

Spinal Cord Injury Rehabilitation

Patient and Family Guide



Introduction

You are receiving this book because you have experienced a spinal cord injury (SCI) and qualify for inpatient rehabilitation in the WakeMed Rehabilitation Hospital or outpatient rehabilitation in one of WakeMed's outpatient rehab facilities. This is part of WakeMed's system of care for spinal cord injury. This book includes basic information about spinal cord injury, what to expect during the rehabilitation process with the WakeMed Rehabilitation team, and how you can help yourself throughout the healing process.

Follow the treatment team's recommendations to remain hopeful and positive throughout this journey of recovery. Learn all you can about your needs to help you improve your function.

Spinal cord injury has a dramatic impact on both patients and their family members. Please know that your treatment team members are happy to answer your questions, address your concerns and offer resources to help you and your family cope with the fear, stress and emotional exhaustion that a medical crisis can cause. We are here for you!

This resource is intended to provide a basic summary of the important topics regarding spinal cord injury recovery. You will also receive more educational materials that provide more detailed information on each of these topics based on your needs and circumstances.

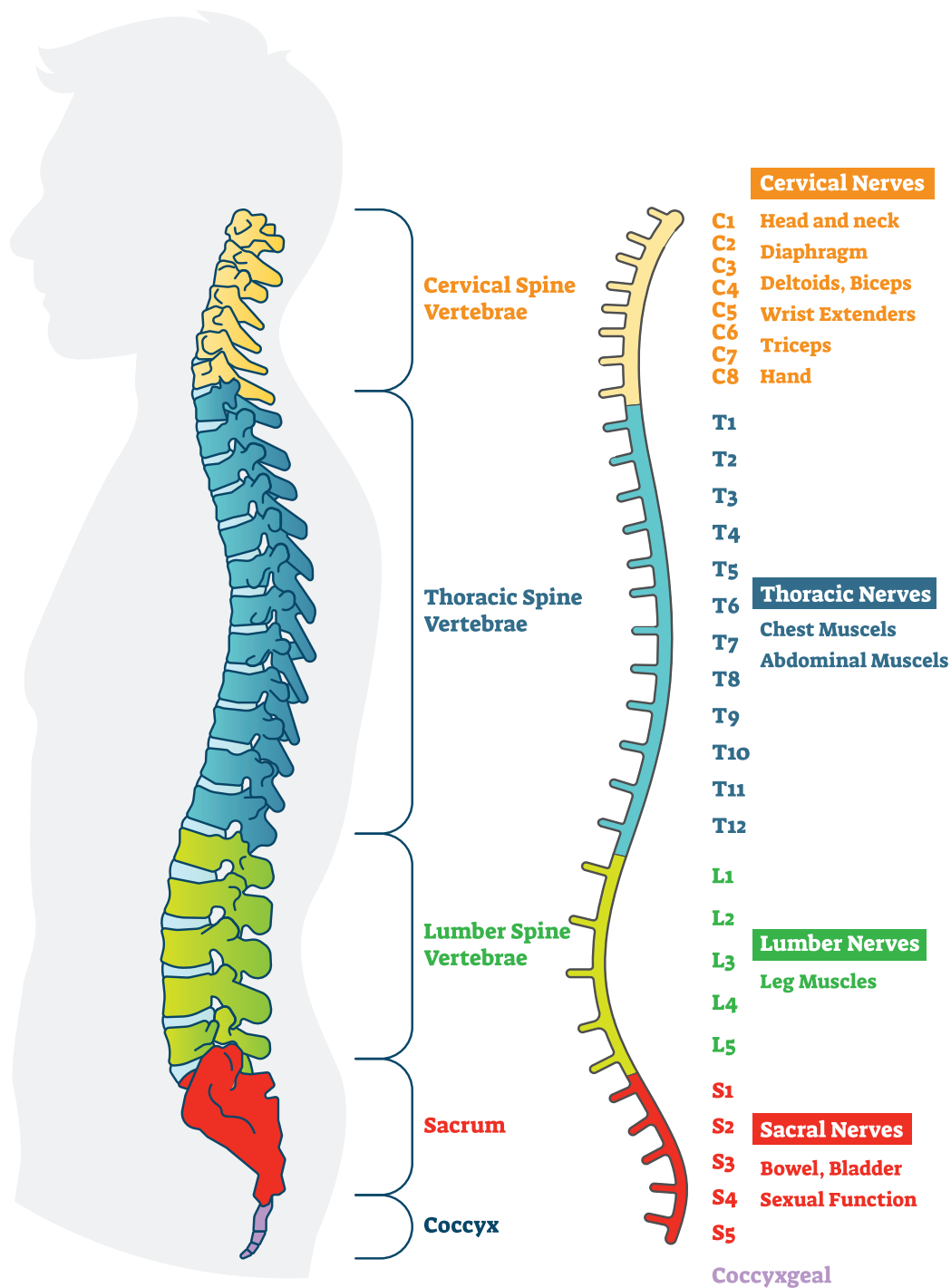
What is a Spinal Cord Injury?

A spinal cord injury (SCI) is damage to the spinal cord. The spinal cord is a soft bundle of nerves that extends from the base of the brain to the lower back. It runs throughout the spinal canal, a tunnel formed by holes in the bones of the spine (vertebrae). The bony spine helps protect the spinal cord.

The spinal cord carries messages between the brain and the rest of the body. These messages allow you to move and to feel touch, among other things. A spinal cord injury stops the flow of messages below the site of the injury. The closer the injury is to the brain, the more the body is affected. Each injury is different, and injuries can affect the body in many different ways.

What causes spinal cord injury?

A spinal cord injury usually happens because of a sudden, severe blow to the spine. Often this is the result of a car accident, fall, gunshot, or sports accident. Sometimes the spinal cord is damaged by infection or narrowing of the spinal canal (spinal stenosis), and some people are paralyzed from the time of birth because of birth defects.



In most injuries, the backbone pinches the spinal cord and it becomes bruised or swollen. Injury to the spinal cord greatly affects the messages that are sent by the nerves between the brain and other parts of the body.

After an SCI, most nerves above the level of injury keep working the way they always have. Below the level of injury, however, the spinal cord nerves can no longer send messages between the brain and parts of the body the way they did before. This is what causes paralysis and numbness that a person with spinal cord injury may experience.

Classification of Spinal Cord Injuries

Spinal cord injuries can be classified based on the function (how much feeling and movement you have) or on where the damage occurred. When a nerve in the spinal cord is injured, the nerve location and number are often used to describe how much damage there is. For example, a C7 injury is associated with the seventh cervical nerve of the neck and its effect on the feeling and movement. C7 is known as the functional level of injury. These classifications are often used by people who have an SCI to describe their injury and capabilities.

