UNC Rehabilitation Services: Guide to Spinal Cord Injury

Tetraplegia

UNC HEALTH®

Tetraplegia

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Chapter 1: General Information/Overview About SCI

A spinal cord injury can occur when there is compression on the spinal cord due to infection or trauma, or if there is a loss of blood flow to the area. Traumatic injury often occurs when the spine (vertebra) cuts or presses on the spinal cord. This can happen after a fall, car accident, or sports injury. A spinal cord injury stops sending messages between the brain and the rest of the body. The closer the injury is to the head, the more of the body is affected.

A serious spinal cord injury in the middle of the back usually causes loss of use of the legs (paralysis). It also usually causes loss of feeling in the legs. Loss of use and feeling in the arms and legs is called tetraplegia.

First treatments for spinal cord injuries include preventing more damage to the spine and spinal cord. This can be done with braces, casts, straps, or surgery. Medicine may reduce swelling in the spinal cord. Depending on your type of injury, you may need surgery, medicine for infection (i.e. antibiotics) or for blood clots, etc. You may need surgery to remove bone, straighten the spine, or make the spine more stable.

Long-term rehabilitation includes exercises to strengthen muscles that still work. You will also get help learning how to use braces and other tools to do everyday tasks. Researchers are working on new treatments. As of now, there are no “cures” for a spinal cord injury.

Realizing you are paralyzed is scary. You will feel many emotions, and you may need help coping. Seek out family, friends, and counselors for support. You also can do things at home to make yourself feel better while you go through treatment.

The following chapters will provide more specific details related to spinal cord injuries.

Chapter 2: Explanation of the Spinal Cord

- The nervous system is made up of the brain, spinal cord, and nerves.
- The brain sends and receives messages or signals to and from the body.
- The spinal cord is a rope-like bundle of nerves. It runs inside the backbone from the neck to the waist.
- The Cervical nerves (C1-C8) are in the neck. The Thoracic (T1-T12), Lumbar (L1-L5) and Sacral (S1-S5) nerves are in the back.
- Messages travel to and from the brain by way of the spinal cord.
- The nerves carry messages of feeling and messages that make muscles move.
- A spinal cord injury blocks the messages below the injury.
- This means messages about movement, feeling, bowel and bladder control are blocked by a spinal cord injury.

Chapter 3: Your “Level of Injury”

Your doctor may perform an International Standards For Neurological Classification of Spinal Cord Injury (ISNCSCI) examination, which helps determine your SCI “level of injury”. You may sometimes hear it called an ASIA exam (which stands for American Spinal Injury Association). It is not an exam that you can pass or fail. It is a way of identifying how much strength and feeling you have at all parts of your body. This can help determine your estimated level of recovery.

- **AIS <u>A</u>: Complete Injury**

  -This type of injury means there is no motor or sensory function preserved in the S4-S5 segments. There may be some areas of feeling below your level of injury.

- **AIS <u>B</u>: Incomplete Injury**

  -This type of injury means there is sensory function preserved in the S4-S5 seg ments AND sensory is preserved below your level of injury, motor function is not preserved.

- **AIS <u>C</u>: Incomplete Injury**

  -This type of injury means there is sensory or motor function preserved in the S4-S5 segments AND some sensory and motor function is preserved below your level of injury.

- **AIS <u>D</u>: Incomplete Injury**

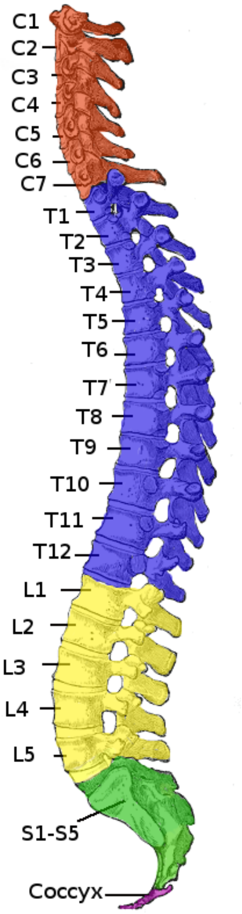
  -This type of injury means there is sensory or motor function preserved in the S4-S5 segments AND some sensory and motor function is preserved below your level of injury. Compared to an AIS C injury, more muscles are stronger and more functional in an AIS D injury.

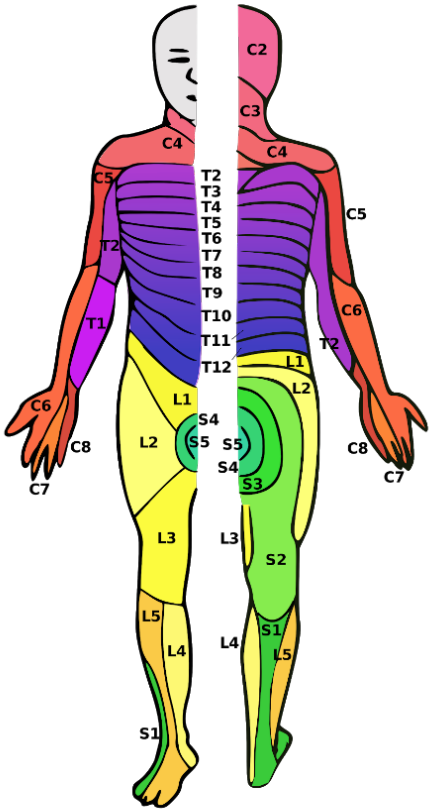
- **AIS <u>E</u>: Incomplete**

  -This type of injury means motor and sensory below the level of injury are fully intact.

My Spinal Cord Injury/Disorder level of injury is:

____





Chapter 4: Skin Care

Avoiding Pressure Injuries

- Pressure injuries, or commonly known as pressure ulcers or sores, are areas of soft tissue that becomes damaged after being compressed over a long period of time. This compression interrupts the blood flow to the tissue, causing the damage.

