

Frazier Rehabilitation Institute

UL Health



Patient and Family Spinal Cord Medicine Handbook

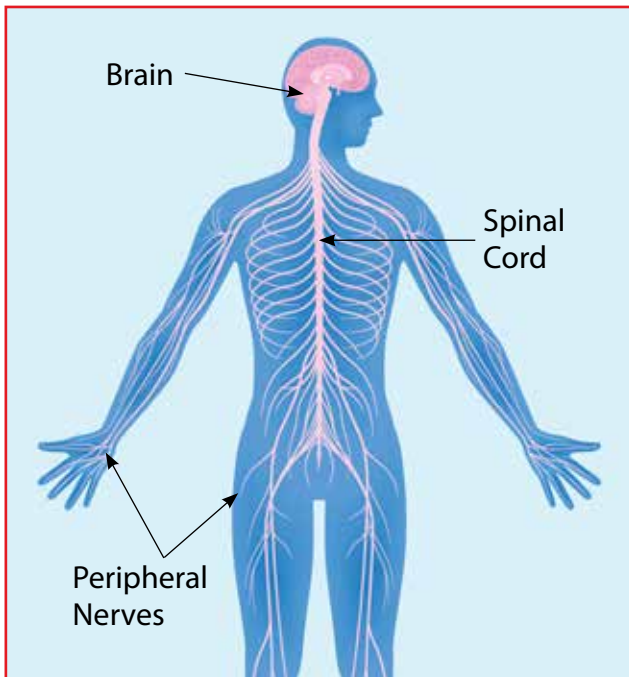
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Chapter 1: Anatomy of the Spinal Cord

Spinal Cord Injury

- A Spinal Cord Injury is an injury to the central nervous system (CNS) which includes two major divisions: the brain (encased by the skull) and the spinal cord (encased by the vertebral column/backbone). In a spinal cord injury, the damage is done to the spinal cord.
- Each Spinal Cord Injury (SCI) is unique and depends on the extent of damage to the spinal nerves.



The Nervous System

Brain and Spinal Cord: the spinal cord is an extension of the brain and is the largest and most complex bundle of nerve fibers and cells that connect the brain with muscles, skin and internal organs.

Spinal Nerves: 31 pairs of spinal nerves branch out from the cord at the upper part and the lower part to innervate the arms, hands, torso, pelvis, legs and feet.

Peripheral Nerves: nerves branch and divide even further to reach the skin, blood vessels, muscles, bones and every part of the body from top to bottom.

Autonomic Nervous System

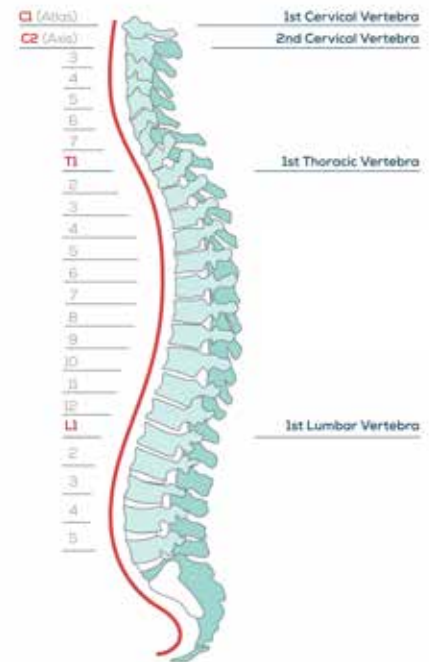
Another system of nervous tissue that controls the automatic functions of the internal organs and glands without any awareness or conscious control. The sympathetic and parasympathetic systems regulate involuntary functions and balance each other. One system predominates depending on the body's needs.

- Sympathetic system: supplies energy for sudden responses such as reaction of fight, flight or fear. Blood pressure rises, heart rate increases and pupils get larger.
- Parasympathetic system: slows down action and prevents body from becoming over excited. Blood pressure lowers, heart beats more slowly and size of pupils decreases.