The spinal cord is surrounded by protective rings of bone called vertebrae. The vertebrae and spinal nerves are organized into segments, starting at the top of the spinal cord. Within each segment, the vertebrae and nerves are numbered. The segments are as follows:

Cervical – The neck area contains 7 cervical vertebrae (labeled as C1-C7) and 8 cervical nerves (C1-C8). Cervical SCI usually causes loss of function in the chest, arms and legs. Cervical injuries can also affect breathing and bowel and bladder control.

Thoracic – The chest area contains 12 thoracic vertebrae (labeled as T1-T12) and 12 thoracic nerves (T1-T12). The first thoracic vertebra, T1, is the vertebra where the top rib attaches to the spine. Thoracic SCI usually affects the chest and the legs. Injuries to the upper thoracic area can also affect breathing. Thoracic injuries can also affect bowel and bladder control.

Lumbar – The lumbar area (between the chest area and the pelvis) contains 5 lumbar vertebrae (labeled as L1-L5) and 5 lumbar nerves (L1-L5). Lumbar SCI usually affects the hips and legs. Lumbar injuries can also affect bowel and bladder control.

Sacral – The sacral area (from the pelvis to the end of the spine) contains 5 sacral vertebrae (labeled as S1-S5) and 5 sacral nerves (S1-S5). Sacral SCIs also usually affect the hips and legs. Injuries to the upper sacral area can affect bowel and bladder control.

The higher the damage occurs in the spinal cord, the more of the body is affected. When the spinal cord is damaged, messages cannot “jump over” the damaged area. This means that messages sent from the brain cannot make it to the body parts below the damaged area, and vice versa. Thus, the body’s functions at and below the level of injury are affected.

You may also hear the following terms related to spinal cord injuries:

Quadriplegia (or Tetraplegia) – This term is used for injuries of the cervical (neck) region affecting function of arms, trunk and legs. These injuries may also affect your bowel, bladder and sexual function.

Paraplegia – This term is used for injuries of the thoracic, lumbar or sacral regions affecting function of the trunk and legs. These injuries may also affect bowel, bladder and sexual function.

Spinal cord injuries can also be described as complete or incomplete injuries. An incomplete injury is further classified into four different types or classifications. The American Spinal Injury Association (ASIA) classifies spinal cord injuries as follows:

CLASSIFICATION	DESCRIPTION
A	Complete: No feeling or movement of the areas of your body that are controlled by your lowest sacral nerves. This means you do not have feeling around the anus or control of the muscle that closes the anus. People with complete SCI do not have control of bowel and bladder function.
B	Incomplete: Feeling but no movement below the level of injury including the lowest sacral segments that control bowel and bladder function.
C	Incomplete: Feeling and movement below the level of injury. More than half of key muscles can move, but without the full strength needed to lift up from a surface.
D	Incomplete: Feeling and movement below the level of injury. More than half of key muscles can move with enough strength to lift up from a surface.
E	Feeling and movement are normal.

Important Things to Know

Spinal cord injury comes with a variety of unique issues that you need to be aware of to stay healthy. These are described in more detail in the next several pages and include both preventative/ health maintenance information and complications that may arise.

HEALTH MAINTENANCE	COMPLICATIONS TO BE AWARE OF
Bowel and Bladder	Be consistent with a program to avoid accidents.
Autonomic Dysreflexia	Know the signs! This is a medical emergency!
Skin	Change position frequently (both in bed and in a wheelchair) and check skin daily.
Pressure Sores	Know the signs! Tell your rehab team, stay off of the area to help it heal.
Pain	Know the different types and talk to your doctor.
Postural Hypotension	Move into positions slowly and build up your tolerance, stay hydrated!
Lungs/Breathing	Do breathing exercises; posture is key!
Pneumonia	Know the signs! Contact your doctor immediately!
Nutrition	Eat a balanced diet , nutrition can help prevent complications and keep you healthy.
Spasticity	Stretch daily , talk to your doctor about changes as this could be a sign of other issues.

Special Considerations with Spinal Cord Injury

Skin Care

When you have a spinal cord injury, the nerves that normally signal discomfort and alert you to relieve pressure by changing position may no longer work. This leads to a higher likelihood of the skin and tissues under the skin breaking down and becoming damaged, which is known as a pressure injury. Skin requires blood flow to survive and pressure decreases the amount of blood flow to the skin, causing tissue to die. Pressure injuries often develop on skin that covers bony areas, such as the hips, heels or tailbone, and are the result of staying in a position too long without shifting weight, not enough padding, or clothing or shoes that fit too tightly. Pressure injuries are described in four stages that range from mild reddening of the skin to severe wounds with complications, including infection of the bone or blood. They can be hard to treat and slow to heal. Skin breakdown can also be caused by friction, shearing, irritation or trauma.

What do I need to know?

- Individuals with SCI are at high risk for developing pressure sores and skin breakdown.
- Pressure sores are life-threatening.

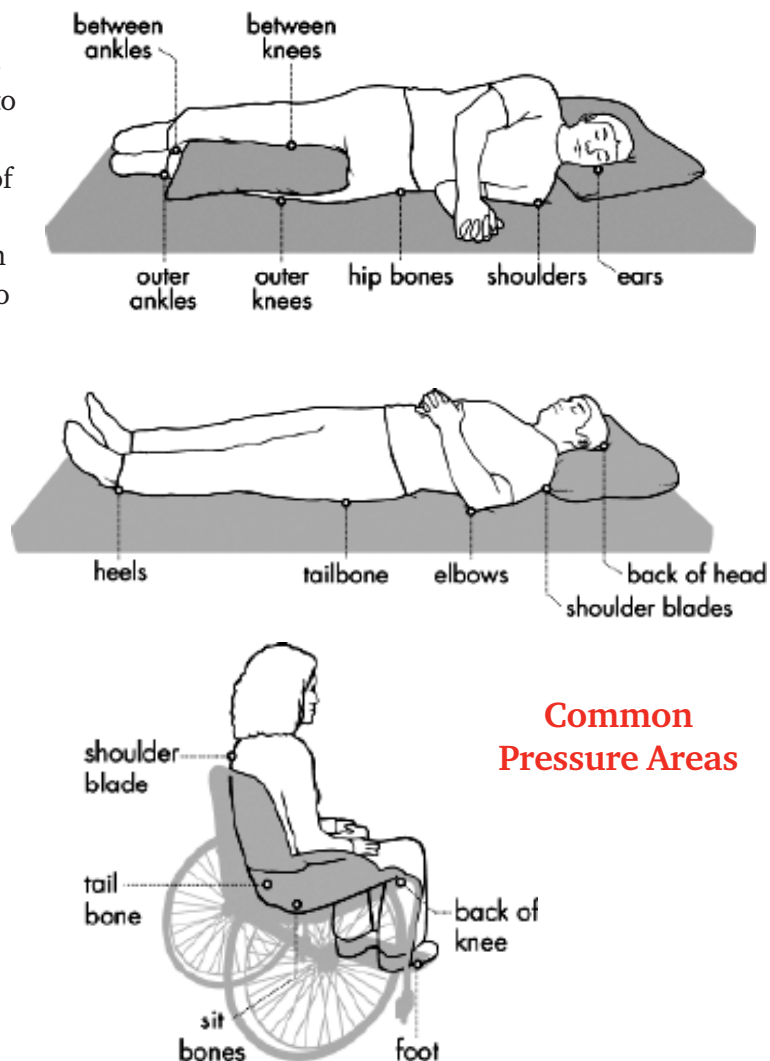
How can pressure injuries and skin breakdown be prevented?