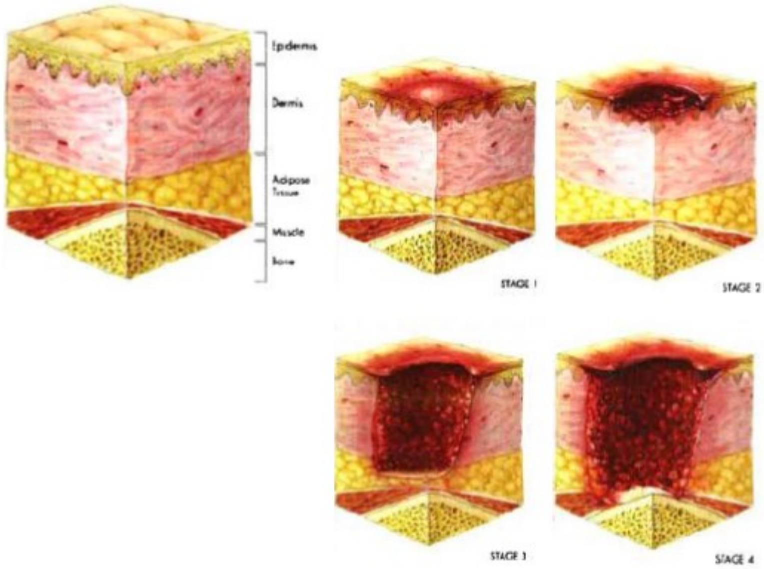
- A person with a spinal cord injury is at risk for pressure injuries. Since loss of sensation and paralysis is commonly associated with spinal cord injury, you often will not know if something is bothering your skin, or if you have had pressure in one spot for too long.

- Muscle atrophy (shrinking of the muscles), which is also commonly associated with spinal cord injury, can contribute to increased risk of pressure injuries due to having less protection over bony areas.

- What does it look like?

Reddish, looks like a bruise, shiny, may have changes in texture (cracked skin, hard, warm)

Skin is non-blanchable. Blanchable skin means that when you press on the area, it will turn white then when the finger is removed it returns to its pinkish color. Non-blanchable means it doesn't turn white when pressed upon nor does it return to its normal color, which is what helps you know if there is good blood flow.



These areas are at risk for pressure injuries:

Anywhere you are bony! Heels, knees, elbows, sitting bones, tail bone, lower back, shoulder blades and back of head.

How you can prevent injuries from happening:

1. Remove the pressure immediately (refer to the following page for suggested positions and how often to change positions)
2. Check if there is good blood flow to the area (if the area is blanchable)
3. Locate the source of pressure and prevent from further damage
4. Notify your doctor if you notice changes on your skin
5. Check skin completely daily

Skin Care

- Keep skin clean and dry
- Skin that remains wet with urine, sweat, or stool will have more problems
- If you begin to notice areas of redness that do not go away, tell your nurse to cover the area with a protective barrier (kerrafoam or mepilex) and let your nurse and doctor know immediately
- Inspect skin frequently using a mirror or ask caregiver to assist

Pressure Relief

- Change positions often - Use the "**Rule of 2s**"
- When in the wheelchair, shift weight every 20 minutes and remain shifted for 2 minutes. Follow your therapists' instructions on how to change position
- When in the bed, turn every 2 hours
- If you use a wheelchair, every so often check your cushion to make sure it is providing good support. If not, please talk to your doctor or therapist.
- Avoid clothes that are tight or have heavy seams. May need to go up a shoe size to avoid rubbing.
- Make sure elastic stockings (TED hose) are put on evenly without wrinkles. The wrinkles cause extra pressure which can result in pressure injuries.

Pressure relief is important for your skin! Remember the:

Rule of 2's

Every 20 minutes while seated in your power chair, ***Tilt*** all the way back in your chair for *2 minutes*

(When lying in bed, change position every ***two hours!***)

Chapter 5: Changes to Your Body Systems

Cardiovascular

SCI and the Risk for Heart Disease

Cardiovascular disease is a broad term that includes many diseases affecting the heart and blood vessels. The most common form of cardiovascular disease is the narrowing or blocking of the arteries or blood vessels that supply blood to the heart. It is the major reason people have heart attacks. Some risk factors you are simply born with and can't do anything about, such as sex, ethnicity, and family history. Other risk factors are things you might be able to change through diet, exercise, medications, and habits. The following are risk factors that can be changed.

High levels of cholesterol in your blood.

- **What you can do about it:**

Have your blood cholesterol checked each year and discuss your individual goals with your doctor. Treatment usually starts with life changes, such as being more active and eating healthier. Choose fats, which come from vegetable oils, fish, and plant food such as nuts and seeds. Avoid saturated fat that are mainly from animal products.

Smoking

Smoking increases the risk of heart disease two- to four times. Smoking injures blood vessel walls, including those that supply blood to the heart muscle and help cholesterol to add up in the injured blood vessel walls.

- **What you can do about it:**

Quit smoking! Ask your doctor or insurance company about programs that may be available to you for free.

Lack of Exercise

If you don't get enough exercise, your body stores extra fat. Too much fat prevents the body from breaking down sugar. Exercise can decrease your risk of diabetes, heart disease and high blood pressure.

- **What you can do about it:**

Get moderate-intensity exercise (work up a sweat) 5–7 times a week for 30 minutes a day. Exercise is more challenging when you have an SCI because of the weakness from your injury, difficulty raising heart rate with exercise, and lack of access to exercise opportunities. The National Center on Physical Activity and Disability website (www.ncpad.org) has many resources to help you become more active, such as exercise videos for people with paraplegia and tetraplegia. Consult with your doctor on ways you can safely increase your exercise.

Overweight

Being overweight is a common problem in the SCI population, and excess fat increases the risk of high blood pressure and diabetes.

- **What you can do about it:**

A combination of healthy diet, exercise and reducing calories by eating smaller portions as well as limiting alcohol.

High blood pressure

High blood pressure increases the risk for heart disease and stroke if it is uncontrolled over months or years.

- **What you can do about it:**

Chronic high blood pressure can be lowered through diet, exercise, weight loss, and medications. If you have chronic high blood pressure, talk with your doctor to determine your blood pressure goals and treatment.

