisms. Symptoms may include fever, cough, weakness, and shortness of breath.
Bladder and Kidney Stones	A solid piece of material that forms from substances in the urine. A stone can stay in the kidney or travel down in the urinary tract. Stones can block the flow of urine, increase infection risk, and cause pain.

Returning to Everyday Life *(Cont'd)*

Your Emotions

It is normal to experience a variety of emotions following spinal cord injury. Your adjustment will undoubtedly take time and patience. How quickly you adapt to the changes in your body will vary, and your friends and family members may also adjust at very different rates. Many people experience a period of mourning similar to the death of a loved one. Others have difficulty believing that the injury is permanent, and treat the recovery period as a temporary inconvenience. You may also experience depression and anger. The way you respond to your injury will be highly variable and your emotional adjustment may take a number of months. Some of the ways to help yourself through this time include:



“Adjusting to using a wheelchair was difficult but when I realized how much I was truly able to do I started to build on the positives.”

Nick, living with T 10 paraplegia 18 years

- Confide in a friend, loved one, or healthcare provider about your thoughts and feelings
- Keep a journal of your challenges and successes, and how you feel about your journey
- Speak with other people with spinal cord injuries to share ideas and experiences. Your rehab team can help you meet other individuals in your community
- Set realistic goals and celebrate reaching them
- Avoid using alcohol, drugs, or smoking as a way to reduce stress and anxiety

If you are having trouble adjusting, you should talk to your healthcare professional. Professional psychotherapy can provide the assistance you need to get back to an active, fulfilling lifestyle.



Sexuality and Intimacy

Most people with spinal cord injury are interested in sex, so you will be happy to know you can still have a healthy sex life and fulfilling relationships. Sexual desire continues after spinal cord injury and the need to love and be loved does not change.

The mechanics of having sex will be different than prior to your injury. You may have to experiment with different activities and body positions. You may need to reassure your partner that you won't be injured by sexual activity, and you may also need to teach him or her about what feels good and where you can feel their touch.

Women with spinal cord injury have menstrual periods, and can still become pregnant. Vaginal deliveries are possible, and while these pregnancies are usually managed at a high-risk birth center, they most often result in healthy deliveries. Some men with spinal cord injury can obtain and maintain erections, while others need to use medications, devices, or other options to obtain this. Retrograde ejaculation (semen enters the bladder instead of going through the urethra) is a frequent consequence of spinal cord injury in men, and this can decrease the possibility of fathering a child. In addition, the motility of sperm often decreases in men with spinal cord injury. As a result of these changes, some men opt for sperm retrieval methods to increase the likelihood of fertilization.

Remember, the risk of getting a sexually transmitted disease is the same as it was before your injury. Safe sex practices include the use of condoms during intercourse, limiting the number of sexual partners, and using effective birth control methods.

Returning to Everyday Life *(Cont'd)*



Travel

It is possible to travel throughout the world after a spinal cord injury. It takes a bit more planning, however. Contact your airline carrier for special accommodations (i.e., ask for assistance to board the plane if needed, request a larger baggage allowance). You should also familiarize yourself with the policies of your airline. Alert hotels about your needs before your arrival and request any equipment you will need (i.e., tub bench, roll-in shower, etc.) Even cruise lines must provide accessible rooms. Be very specific about what you need when making reservations.

Research your travel destination to prevent surprises with regard to physical barriers. Be sure to carry your medications and supplies for catheterization and other self-care routines in your carry-on luggage. Get as much rest as possible, maintain your usual care routines, and drink plenty of fluids. Drink bottled water if the tap water quality is questionable.



Driving

Bill has regained independence through driving. He focused on choosing the right kind of vehicle, outfitting it properly, and finding the most effective method of transferring to the vehicle from his chair.



Closing Advice



“Design the spaces you live and work in so as to maximize your productivity and your comfort level. Doesn’t matter what others think, it’s your space and it needs to work for you.”

Ian, living with C-5 injury
17 years

Coping with a spinal cord injury is very challenging. You may feel physically and emotionally exhausted. It’s hard to remember all of the information being given to you, and you may find it difficult to acquire new skills as quickly as you would like.

Here are some helpful tips from people who have been through similar situations with spinal cord injury:

- Ask questions! Write down your questions, and write the answers also.
- Be patient with yourself and with those around you. It will take time for you to feel comfortable and adjusted to the changes created by your injury
- Set small goals each day. Celebrate reaching those goals
- Find someone you can truly connect with; someone who can support you emotionally. This might be a nurse or doctor, a friend or family member, or a member of a support group
- Be proactive. Ask for what you need and learn about the ways you can adapt to your injury





Research About Spinal Cord Injury

A cure for spinal cord injury does not currently exist. Research is ongoing in many areas of treatment and adjustment, including such topics as medications, surgery, nerve cell transplantation, and almost every aspect of health and spinal cord injury. You can learn more about some of the results of recent studies by talking with your healthcare team and visiting websites such as those listed here. If you are interested in participating in studies, there are many opportunities; the choice is yours.

“Learning to ask for help was one of the hardest things I had to learn. Pre-injury, I rarely asked for help. Now I need help with nearly everything. I found most people are willing to help they just need guidance on how to help you. Always remember please and thank you.”

John, living with C3 quadriplegia for 18 months

Information about Spinal Cord Injury Research:

Miami Project - www.miamiproject.miami.edu or 1.800.STANDUP

Wings for Life – Spinal Cord Research Foundation, wingsforlife.com

Shepherd Center Research: Brain and Spine Medical Research: www.shepherd.org/research

United Spinal Association: <https://www.unitedspinal.org/ask-us/>

Support and Information Networks

The following are some support and information networks to assist you in answering your questions.

**Christopher and Dana Reeve
Foundation**

www.ccrpf.org
1.800.225.0292

**National Spinal Cord Injury
Statistical Center**

<https://www.nscisc.uab.edu/>

Paralyzed Veterans of America

www.pva.org
1.800.232.1782

**Spinal Cord Injury
Information Network**

www.spinalcord.uab.edu
1.205.934.3283

United Spinal Association

www.unitedspinal.org
800-962-9629

Wheel:Life

www.wheel-life.org

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