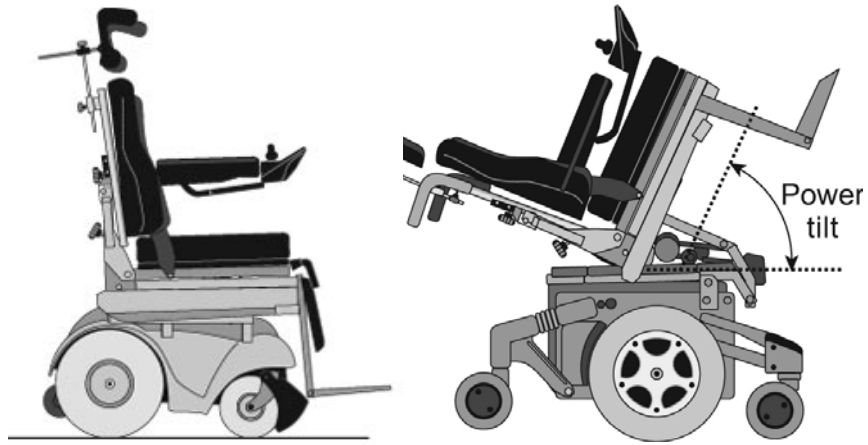
- 95% of pressure injuries are preventable.
- Relieve pressure on the skin often.
- Check your skin daily.

Relieving and spreading out pressure is the most important part of both preventing and treating pressure injuries. Pressure can be relieved and spread in several ways. Often a combination of methods is best.

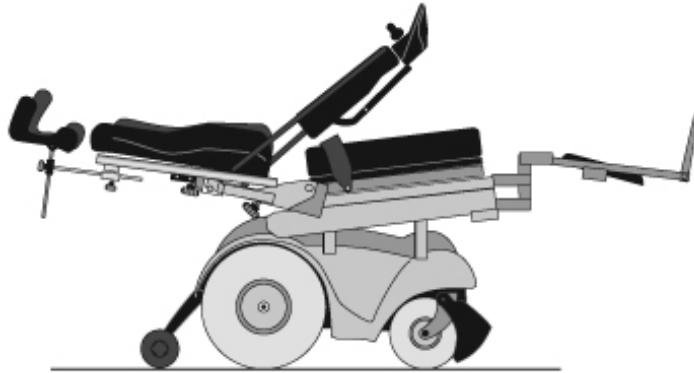
To relieve and spread pressure

- Change positions at least every 2 hours while in bed. Change as often as every 15 to 30 minutes while you are in a wheelchair to help reduce constant pressure on the skin. Your pressure relief position needs to be held for at least 2 minutes to provide enough blood flow to the area.
- Avoid sliding, slipping, or slumping, or being in positions that put pressure directly on an existing pressure injury or area that is likely to have skin breakdown.





Tilt angle must be between 45-65 degrees to provide adequate pressure relief. Tilt your wheelchair first, then recline to 120 degrees and elevate legs if possible.



- Spread body weight. Use pressure-relieving supports and devices, especially if you are using a bed or chair for any length of time, to help prevent pressure injuries.
- Monitor your equipment. Get a seating evaluation completed by a therapist to determine what wheelchair and cushion best support your needs.
- Complete a proper pressure relief. There are several strategies to achieve this and your therapy team will determine the best technique for you and train you on how to complete.

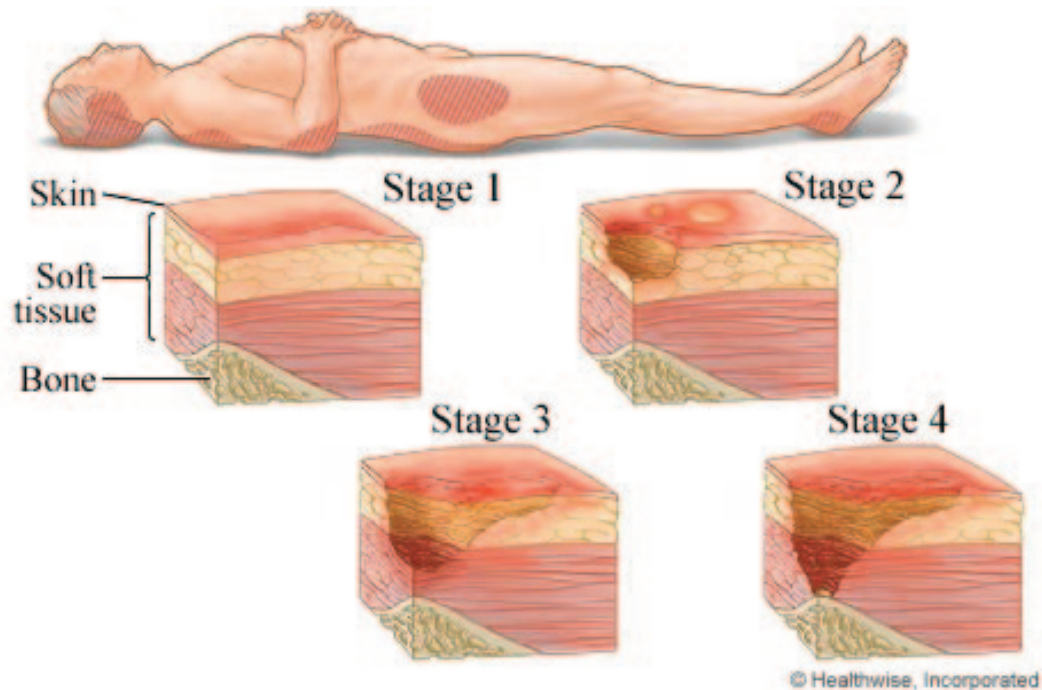
Check your skin

- Check your skin at least twice a day (morning and evening) for signs of pressure injuries. The morning check is to observe for pressure areas that may have happened at night and the bedtime check is to observe areas that may have happened from sitting all day.
- Look for areas of redness or other discolorations that don't disappear within 20-30 minutes. Check also for blisters, bruises, cracked, scraped or dry skin. We all have different skin tones so get to know what is normal for you!
- Feel for hardness, swelling or warmth that may signal skin breakdown.
- Pay special attention to bony areas such as the hips, elbows, knees, heels, sacrum (lower back), coccyx (tailbone), ischium (base of buttocks or "seat bones"), ankles, toes and back of the head. These areas are at the highest risk for breakdown.
- Use a mirror to look at your skin in hard-to-see areas.
- Pay close attention to fingernails and toenails: an ingrown toenail or cut along your nail bed may lead to a sore which can easily be infected.
- **As soon as you notice a discolored area, stay off the area until it returns to normal skin color.**



Pressure Relieving Strategies

Check with your therapist to determine which is best for your needs.