Orthostatic Hypotension

Orthostatic or postural hypotension is a sudden drop in blood pressure caused by moving from a lying to a sitting position or sitting to standing. It often occurs after spending a long time in bed and then suddenly getting up. Although orthostatic hypotension can happen to anyone, it is more common following a spinal cord injury (SCI). This is due to the loss of nervous system control which works to keep the blood pressure stable, as well as loss of muscle tone which helps to return blood to the heart.

Orthostatic hypotension is most common right after an injury and in the first few weeks of recovery. In most cases, the problem stops and only happens after being in bed for long periods of time, such as in the morning. For a few people, however, hypotension can continue and medications may be needed.

How to manage orthostatic hypotension:

- At first you may need a wheelchair that leans back. The first few times you get out of bed the back of the chair will be tilted back and then slowly raised to an upright position as you are better able to sit up.
- An abdominal binder (wrap around your stomach) and compression stockings or ace wrapping may help to stop the blood pressure from dropping as you sit up.
- If possible slowly, raise the head of your bed and sit up in bed for a few minutes before transferring to your wheelchair.
- Stay active and hydrated, and avoid staying in bed for long periods of time unless it’s your doctor’s order.

Signs of orthostatic hypotension:

- Feeling lightheaded or dizzy
- Loss of vision or seeing dots before your eyes
- Loss of hearing or a roaring in the ears
- Fainting

What to do if you are having orthostatic hypotension:

If you are sitting on the edge of the bed before transferring to the wheelchair and begin to feel dizzy:

- Lie down on the bed.
- Check your abdominal binder to make sure it is tight enough.
- After the dizziness has passed, slowly attempt to sit up on the edge of the bed. Wait to make sure you do not get dizzy again before transferring to the wheelchair.

If you are already in the wheelchair when you begin to feel dizzy:

- Recline the back if you have a reclining wheelchair or have someone tip you back.
- You may also need to have your legs raised over your head.
- Once the dizziness goes away, slowly sit up again.
- You may need to do this a few times until your body becomes used to being upright.
- If it continues, return to bed.

IMPORTANT NOTE: Do not attempt to fight the dizziness. It is not a matter of will power. If you ignore the early signs you might faint. If this happens and you do not sit back or lie down you will deprive your brain of blood and oxygen.

Ace Wrapping/ Compression

WHY do we do it?

After a spinal cord injury, your blood flow may decrease leading to low blood pressure. When out of bed, you may need some extra support to keep a safe blood pressure. Extra support may be ace wraps, support hose, and/or an abdominal binder.

WHEN do we do it?

- Only perform if ordered by your doctor
- Apply ace wraps just before getting out of the bed
- Leave ace wraps on while you are up out of the bed
- Remove ace wraps if you will be lying down or in bed for longer than 1 hour
- Always remove ace wraps at night

Things **TO** do:

Check the skin each time wraps are applied or removed; report any areas of concern to your nurse, therapist, or doctor. Remove ace wraps and re-apply if sliding down, wrinkled, or are causing any blood flow issues and/or pain.

Things **NOT** to do:

Do not ignore problems or concerns about wrapping if it is doesn’t feel right or no longer in good condition. Do not apply if new skin issues arise. In this case, get directions from your doctor to address skin issues so that wrapping can still be done to support your blood pressure. Ask for help if needed.

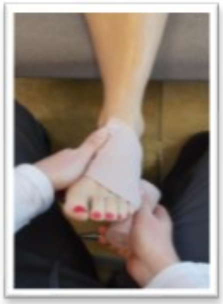
Getting the proper stretch with ace wrapping:

- 0% stretch is when you do not put any tension or stretch on the ace wrap
- 100% stretch is when you stretch the ace wrap as far as it will go. We do not wrap with this tight of compression.
- 75% stretch is when you stretch the ace wrap about ¾'s of what it will go. We most often start with this compression at the foot and slowly reduce the stretch as you wrap higher up your leg.

Directions for Ace Wrapping:

Anchor the first pass at an angle, beginning at the end of the toes.

Form a Figure 8 pattern, beginning with 75% compression at the foot.
Be sure there are no gaps or wrinkles.



Proceed up the leg with the Figure 8 pattern- an “x” will appear each time the wrap overlaps. Wrap it less tight around the knee, about 25%.

Anchor the end of the wrap with tape, never metal clips! Monitor toes for blood flow and re-apply wraps if wrinkles or gaps occur.

Pulmonary

Breathing concerns following SCI:

Pulmonary Embolism:

After sustaining an SCI, you may have difficulty moving your arms and legs and may be much less mobile than you were prior to your injury. Because of this, you are at risk for developing blood clots since the blood flow to your arms and legs will be reduced due to the lack of movement. You are also at risk because your body's response to trauma is for the blood to thicken and clot. If you get a blood clot, it could travel up to your lungs and result in what is called a pulmonary embolism.

A pulmonary embolism is the sudden blockage of an artery in the lung. They can be very serious and if you have one pulmonary embolism, you are at greater risk for having another one.

You will probably take a prescription blood-thinning medicine to prevent blood clots. A blood thinner can stop a blood clot from growing larger and prevent new clots from forming.

Prevention of pulmonary embolism:

- Remain as mobile as possible and exercise if possible. If needed, have a family member or a caregiver gently move your arms and/or legs if you are unable to move them on your own daily.
- Do not smoke. If you need help quitting, talk to your doctor about stop-smoking programs and medicines. These can increase your chances of quitting for good.
- Check with your doctor before taking hormone or birth control pills. These may increase your risk of blood clots.
- Ask your doctor about wearing compression stockings to help prevent blood clots in your legs. You can buy these with a prescription at medical supply stores and some drug stores.

CALL 911 for anything you think you may need emergency care.

For example, call if:

- You have shortness of breath.
- You have chest pain.
- You pass out (lost consciousness).
- You cough up blood.

Call your doctor or seek immediate medical care if:

You have new or worsening pain or swelling in your leg.

Pneumonia:

Pneumonia is an infection of the lungs. Most cases are caused by infections from bacteria or viruses. It can be mild or severe. If it is caused by bacteria, you will be treated with antibiotics. It can take anywhere from a few weeks to a few months to recover fully from pneumonia, depending on how sick you were and whether your overall health is good.

Pneumonia is common after an SCI because lack of movement in general, can increase your risk of pneumonia. Depending on the level of your SCI injury, it may be difficult to breathe on your own or even to cough. This is because an SCI can affect the muscles we use to breathe or cough, which could make it difficult for us to take deep breaths and for our lungs to expand or to get any mucous out of our lungs and throat. When we take shallow breaths or have fluid sitting in our lungs that we cannot cough up, we are at a high risk for developing pneumonia.

If you have trouble coughing, have someone help you with an assisted cough (see pictures below). This is done by having another person press just above your belly button while you cough. Practice deep breathing. This can strengthen the muscles that help you breathe.

Your therapist may give you exercises to strengthen the muscles that may have been affected by your SCI to help improve your breathing and to help prevent pneumonia from occurring.

You may want to get shots to prevent flu and infection.

Call 911 if you think you may need emergency care. For example, call if:

You have severe trouble breathing.

Call your doctor or seek immediate medical care if:

- You cough up dark brown or bloody mucous (sputum).
- You have new or worse trouble breathing.
- You are dizzy or lightheaded or feel like you may faint.

Watch closely for changes in your health, and be sure to contact your doctor if:

- You have a new or higher fever.
- You are coughing more deeply or more often.
- You are not getting better after 2 days (48 hours).
- You do not get better as expected

Autonomic Dysreflexia

Autonomic dysreflexia (AD) is an emergency condition that needs immediate attention. It is more likely to occur if you have a spinal cord injury at or above thoracic level 6 (T-6). It is important for family, friends, and caregivers to know about this as well to be better prepared to help.

AD is an abnormal response to a problem in your body below your SCI. It is more commonly caused by a bladder or bowel problem. Because of your SCI, your body can't respond properly to signals that something is wrong. Instead you may develop a rapid rise in blood pressure. High blood pressure is a serious medical problem because it can cause seizures, stroke, and sometimes death.

What causes AD?

Bladder issues are the number one cause of autonomic dysreflexia. Any other problem below your level of injury can cause this condition including:

- Constipation
- Pressure ulcers
- Ingrown toenails
- Clothing (tight fit, tags, different materials)
- Other Causes (labor, menstruation, blood clots, heterotopic ossification– see page 22 for further explanation.)

Warning signs include:

- Rapid increase in blood pressure
- A pounding headache
- Heavy sweating especially in your face, neck, and shoulders
- Flushed/reddened skin usually above your SCI
- Goosebumps
- Blurry vision or seeing spots
- Anxiety or jitters

What should you do if you are experiencing Autonomic Dysreflexia?

- It’s an emergency so don’t be afraid to call 911
- Sit-up to 90 degrees
- Loosen tight clothing (remove abdominal binder, TED hose)
- Check bladder for drainage (check foley for kinks or being tugged, flush foley, cath if necessary)
- Check to see if your bowel is full
- Check for other causes (pressure ulcer, ingrown toenail, etc)

My baseline blood pressure is:____________________________________

If the top number is more than 20 points higher then it can be a sign of AD which is a medical emergency.

Muscles and Bones

A spinal cord injury can cause you to lose control of several of the muscle groups in your body. You may notice that the muscles start to get smaller in your legs and arms in the first weeks after injury. This is called “atrophy.” If you do have at least some control of these muscles, exercise is the best way to keep the strength you have, and to build up new strength. Your physical and occupational therapists will review an exercise program with you early on in your therapy that you can do on your own or with help from your family members.

Because you may have lost strength in several muscle groups, your joints are not moving as much and/or often. A joint is an area where two bones attach, and often allows movement such as the elbow, wrist, or knee joint for example. When our joints don’t move, they become stiff, and if they are not moved for a long period of time, can become “stuck.” This is called a joint contracture. The best way to prevent contractures is exercise, stretching and positioning. Your physical and occupational therapists will review specific exercises, stretches, and ways to position yourself early in your rehabilitation that you can do on your own or with help from your family members to help you preserve your joint motion.

Heterotopic Ossification (HO) is the term for bone growth in soft tissue areas where bone does not normally grow. This can lead to loss of joint motion, pressure ulcers, and nerve compression. Tell your doctor if you experience joint tenderness, swelling, redness, and fever.

Chapter 6: Medications

Your doctor may prescribe different medications. Examples include:

- Medication for spasticity

  -Spasticity is a catch or tightening of the muscle when stretched, muscles can also be tight at rest

- Medication for bowel and bladder programs
- Medication for different types of pain
- Medication for blood pressure

Chapter 7: Activities of Daily Living (ADLs)

Daily living tasks:

After a spinal cord injury, you will have to readjust how to perform activities of daily living (ADLs) which include the following:

- Feeding, grooming, dressing, bathing, toileting, sexual activity, and sleep/rest.

Dressing:

Getting dressed can be difficult following a spinal cord injury. There can be mental and physical challenges to overcome.

Improving Lower Body Dressing:

- Wear a larger size of clothing for an easier fit and comfortable garments with elastic waistbands.
- Use adaptive equipment and adapted positioning (ask an occupational therapist for more information regarding any adaptive equipment covered in the below sections):

Positioning:

Long Sitting

Circle Sitting

Figure—4

Improving Upper Body Dressing:

- Dress the weaker side first
- Replace fasteners with Velcro or zippers
- Use equipment that helps you adapt

Feeding:

Physical changes following a spinal cord injury can affect your ability to feed yourself during meals. Feeding skills include managing utensils, drinking from a cup, cutting and preparing food, and opening containers.

Ways to improve feeding skills:

- Use adaptive equipment:
  -Dycem (non-slip material)
  - Plate guard

  - Built-up handles
  - Universal cuffs

- Improve posture to ensure safe swallowing and to lower chance of spilling food
  –Find midline (the center) while sitting
  –Strengthen trunk, including stomach and back muscles
  –Weight shift through the pelvis (bones that move the trunk front to back and side-to-side.)
  –Add wheelchair supports and change the height of the table or chair.