- Test your skin with the blanching test – Press on the darkened area with your finger. The area should go white; remove the pressure and the area should return to red, pink, or darkened color within a few seconds, indicating good blood flow. If the area stays white, then blood flow has been impaired and damage has begun.
- Individuals with dark skin – Blanching may not have been visible even when healthy, so it is important to look for other signs of damage like color changes or hardness compared to surrounding areas.
- **WARNING:** What you see at the skin's surface is often the smallest part of the sore, and this can fool you into thinking you only have a little problem. But skin damage from the pressure doesn't start at the skin surface. Pressure usually results from the blood vessels being squeezed between the skin surface and bone, so the muscles and the tissues under the skin near the bone suffer the greatest damage. Every pressure sore seen on the skin, no matter how small, should be regarded as serious because of the possibility of damage below the skin surface.

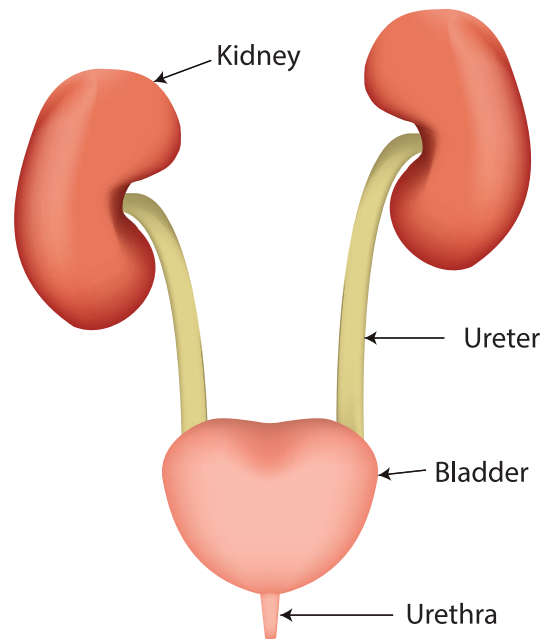
Bladder Care

After an SCI, the kidneys usually continue to filter waste, and urine is stored in the bladder. However, messages sent from your brain through your spinal cord to your bladder and the muscles that control it, may not be able to get through. The bladder can be affected in two ways after an SCI:

- **Spastic (Reflex Bladder)** – When your bladder fills with urine, a reflex automatically triggers your bladder to empty. You may not know if or when your bladder will empty.
- **Flaccid (Non-Reflex Bladder)** – When the reflexes of the bladder muscles are sluggish or absent, urine continues to build up in the bladder but it does not empty. This can cause your bladder to be overstretched or distended affecting the muscle tone. Urine can also back up into the kidneys which may cause kidney damage.

Bladder programs

After an SCI, you will need to establish a bladder program. A bladder management program allows you to schedule when your bladder empties. Emptying your bladder on a regular schedule helps to prevent bladder accidents or incontinence, decrease urinary tract infections, avoid damage to your urinary tract, and limit autonomic dysreflexia (see description later). Your rehabilitation team can help you decide which of the following is the best bladder program for you. Below are the most common and effective ways of managing your bladder:



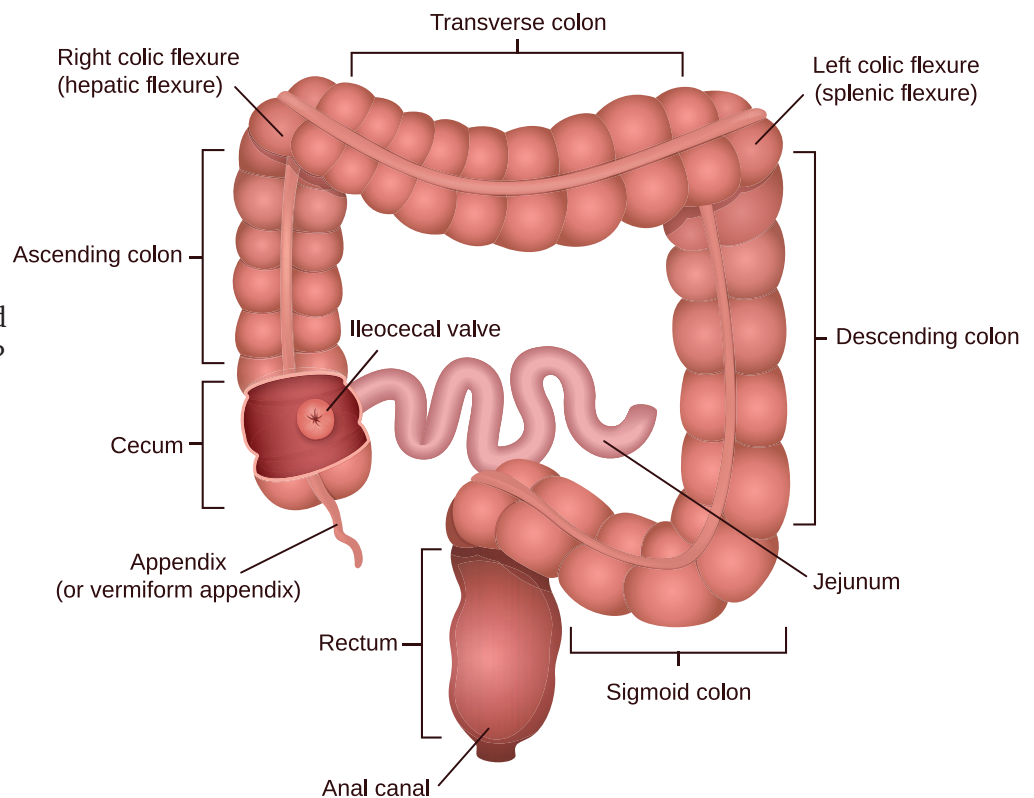
- **Intermittent catheterization programs (ICPs)** – You or a caregiver inserts a catheter through the urethra into your bladder allowing urine to drain out of your bladder, and then the catheter is removed. This is done at scheduled times.
- **Indwelling/Foley catheter** – A catheter is placed into the urethra to the bladder and continuously drains urine. This catheter is changed at least once a month. Urinary tract infections are more likely to occur with long-term use of an indwelling catheter than with an intermittent catheterization program.
- **Suprapubic indwelling catheter** – This is a catheter that is surgically inserted above the pubic bone, in the front of your pelvis, directly into the bladder. It can continuously drain urine or a valve can be placed on the catheter tubing to allow scheduled emptying of the bladder. It does not go through the urethra. This catheter is changed once a month and usually is a better option for long-term indwelling catheter use with fewer complications than occur with long-term indwelling catheters inserted into the urethra.