Grooming:

Grooming tasks, such as shaving, brushing/combing hair, applying makeup or even washing your hands can be difficult to do following a spinal cord injury.

Improving grooming skills

- Use adaptive equipment:
  -Long handles on a toothbrush, comb/brush, makeup, or razor
  -U-cuff
  -Wash mitt

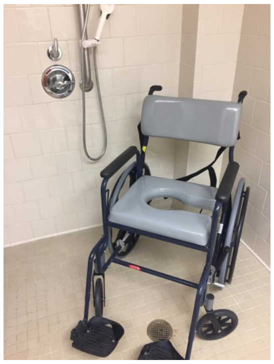
  -Dycem

Bathing:

Taking a shower or a bath in a slippery, wet bathroom can be a big risk to your safety following a spinal cord injury.

Improving one’s safety and performance while bathing

- Durable medical equipment (DME) such as:
  -Tub transfer bench (used for getting in and out of a bathtub)
  -Tilt-in-space shower chair
  - Rolling shower chairs



- Changes to your home
    - –Grab bars
    - –Handheld shower spray
    - –Remove throw rugs
    - –Use non-skid mats inside and outside of the shower to secure foot placement
- Adaptive Equipment
    - –Long-handled sponge
    - –Wash mitt

Chapter 8: Mobility

Mobility

Moving around in the bed is one of the first things you will learn how to do during therapy. This may involve learning how to coach a caregiver so they can properly assist you. Bed mobility may include rolling, scooting, and repositioning yourself. This will help you gain independence and keep your skin healthy and free from pressure injuries.

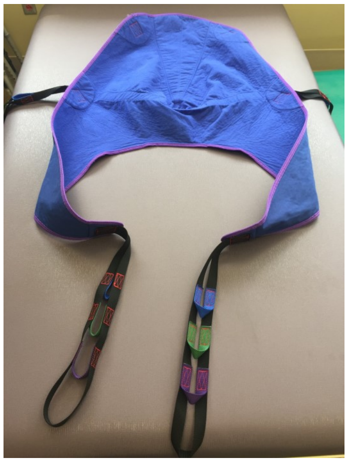
Learning how to move around with your current abilities can help you gain independence. You may learn how to drive a power wheelchair to help you transport yourself from place to place in the home and community. There are many varieties of power wheelchairs. The therapists will work with you to help find the best fit for you, your abilities, and your lifestyle and teach you how to use it correctly.

What equipment do people with spinal cord injuries use?

The use of equipment may help you move around more easily and with less assistance from a family member, care partner, or therapist. Equipment used by people with spinal cord injuries can include:

- Mobility devices, such as wheelchairs

- Transfer devices, such as mechanical lifts



- Hospital beds
- Other devices (such as: splints, braces, or cushions)
- Self-care equipment (such as: cuffs, adapted utensils, reachers, shower/tub benches, hand-held shower sprayer, and adapted toilets)
- Breathing equipment (ventilators, suctioning, CPAP machines)
- Environmental devices (hand controls for lights, tools to help you use a computer)
- Changes to your home (ramps, modifications for opening/close doors)

Information about the equipment I use:

Chapter 9: Bowel and Bladder Function

Bladder management:

After you experience a spinal cord injury you may not feel the urge to pee when your bladder is full and/ or, you may not have control of your bladder. The bladder is usually affected in one of two ways:

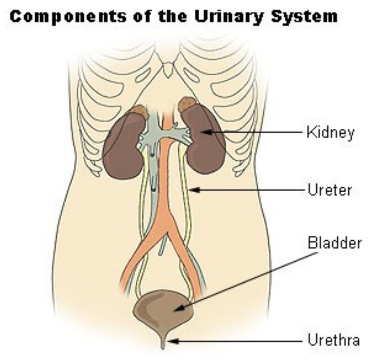
Spastic (reflex) bladder- This is where the bladder will fill with urine and a spasm may automatically trigger your bladder to empty. The major problem with a spastic bladder is that you do not know when or if the bladder will empty and you may not be able to fully empty your bladder. If you experience this, you will likely be placed on an intermittent catheterization program which drains your bladder on a set schedule, usually every 4 to 6 hours. You may require medication to stop your bladder from spasming. Your nurse and occupational therapist will work with you on developing and training you or a family member on your program. Your max amount of pee should be less than 500cc.

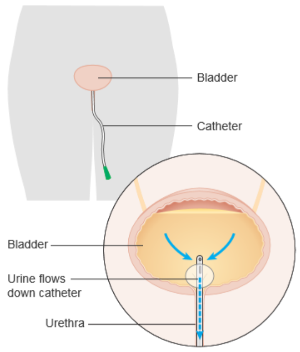
Flaccid (non-reflex) bladder- This is where the bladder muscles are weak and floppy. It may store but can not empty the urine. If you are experiencing a flaccid bladder, you will likely be started on a scheduled catheterization program as mentioned above.

My bladder care method:____

Supplies:____

Steps:____





Bowel management:

After you experience a spinal cord injury, messages from your body are not able to reach your brain like before which often results in a loss of sensation that your bowel (tube that carries solid waste from the stomach out of the body) is full, you may not feel the urge to poop and/or you may experience a loss of muscle control. Like the bladder, there are two types of bowel that can occur after an SCI:

- **Spastic sphincter (upper motor neuron) bowel**-this is where the anal sphincter (muscles that close the anus) is spastic and tight however, a bowel movement can still occur at any time without warning when stool fills the rectum. Constipation can be a problem with this bowel pattern.
- **Flaccid sphincter (lower motor neuron) bowel-** this is where there is a loss of anal sphincter tightness so the bowel is not able to keep the stool in. This can result in bowel leakage.

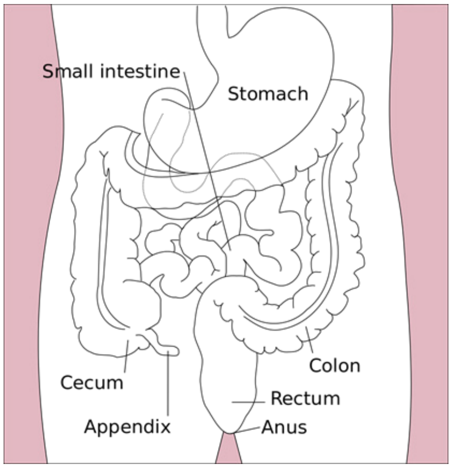
In order to eliminate or to decrease the number of unplanned bowel movements, you will need to be placed on a bowel program based on your bowel type. Your therapy team will help you to find the correct bowel program and your nurse and occupational therapist will work with you and/or your family to train you on the program.

My bowel type:____

Supplies:____

Steps:____

____



Chapter 10: Sexuality

The potential nerves damaged in an SCI can impact your sexual function. The extent to which your sexual function is impaired depends on a variety of factors including the level of injury, how much damage there is to the spinal cord, and whether you are male or female.

Sexual Function for Females:

Pregnancy

- Fertility is not interrupted after an SCI. Women with an SCI can still become pregnant and carry a baby to term. For an injury above T6, monitor for signs and symptoms of AD (see page 20) in the final months of pregnancy and during delivery.

Birth Control

- If you do not want to get pregnant, using birth control is a good idea. There are many different types of birth control available and your gynecologist can discuss the options that will work for you.

Menstruation

- Menstrual periods frequently stop for a period of time due to the shock the body has received. They will usually start again within a year. Either tampons or menstrual pads can still be used.

Intercourse

- Depending on your level and completeness of injury, you may experience several changes; your vagina may lubricate less, have less surface sensation, less ability to contract your muscles, and it may become more difficult to have a genital orgasm. While the majority of women with an SCI are able to experience orgasm, it may take more stimulation than prior to injury. In addition, it might take longer for an orgasm to occur and/or it feels different.

- In general, the more sensation you can feel between your belly button and pocket area, the greater chance of genital arousal (lubrication) and a normal orgasm.

- While most women with SCI maintain some degree of lubrication, those who experience less may wish to utilize a water-based lubricant, such as K-Y Jelly, to facilitate sexual activity.
- If you are having difficulty achieving an orgasm, the use of aids and devices can be beneficial

Sexual Function for Males:

Erections

After an SCI, men may get erections in 2 ways:.

- Thoughts or seeing or hearing something stimulating.

  -If your level of SCI is above T10, the message (sexy thoughts) from your brain cannot get through the damaged part of your spinal cord.

  -Generally, men with an incomplete injury at a low spinal level are more likely to have psychogenic erections than men with high-level (above T10), incomplete injuries.

  -Men with complete injuries are less likely to experience psychogenic erections.

- Direct physical contact to the penis or other erotic areas such as the ears, nipples, or neck. A reflex erection is involuntary, so it can occur without sexual or stimulating thoughts. Some instances could be when the catheter is being changed or when your penis is being cleaned or wiped or even by just pulling clothing or blankets over the body. It’s important for you to pay close attention to what causes an erection as that may be useful for future occasions.

  -The nerves that control a man's ability to have a reflex erection are located in the sacral area (S2–S4) of the spinal cord. Most paralyzed men are able to have a reflex erection with physical stimulation unless the S2–S4 pathway is damaged.

Fertility

Most men with SCI will experience some problem with getting an erection or ejaculation. As a result, assistance with fertility for biological fatherhood is often necessary. For men with incomplete lesions, natural ejaculation and insemination with vaginal intercourse may be possible. If you are unable to perform natural insemination, talk to your doctor about ways that can be considered in the clinic

Ejaculations

- Each individual will have a unique sexual profile
- Researchers report that ejaculation occurs in up to 70 percent of men with incomplete lower-level injuries, and in as many as 17 percent of men with complete lower-level injuries. Ejaculation occurs in about 30 percent of men with incomplete upper-level injuries and almost never in men with complete upper-level injuries.
- Even when a normal ejaculation might not occur, a small percentage of males can feel an ejaculation but show no outward sign of semen. In some of these instances, the semen is ejaculated into the bladder instead of out the penis - this is called retrograde ejaculation.
- Despite the difficulty with ejaculation, many men describe pleasurable sensations that they characterize as orgasms. While most men are unable to ejaculate during intercourse, they can still do so with manual or partner masturbation. The use of a vibrator in either genital or non-genital areas also may significantly improve the chances for ejaculation.

Managing Erectile Dysfunction

- There are several devices that can be used to help you achieve and maintain an erection
- It is important to see your doctor or urologist for accurate information on the various treatments and/or devices as they relate to specific conditions.

Considerations:

- There are many parts of your body which can be aroused and provide a pleasant sexual response. These areas of the body are called the *erogenous zones* and are not limited to the genital area.
- Before engaging in sexual contact, it is important to time your bowel/bladder routine.
- It is important for both partners to communicate and express their needs.
- AD can be triggered during sexual activity. It is important to monitor for symptoms of AD during activities if you injury is a T6 or above.
- Viagra will not cause an erection. It can however help you sustain an erection.
- Medications may affect your sexual function: narcotics, antidepressants, baclofen, blood pressure medicine, bladder medicine, and anti-seizure medicine. Talk to your doctor about how different types of medicines may affect your sexual function.
- One resource for more detailed information about sexual aids and devices is a manual called "PleasureABLE", which can be found online.

Nutrition for Good Overall Health

People with SCI will require close attention to diet and nutrition due to the changes in the digestive function and their increased caloric demands associated with exercise and mobility. Eating wholesome, nutrient dense foods will help decrease the risk of any secondary health complications associated with SCI. Make sure your diet consists of protein, carbohydrates, fruits, vegetables, good fats, and plenty of fluids.

Foods to Avoid:

1. Avoid processed or packaged foods and commercial baked goods
2. Avoid sugar and artificial sweeteners
3. Limit alcohol as much as possible
4. Avoid or limit caffeine
5. Avoid soda

SCI and Bowel Management

Following a spinal cord injury, bowel movements may change. Ideally, food should take 18-24 hours to pass through however. However, for people with SCI, it may take up to 80 hours! Having regular bowel movements is important because it can help remove toxins from the body and prevent the risk of constipation, gas, and hemorrhoids.