Bowel Care

After an SCI, you and or a caregiver can manage your bowels to prevent unplanned bowel movements, constipation and diarrhea. The goal is to train the bowel to empty on a schedule so that it is predictable.

How does your level of spinal cord injury affect your bowel program?

- **Injury above T12** – you do not receive the messages telling you the bowel is full. The muscle that controls the opening and closing of the anus stays tight. When the bowel gets full, it will empty by reflex (or automatically). This is called a reflex bowel.



- **Injury below T12** – the messages do not get to the spinal cord. That means your reflexes do not work normally and the anal muscles stay relaxed. This is called a flaccid bowel.
- **Incomplete SCI** – your bowel may be receiving some messages and you and your caregivers may have to make more adjustments to your bowel program depending on your particular needs.
- Regardless of the level of your spinal cord injury or if your injury is complete or incomplete, it is important to remove the stool from the body. Therefore, a bowel program must be established. Not emptying your bowels can trigger autonomic dysreflexia (see description later).

Bowel programs

Your rehabilitation team can help you decide which of the following is the best bowel program for you:

- **Reflexive bowel program** – You may need to take a stool softener/laxative by mouth and then 8-10 hours later insert a suppository into your rectum to trigger the bowel movement, and/or stimulation with your finger (digital stimulation). There are many stool softeners/laxatives and suppositories available. You will have to experiment to find what works best for you.
- **Flaccid bowel program** – You will need to use digital stimulation and manual removal of the stool. You may need to do this 1-2 times a day or every other day to prevent accidents. You may also have to adjust how much and when you eat.

Pain

Pain after SCI can be complicated and confusing. You may feel pain where you have feeling. But you may also feel pain in an area where otherwise you have no feeling. There are different types of pain. It is most important for you and your care team to determine what specific type of pain you are feeling so that you can get the most appropriate treatment.

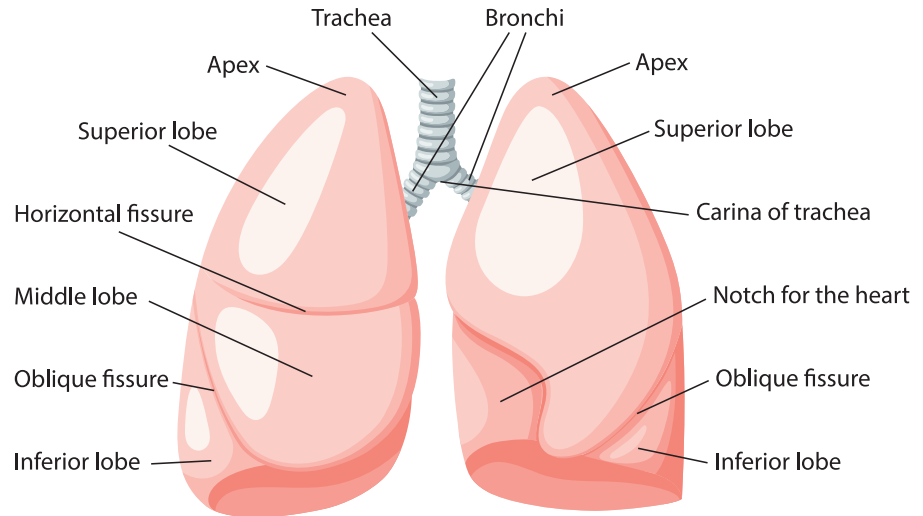
- **Neuropathic pain** – The most common type of pain is neuropathic pain which is caused by damage to the nervous system. This is often described as tingling, numbness, throbbing or burning. People with SCI often report pain around the border of where they have normal feeling and where they begin to lose feeling. You can also be hypersensitive in this area.
- **Musculoskeletal pain** – This pain occurs in the bones, joints and muscles. Unlike neuropathic pain, movement affects it and it tends to get better with rest. It is often described as dull or aching pain. This type of pain may be the result of overuse of certain muscles, for example, pain in arms and shoulders from pushing a wheelchair or from repetitive transfers. Muscle spasm pain is painful involuntary movements of a body part that you cannot move or can only partially move. With an SCI, the connection between your brain and your muscles is disrupted, and the brain may no longer be able to control or prevent these reflex movements. Spasms can be triggered by any irritation below the level of your injury.
- **Visceral pain** – This pain typically occurs in the abdomen (stomach area). The pain can be described as burning, cramping, and constant. It is likely related to a medical problem such as constipation and gas but may be more complex. If it is new and you are unsure what is causing it, make sure to let your doctor know.

Treatment for pain will depend on the type of pain you feel. If you have pain, do not ignore it. Talk to your doctor before trialing any treatment options for pain. Possible treatment options include: medications, stretching and range of motion exercises, daily exercise, position changes and psychological support.

Lung/Breathing Function

Breathing is usually something you do without thinking. But an SCI may affect some of the muscles needed for breathing. This makes it hard to breathe, cough, and bring up mucus from the lungs, which leads to a greater risk of lung infections such as pneumonia.

The effect your injury has on your breathing muscles and how it changes your ability to breathe depends on which part of your spine was injured.



- People with injuries high on the neck may need a machine that controls breathing, called a ventilator.
- People with injuries between the lower part of the neck (cervical), trunk (thoracic), and lower back (lumbar) can have a partial loss of the breathing muscles but can usually still breathe on their own.
- People with injuries lower on the spinal cord (below T12) usually don't lose control of these muscles and have no trouble breathing.

There are a few things that you can do to help prevent lung problems.

- **Know the symptoms of pneumonia:** shortness of breath, loss of appetite, headaches, confusion and chest pain. If you have symptoms, contact your doctor immediately.
- **Practice coughing.** A forceful cough is important because it will help you bring up mucus in the lungs, which can help prevent some lung complications. If your cough is weak and you have trouble bringing up mucus, you may need an assisted cough.
- **Practice breathing.** Doing exercises, such as breathing out forcefully, can help strengthen the muscles you use for breathing. Work with your speech language pathologist and respiratory therapist to identify the best breathing exercises for you.
- **Sit up straight and move around as much as possible.** This helps prevent mucus buildup.
- **Eat a healthy diet.** Eating healthy foods will help keep you from gaining or losing weight. Being either overweight or underweight can lead to lung problems.
- **Drink plenty of fluids, preferably water.** This helps prevent the mucus in your lungs from getting thick and it makes the mucus easier to cough up.

Mobility

Mobility, and in particular how mobility may change, is an important aspect of a spinal cord injury. The ability to move lets you participate more fully in community life and do the things you would like to do. You are not "confined" to a wheelchair or walker – they make you independent. Mobility devices can help you get to work, go shopping, and get around outside your home. They may allow you to participate in races, basketball, tennis and other sports. You can often get around as quickly as anyone else can walking.

Most people with an SCI use a wheelchair at some point. Even if you can get around with a walker, there will probably be times when you need a wheelchair. The two main types of wheelchairs are:

- **Manual wheelchairs** – You move a manual wheelchair yourself, which requires good upper body strength. There are many different types of manual wheelchairs and your therapists will help you to determine which type of wheelchair and seat support work best for you.
- **Power wheelchairs** – Power wheelchairs contain a motor, control system and battery pack that you need to recharge. They are used by people with less upper body strength or other mobility concerns. They come in different models and are getting more diverse. Your therapists will help determine if your needs are best met by using a power chair and which type would be most appropriate.

A wheelchair is selected based on how much movement and feeling you have (your functional level of injury), how much you are able to do, how strong your upper body is, where and how the wheelchair will be used, and its cost.

Other types of mobility devices include:

- **Braces, crutches or walkers** – Some people with SCI have enough strength to use these devices. There are many types available, and your rehab team will help you find the best fit.
- **Scooters** – These are usually used by people who don't need help getting around all the time. Scooters are usually motorized, used for community access, and sometimes can be less expensive than wheelchairs but do not provide the same level of support or customization as power wheelchairs.

Safe Transfers

Your ability to move between surfaces will likely be affected by your spinal cord injury. Movement from your wheelchair to another surface is called a transfer. Your injury level and strength will determine what type of transfer you can do. There are also devices that can assist you to transfer more safely and independently (i.e.: sliding boards or lift). You may be able to do it yourself, or you may need help.



Here are some important things to know for safe transfers:

- Lock your wheelchair and make the distance between the transfer surfaces as small as possible.
- Make sure the transfer surfaces are stable so that they won't move.
- Be aware of objects your skin can scrape against. This can cause skin breakdown.
- Remove armrests or leg rests as able to minimize barriers.
- Ask for help if you need it and explain to the person helping you exactly what you need them to do.
- Your therapists will train you and your family on how to safely perform transfers according to your functional ability.

Adapting your Home

During your stay in inpatient rehab, you and your family need to start thinking about what changes your home may need to become more accessible. It is important to work with your therapy team to guide these changes depending on your level of injury and equipment that you will need. Your therapy team may complete a home evaluation to best assess your home environment and propose changes that are specifically suited to your needs. Considerations for adapting your home may include building, purchasing or renting ramps and widening doorways.



Intimacy and Fertility



All spinal cord injuries are different. How they affect intimacy and sexual function – and how people will react to the change – varies. Because of this, you need to make your own observations and evaluate your experiences to understand your changes in sexual function and how to best deal with them.

After SCI, how you look and what you are able to do changes. An SCI may also affect how your sexual organs work. But being intimate means more than just having sex. Your interests, ideas and behavior play a greater role in defining you than your appearance or your ability to have sex. The most important thing is how well you communicate. Talk to your partner. Be honest about how the SCI has affected your

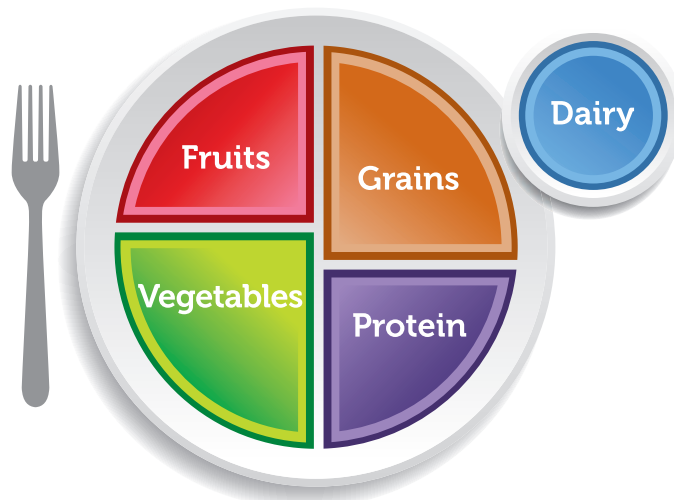
sexual function and how you feel about it. Always keep in mind that people with SCIs have relationships, have active sex lives and have children.

Usually, men and women are sexually aroused through two pathways: direct stimulation of the genitals or other erotic areas or through thinking, hearing, or seeing something sexually arousing. An SCI can affect either of these pathways and may change a person's physical response to arousal. Most people remain interested in sexual activity after an SCI, although the level of interest may decrease. Your sex life will probably be different after your SCI, but sexual intimacy is still possible and encouraged. Your rehabilitation team can help provide further resources regarding intimacy and fertility.

Nutrition

Nutrition is an important aspect of your overall health and having proper nutrition can help reduce your risk of some complications and make other tasks, such as your bowel program, easier. Maintaining a healthy weight can also reduce your risk of pressure injuries. After an SCI, you will have different nutritional needs and may need to adjust how and what you eat. General guidelines for optimal nutrition are as follows:

- **Protein** (Examples: Fish, plain Greek yogurt, eggs)
Eat 2-3 servings of lean protein a day
- **Carbohydrates** (Examples: Quinoa, brown rice, whole grain bread/pasta)
Eat 1-2 servings of legumes/lentils a day
Eat 1 serving of grain a day
- **Fruits** (Examples: cherries, berries, apple)
Eat 1-2 servings of fruit a day
- **Vegetables** (Examples: Sweet potato, asparagus, squash, peppers)
Eat 5+ servings of vegetables a day
- **Fats** (Examples: avocados, raw, and unsalted nuts/seeds)
Eat 2 servings of healthy fats a day
- **Fluids** (Examples: water, broth, diluted juice)
Drink 6 -8 cups of fluids a day



Adjustment

Recovering from SCI involves the whole person – body, mind and spirit. Recovery is emotional as well as physical. Each person has his or her own way of dealing with the events that happen from day to day. After SCI, this does not change. You may feel a variety of emotions including anger, frustration, depression, fear, sadness, anxiety, helplessness, resentment, or grief. You may also experience a sense of relief, hope or confidence that you are succeeding in dealing with a difficult life situation. These feelings often come and go.