Standard bowel management for individuals with SCI often includes a combination of pharmacological and non-pharmacological aids such as stool softeners, laxatives, rectal suppositories, enemas and/or digital stimulation.

Diet is important! What and when you eat and how much fluid you drink can ensure regular bowel movements.

Bulking Agents

Oat bran can help increase stool volume and ensure softness, making it easier for you to eliminate your stool.

Stimulant Laxatives (Oral & Suppositories)

Bisacodyl, Ducolax, and Senokot are common laxatives used that will help you have a bowel movement. However, some negative side effects from these laxatives are abdominal cramping and diarrhea.

Stool Softeners

Docusate sodium is commonly used to help the colon (large intestines) absorb more water resulting in softer stool, allowing your body to easily eliminate the stool. These softeners will not have any impact in helping your body move stool through the digestive system.

Avoiding constipation

Constipation is one of the primary complaints from people following a spinal cord injury. Medications prescribed to aid bladder function, pain medications, or even antidepressants can contribute to constipation. Simple dietary changes can decrease your chances of constipation:

- Increase fiber intake – increasing amount of stool, create better stool consistency, and help push the stool through the intestines. Recommended for 19-30 g of fiber a day

- Increasing water intake – drinking 8 to 10 cups of healthy fluids such as water, herbal teas, and diluted juices can help. Avoid alcohol, caffeine and soda. If you are on a cathing program for your bladder, you typically want to limit your daily intake to 2L.

- Diarrhea can also be a symptom of constipation. When someone has a significant amount of stool due to constipation, the body may try to get rid of the stool by increasing the amount of fluid in the stool, causing diarrhea and frequent bowel accidents.

SCI and Bladder Health

The role of your bladder and your urinary system is to help your body remove waste. The kidneys help to filter out wastes from your blood where the waste becomes urine and flows down to your bladder. The bladder acts as a storage tank until you eliminate the urine. Following an SCI, you may need catheterization or other urinary devices to help drain your bladder. Since an external device is used, this can introduce unwanted bacteria into your bladder leading to urinary tract infections (UTIs).

Eating a diet with nutrients that are needed to build and maintain your immune system can help prevent bacteria from attaching to your bladder leading to an infection:

Boost your immune system

1. Garlic – helps the body fight infection, however too much garlic may cause stomach upset

2. Vitamin A& C – helps activate and enhance white blood cells and plays important role in antibody production. Foods that are rich in Vitamin C are red & green peppers, broccoli, brussel sprouts, papaya, strawberries, and pineapple. Foods that are rich in Vitamin A include sweet potato, spinach, carrots, kale, and squash

3. Zinc – helps fight off infection by increasing production of white blood cells. Foods high in zinc include pumpkin seeds, red meat, sesame seeds, yogurt, and oats.

4. Cranberry juice – contains tannins which can help prevent E.coli (a bacteria) from attaching to your bladder wall. Important to drink unsweetened and pure cranberry juices which contains less sugar.

5. Taking probiotics – probiotics are essential to keeping your digestive health balanced since many individuals with SCI will take antibiotics to fight other infections. Taking antibiotics may disturb and alter normal and good bacteria in your balance.

Increase daily flow of urine

Increasing fluid intake is necessary to help your body flush out toxins and prevent urine from staying in your bladder for too long, which can contribute to infection. Drinking 8 cups of water a day will help flush bacteria from your system.

Chapter 12: Thinking, Communication and Swallowing

Cognitive Rehabilitation:

You may notice changes in cognition following a spinal cord injury, which can affect attention/concentration, memory (short-term and long-term), executive function (problem solving, reasoning, thinking) and social language. If changes in your cognition occur, a speech language pathologist (SLP) will introduce you to various compensatory strategies and work with you to improve your cognitive abilities.

Eating, Chewing, Swallowing

Dysphagia is a term that means difficulty with chewing and swallowing food. This can occur after a spinal cord injury and can make eating and drinking difficult and unsafe. Dysphagia can affect your swallowing in many different ways.

General Signs and Symptoms of Dysphagia are:

- food or liquid spilling out from the mouth
- food remaining in the mouth following a swallow (e.g., pocketing or holding)
- extra effort or time needed to chew or swallow
- the sensation that food or liquid is “going down the wrong pipe”
- coughing, throat clearing, wet or gurgly sounding voice during and/or after eating or drinking
- repeated pneumonia or chest congestion after eating
- weight loss or dehydration from not being able to eat or drink enough
- If food or liquid go down the airway, this is called aspiration. It can lead to aspiration pneumonia. Coughing is often our bodies’ way of clearing any food or liquid from our airway. A cough is performed with help from our vocal cords (voice box) and our diaphragm, a muscle that sits below the lungs and powers our breath support. Sometimes after a spinal cord injury, our diaphragm cannot generate enough power to cough. In this case, your Rehab team may teach you and your care partner how to perform a cough to protect your airway when you are eating and drinking.

- Your Rehabilitation team can help you with these issues by teaching strategies to improve the quality of chewing and swallowing to prevent aspiration (i.e., food/ liquid enters the airway/lungs). They may also make changes to the consistency of the foods (e.g., puree, ground, soft solids) and liquids (e.g., honey-thick, nectar-thick) to ensure safe swallowing and reduce your risk for aspiration. If you have difficulty with eating and drinking, a speech-language pathologist (SLP) will work with you to improve your ability to safely eat and swallow foods and drinks.

Here are a few guidelines to follow to ensure safe swallowing:

- Sit upright in your chair or bed
- Eat only while awake and alert
- Take small bites and sips
- Eat/drink at a slow pace
- Check your mouth for food that may be stuck in your cheeks or on the tongue
- Take turns taking a bite of food, then drinking during your meal.

Chapter 13: Mood and Adjustment

Rehabilitation Counselor/Rehabilitation Psychologist/Neuropsychologist:

The counselor/psychologist will help you and your family deal with typical emotions such as depression, anger, and frustration associated with adjustment to spinal cord injury and disability. They will provide treatment to address these areas and enhance your emotional skills that will assist in coping, adjustment, and re-entry into your work and family life. Resources for community follow up with emotional support services and vocational rehabilitation (helps people with disabilities achieve their goals for employment and independence) and independent living services may be provided.

Chapter 14: Returning to the Community

Recreational Therapist (RT): In the Rehab setting, the Recreational Therapist will work with you and your family to become more independent in your life and leisure activities. Your RT's treatment plan may include leisure engagement, community re-entry activities, and education of community resources to use when you go home. The RT will also help you practice your social skills with activities to help ease the transition back into the community. The recreational therapist will work with other therapies to assist with overall recovery through different activities provided.

Americans with Disabilities Act (ADA)

- This law states that physical or mental disabilities in no way lessen your rights to fully participate in all aspects of society, particularly in employment, housing, access to public areas, education, transportation, communication, recreation, health services, voting, and access to public services.
- This law also states that no one with a disability can be discriminated against in any part of the community.
- More information can be found at both the national and state level of government:

  -United States Access Board

  -Access North Carolina

Community Re-entry

- Community Re-entry tasks can be an educational opportunity during your length of stay for patients to apply learned skills into a community setting. During your admission to UNC Rehab, you can participate in off-unit activities within the UNC Healthcare Campus environment. Community re-entry is focused on applying skills learned in therapies to complete tasks that you often may face in your home and community.

- Education related to environmental, social, and physical barriers is provided during this time to help continue your success for community functioning.
- Recreational Therapy can provide help with finding resources for support during your recovery. This may include spinal cord injury networks and peer support programs to use even past your hospital stay. Your therapy team wants to set you up for success and help with coping in a positive way.

DMV/Handicapped Parking Stickers

Following an SCI you may need assistance with transportation to provide wheelchair accessibility. The vehicle you utilize can have access to handicap parking in the community setting to assist with ongoing needs.

The North Carolina Department of Transportation: Division of Motor Vehicles is responsible for processing and providing requests for parking stickers for individuals with disabilities.

Three types of handicap licensing:

- Five-year handicap parking placard
- Temporary (up to six months) handicap parking placard
- Handicap driver registration plate/tag

Community Resources

- There are many local resources, as well as state-wide programs, designed to help you with new and existing needs. Areas in which you may need help:
- Finances
- Mental Health Services
- Food/Meal Preparation
- Medication
- How to make your home easier to get around
- Transportation
- Assistive Devices
- Leisure Interests/Adaptive Sports
- Peer and Caregiver Support Groups
- Community Advocacy Support
- Vocational Rehabilitation/Employment
- Community resource packets are available for education of services in your area with education of ongoing support programs promoting re-entry following a hospitalization.
- Each 1 of the 100 North Carolina counties offers various programs. While in Rehab, your Recreational Therapists can inform you of resources available in your community. For more specific information you may also contact your local Chamber of Commerce/ Town Hall for services available in your community.

Chapter 15: Changes to your home

When you eventually return home, there are some helpful changes you may want to consider making in order to make your home easier to get around

- Building or installing a ramp outside the home at the entrance you will be using helps avoid barriers or difficult environmental obstacles such as stairs and improves ease of access.
- Widening doorways in the home may be necessary to ensure a wheelchair can maneuver around the various rooms in the home. Also, arranging furniture so that common traffic areas in the home are open and free of clutter make them easier to move around.
- Level out any thresholds or steps in the home to make it easier to get around and prevent the possibility of tipping.
- Rearranging items in cabinets in both the bathroom and the kitchen so that commonly used items are more easily reached from a seated height.
- Removing the storage cabinets below the sink so you can wheel straight up to the sink and your legs can go underneath the sink make it more easily used and accessible for sink side grooming tasks (please place insulation around sink pipes if you choose to do this in order to protect legs from possibly getting burned).
- Getting a tub transfer bench or shower chair to make the shower or tub easier to get in/out of.
- Pull up any loose rugs to avoid tipping in your chair and pick anything that may block your path.
- Depending on your level of injury, you may want to consider installing railings or grab bars around your toilet and shower.

Chapter 16: Emergencies

Follow-up care is a key part of your treatment and safety. Be sure to make and go to all appointments, and call your doctor if you are having problems. It's also a good idea to know your test results and keep a list of the medicines you take.

When should you call for help?

Call 911 anytime you think you may need emergency care. For example:

Call if you notice signs and symptoms of AD and if the symptoms do not go away after 20 minutes. **see pages 20-21**

Call your doctor now or seek immediate medical care if you have signs of infection:

- Increased pain, swelling, warmth, or redness.
- Red streaks leading from an incision.
- Pus draining from an incision.
- A fever.
- If you need help with urination and bowel movements.
- If you have cloudy or foul-smelling urine.
- If you have pressure injuries.
- If you feel hopeless and depressed.

Watch closely for changes in your health, and be sure to contact your doctor if you have any problems.

Where can you learn more?

Go to MyUNC at https://myuncchart.org.

Select Preferences in the upper right hand corner, then select Health Library under Resources. Enter Z114 in the search box to learn more about "Spinal Cord Injury

Glossary

Term	Definition
Autonomic Dysreflexia	A sudden increase in blood pressure, 20-40 mm Hg systolic higher than usual, resulting from harmful, painful, or injurious stimuli below the level of injury in persons with an SCI
Bladder	A pouch where urine is stored
Blanchable	Area of skin where it becomes white when pressed, however, when pressure is removed, area becomes red again indicating blood flow
Bowel	Tube that carries solid waste from the stomach out of the body
Diaphragm	A muscle that helps with breathing that separates the chest from the abdomen
Fertility	The ability to give birth to a child
Lubrication	A liquid or gel that women and their partners can apply during sex to make the vulva, vagina or anal area wetter
Muscle atrophy	Shrinking muscles
Pneumonia	Infection in the lungs
Urinate	To pass urine out of the body