Having these feelings is a NORMAL part of the adjustment process. However, letting your emotions control you can result in unhealthy decisions and maladaptive behaviors, a longer rehab stay, and taking longer to adjust to your SCI. Here are a few suggestions that have helped others through tough times and may get you thinking about your own situation:

- **Talk about it** – Talk to others about how you feel, whether that be family, friends, your rehabilitation team members, or a peer who has also experienced an SCI. Talking about it will help you feel more solid and in control. Discussing your feelings doesn't change the situation, but it will help to lighten your burden. Another available resource can be talking to a professional counselor who has experience working with rehabilitation populations and can be very helpful during tough times.
- **Attitude** – Develop a win/win attitude. Every time you say "I can't" you give yourself that message and pretty soon you'll be convinced that you can't before you even give it a try. Believe in yourself and trust your rehabilitation team's belief in you. Develop a sense that there is always something for you to gain in a situation, exercise or challenge. Substitute phrases like "that's worth a try" or "I don't see why not."
- **Take one day at a time** – Thinking of having pain or numerous limitations for the rest of your life would be very overwhelming. In fact, dealing with any situation forever would be hard to take. So break it down into smaller, manageable parts – a few minutes of therapy? Sure.

- **Be good to yourself** – Do something good for yourself each day. For example, take a long, relaxing shower at the end of the day, dress up in your favorite outfit, spend time reading, listen to music, or watch an enjoyable TV show. Also, make sure you rest at night and eat a healthy diet.
- **Easy does it** – Set your goals so that they can be achieved in a manageable timeframe.
- **Develop a sense of humor** – Everyone has a sense of humor, but when we are under stress we sometimes forget to take advantage of one of our greatest and most healing power. So share a funny story or a joke. Get involved with recreation programs, play games, and have fun just for the fun of it.
- **Relax** – As crazy as it may seem, relaxing can be hard to do. There are simple exercises and relaxation techniques that can be done. Practice relaxing every day.
- **Practice** – With time and practice, your new skills will become more natural, your confidence will increase, and you will begin to feel more like yourself again.
- **Work on accepting life on its terms** – Change is change. Don't attach judgment to it. When we experience a change, quite often we tend to say it's "bad" or "good" when in fact it's just different. So avoid attaching judgments and look for what you need in each change you experience. Look for opportunities for growth.

Potential Complications with Spinal Cord Injury

Autonomic Dysreflexia

This is a condition in which your involuntary nervous system overreacts to something happening to your body, usually below your level of injury. This is most often seen in people with SCI at T6 and above. This is a **medical emergency** as it can cause a dangerous increase in blood pressure. Be prepared to call 911 or other emergency services if you notice the symptoms of autonomic dysreflexia. If you or a caregiver cannot treat it promptly and correctly, it may lead to seizures, stroke and even death.

Symptoms include:

- Pounding headache
- Flushed face and/or red blotches on the skin above the level of spinal injury
- Sweating above the level of spinal injury
- Nasal stuffiness
- Nausea
- Slow heart rate
- Goosebumps below the level of spinal injury
- Cold, clammy skin below the level of injury

IMPORTANT: What to do if you feel you have autonomic dysreflexia:

- **Sit up straight, or raise your head so you are looking straight ahead. If you can lower your legs, do so. You need to be sitting upright until your blood pressure is back to normal.**



- Loosen or take off any tight clothing or accessories. This includes braces, catheter tape, socks or stockings, shoes, and bandages.
- Empty your bladder via catheterization.
- Empty your bowel.
- Check your skin for red spots that mean you might have a pressure injury.
- Check your blood pressure every 5 minutes to see if it improves.
- Call your doctor, even if symptoms go away and your blood pressure is decreasing.
- If the symptoms return, repeat the above steps and go to the emergency room or call 911.

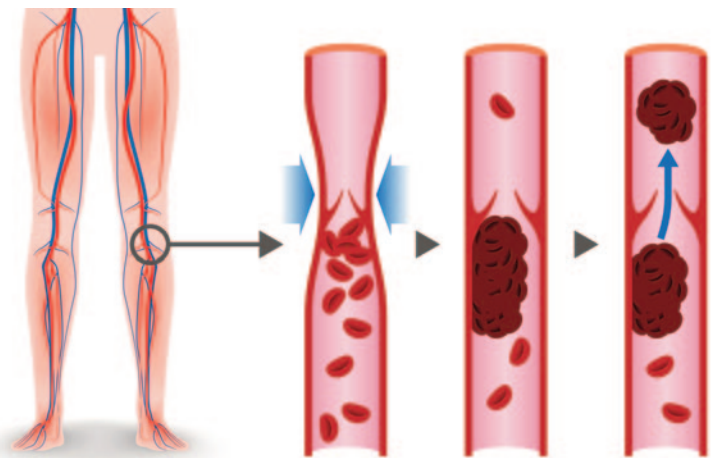
Postural Hypotension

Changes in blood pressure can occur especially when moving into a seated or standing position. Many times these position changes cause blood pressure to drop low and can cause dizziness, lightheadedness, nausea, sweating, fainting, or cool/clammy skin. Your body will need to slowly get used to these positions. To prevent this, move slowly when changing position, stay hydrated, and use compression socks or an abdominal binder. If you experience these symptoms, lean back and elevate your legs to help bring your blood pressure back up.

Pulmonary embolism and deep vein thrombosis (DVT)

These are conditions caused by blood clots that happen in your lungs (pulmonary embolism) or arms/legs (DVT). Blood clots can occur due to limitations in mobility and you may be on medications to prevent these.

- **Signs of pulmonary embolism are:** chest/shoulder/jaw pain, difficulty breathing, fast heart rate, pale complexion, bluish tint to lips, red streaks in coughed up secretions.
- **What to do:** CALL 911/GO TO THE EMERGENCY DEPARTMENT, decrease activity, sit up to assist with breathing, remove tight clothing, use oxygen if available.
- **Signs of DVT are:** swelling (especially one arm or leg more swollen than the other), warmth, redness in arm or leg, fever, pain if able to feel, spasticity.
- **What to do:** CALL 911/GO TO THE EMERGENCY DEPARTMENT, elevate affected arm/leg, remove compression socks, DO NOT exercise/massage the arm/leg.



Spasticity

Spasticity is an abnormal increase in muscle tension that often happens with SCI. Muscles can “draw up” or “jump” or move without you intending them to. This can be painful and annoying. You may also experience an increase in spasticity as your body’s response to something else going on like a urinary tract infection, skin sore or other irritating stimuli below your level of injury.

- **What to do:** stretching exercises and weight-bearing exercises can help to decrease the spasms. If spasms are affecting your mobility or causing pain or skin breakdown, talk to your doctor about options for medicines. If you notice a sudden change in spasticity, consult your doctor or rehab team to determine the cause.

Pneumonia

Pneumonia is a lung infection that can make you very sick and it happens when bacteria get into your lungs. With SCI, it may be more difficult to complete a strong cough due to weakness in your muscles and this makes it harder to cough up mucus from your lungs. As this mucus stays in your lungs, it creates a place for bacteria to grow. It is important to know the signs of pneumonia:

- Cough
- Fever, chills, sweating
- Fast breathing and feeling short of breath
- Chest pain that often feels worse when you cough or breathe in
- Fast heartbeat
- Feeling very tired or very weak
- **What to do:** contact your doctor immediately and seek treatment!



Edema

Edema is swelling that often happens in feet, ankles, hands or fingers. It usually is worse after sitting up all day. Unlike DVT, it usually happens on both sides of your body and does not come with the associated warmth or redness.

- **What to do:** use compression socks, prop up your legs and feet, exercise, complete range of motion exercises.

Temperature Regulation

Your ability to regulate body temperature can be limited after SCI. This is caused by having decreased feeling below your level of injury which would normally signal the brain to either cool down by sweating or constrict blood vessels to keep you warm. Your ability to sweat especially below your level of injury may be limited.

- **What to do:** Control the temperature of your environment as best as you can.
- **Avoid low body temperature** – dress warmly in cold weather and cover up to prevent exposed skin, drink warm fluids, use blankets. DO NOT use electric blankets or heating pads on areas of your body with limited sensation because they could cause burns on your skin.
- **Avoid high body temperature** – stay out of the sun on hot/humid days, drink cool fluids, spray self with cool water, use a fan.

Osteoporosis

Osteoporosis happens when bone tissue breaks down from decreased minerals in the bones, causing bones to become weak and thin and increasing the risk for bone fractures. After spinal cord injury, your metabolism changes, and calcium and other minerals are lost more quickly. Also, limited pressure through your bones from standing and walking can speed up osteoporosis. People with SCIs need to have a bone density study yearly to monitor the strength of their bones. There are treatments available to address bone density. Speak with your therapist about exercises to help with this.

Depression

- Depression is a serious medical illness that involves the brain. It's more than just a feeling of being down in the dumps or blue for a few days. Depression is a mood disorder that causes a persistent feeling of sadness and loss of interest but impacts everyone differently. It can affect how you feel, think, and behave and can lead to a variety of emotional and physical problems including changes in your mood, outlook, ambition, problem solving, activity level, and bodily processes (sleep, energy, and appetite). Depression can also affect overall health and wellness. If you are depressed, you may not look after yourself as you need to, like not drinking enough water, taking care of your skin, or managing your diet.
- Depression is common among people who experience paralysis but there are effective ways to cope with the stresses of paralysis. Depression is highly treatable using psychotherapy, medications (antidepressants), or a combination of both. It is important to talk to your doctor about your feelings and concerns.
- Thoughts of suicide can also occur when things look most hopeless. In SCI, for example, risk of suicide is highest in the first five years after the injury when you are still navigating your new normal. The most important factors in preventing suicide are spotting depression early, getting the right treatments, and developing problem solving skills.
- Talk to others about how you feel, whether that be family, friends, your rehabilitation team members, or a peer who has also experienced an SCI. Talking about it will help you feel less alone and more in control. Another available resource can be talking to a professional counselor who has experience working with rehabilitation populations.

Maladaptive behaviors

- Occasionally, people react to situations in ways that are not effective for their health. When the behavior is used to continuously avoid the perceived negative situation, maladaptation occurs. Maladaptive behavior can result when you do not see a path to your desired future. This can happen with any chronic illness or major lifestyle change. With maladaptive behavior, self-destructive actions are taken to avoid undesired situations.
- One of the most used maladaptive behaviors is avoidance. This involves not doing something that should be done. It can be avoiding a person, like your health care professional; an activity, such as not performing a bowel program; or it can even be a thought, such as not recognizing changes due to SCI. Avoidance becomes maladaptive when your physical or mental health is harmed or in danger of being harmed.
- Self-destructive behavior can also include self-harm, eating disorders, and substance abuse. Self-harm is the physical destruction of the body that can appear in a variety of ways. For individuals with SCI, it can be exhibited by picking at or keeping wounds from healing, or refusing to follow needed activities such as catheterization, bowel program, or pressure reliefs.
- Eating disorders are a form of maladaptive behavior that cause self-harm. They can result in under or overweight issues, which are particularly dangerous for individuals with SCI because both affect skin integrity, mobility, catheterization and bowel issues, body image, and general health.
- Substance abuse occurs when a person's use of alcohol or other substances becomes problematic or hazardous. Some people use these substances to numb the anxiety and stress perceived in their lives. As with other maladaptive behaviors, substance abuse often serves to create a false view of life where problems and issues do not exist. Substance abuse can lead to addiction which can happen when the substance use reaches a level where everyday life is affected.

- Individuals with SCI have compounded issues with substance abuse because pain medication might be needed to control comfort. However, some pain and spasticity medications are addictive. This can set up a difficult situation for you as some medication may be necessary for quality of life but also have the undesired consequence of addiction. In this case, an educated choice has to be made. Talk with your doctor about your medications and any alternatives that may be effective for you.

Caregiver Tips

How I Can Help My Loved One?

Your first experience as a caregiver for SCI usually comes during rehabilitation. Although the rehab team takes the lead at this point in your loved one's recovery, there are also some things you can do to help while your loved one is in rehab.

- Visit and talk to your loved one often. Find out what they can do independently and what they need help with. Avoid doing things for your loved one that they can do without your help. This will give them a sense of control and accomplishment.
- Help your loved one learn and practice new skills.
- Find meaningful activities you can do together. Bring in their favorite music, pictures or pastimes.
- Ask your loved one if they are ready for visitors. Keep visits brief because rehab is physically and mentally challenging and rest is a key component to recovery.
- Observe and learn how to care for your loved one with their new SCI. The rehab staff will demonstrate care skills for you and provide educational materials. Let the staff know if you prefer printed or video learning. The more you practice, the more comfortable you will be when it is time to bring your loved one home.
- ASK QUESTIONS! The rehab staff is here to teach you everything there is to know about a SCI.

After inpatient rehab

- When you return home, help your loved one create a new daily schedule and routine. Encourage your loved one to be as independent as possible. Help arrange transportation to therapy and medical appointments.
- Continue to keep your loved one connected to family and friends. Get involved in the SCI community by joining the North Carolina Spinal Cord Injury Association, United Spinal Association, or social media groups online.
- Caring for a loved one can be extremely stressful. It is important to take care of yourself and ask for help when needed. Schedule respite time from your loved one to attend your own medical appointments and social activities.
- Consider finding a counselor to help you discover and strengthen your coping skills and share your feelings to prevent caregiver burnout.
- Once you are in a daily routine explore any further home modifications that may be needed to facilitate your loved one's care and independence.
- Participate in outpatient family training opportunities for you or other caregivers who will be helping with your loved one's care.
- Call if you need help! The case management team is always available to answer your questions, provide support, and help connect you to community resources.

SCI Resources

- www.ncscia.org
- unitedspinal.org
- www.christopherreeve.org
- facingdisability.com
- facingdisability.com/voices-of-experience-videos
- www.pva.org
- www.msctc.org/sci

Research and Clinical Trial Resources

- www.christopherreeve.org/research/nactn/the-nactn-data-registry
- scitrialsfinder.net/home
- scitrials.org
- www.themiamiproject.org
- www.carecure.org





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