The Spinal Column

Individual bones called vertebrae make up the spinal column. The vertebrae are stacked one on top of the other and surround the spinal cord in a canal, which serves as protection for the cord itself and other elements within the canal.

- **Cervical vertebrae (C1-C7) are located in the neck.**
 - Cervical nerves (C1-C8) control motor and sensory functions in the shoulders, arms, wrists, fingers, and diaphragm
- **Thoracic vertebrae (T1-T12) are located in the middle and upper trunk.**
 - “Upper” thoracic nerves (T1-T2) contribute to pinky finger and under arm motor and sensory function.
 - “Lower” thoracic nerves (T2-T12) control trunk (back and rib muscles) and abdominal musculature and the sensory function in those areas. (They also contribute to the autonomic function, which include unconscious bodily functions such as heart rate, sweating, and digestion).
- **Lumbar vertebrae (L1-L5) are located in the low back.**
 - Lumbar nerves (L1-L5) control motor activity of the low back, leg, and feet muscles and the sensory function in the front of the legs.
- **Sacral vertebrae (S1-S5) are located in the pelvis and are normally fused with the coccyx located at the end.**
 - Sacral nerves (S1-S5) control motor activity of the muscles in the legs, feet, and pelvis and the sensory function in the back of the legs and buttock area.



Total Vertebrae: 29

- Cervical (neck): 7
- Thoracic (chest and rib cage): 12
- Lumbar (low back): 5
- Fused Sacrum (tailbone): 5

Other support: ligaments, muscles and tendons provide stability to the column and support body movement.

Intervertebral Discs: in between each vertebrae a fibrous disc cushions the vertebra and protects the spinal nerves that extend from the cord to the rest of the body.

Spinal Cord Classification

The International Standards for Neurological Classification of SCI (ISNCSCI) exam is a neurological examination that determines how far down from the brain the spinal cord is functioning as it was prior to the injury. This level is known as the neurological level of injury (NLI) and indicates where movement (motor) and sensation (sensory) are both normal.

- Motor nerves: carry messages the brain sends through the spinal cord to control the movement of muscles.
- Sensory nerves: send signals back to the spinal cord and then the brain so we can feel hot, cold, touch, pain and pressure.
- **Injury can impact motor nerves, sensory nerves, or both.

Injury Severity

The ISNCSCI exam will also provide the severity of the injury. The severity is reported as an ASIA impairment scale (AIS) grade, A, B, C, D, or E. In general, these grades are based off the person's ability to feel and/or have motor function in the lowest part of their spinal cord (S4-5), and then the spared activity between there and their NLI.

Specific Classifications

- **Complete Spinal Cord Injury:** no sensory or motor function is maintained in the lowest sacral segments S4-S5.
- **Incomplete Spinal Cord Injury:** partial preservation of sensory and/or motor function in lowest sacral segments S4-S5. Sacral sensation includes sensation at the anus as well as deep anal sensation. The test of motor function is the presence of voluntary contraction of the external anal sphincter upon digital examination.
- **Zone of Partial Preservation:** refers to those dermatomes (sensory) and myotomes (motor) at or below the NLI that remain partially innervated.

Exam Sample Page

ASIA INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY (ISNCSCI) ISNCSCI

Patient Name _____ Date/Time of Exam _____
 Examiner Name _____ Signature _____

RIGHT MOTOR KEY MUSCLES **SENSORY KEY SENSORY POINTS** **MOTOR KEY MUSCLES** **LEFT**

Light Touch (LTR) Pin Prick (PPR) Light Touch (LTL) Pin Prick (PPL)

UER (Upper Extremity Right) **UEL** (Upper Extremity Left)

Elbow flexors C5
 Wrist extensors C6
 Elbow extensors C7
 Finger flexors C8
 Finger abductors (little finger) T1

LER (Lower Extremity Right) **LEL** (Lower Extremity Left)

Hip flexors L2
 Knee extensors L3
 Ankle dorsiflexors L4
 Long toe extensors L5
 Ankle plantar flexors S1

(VAC) Voluntary Anal Contraction (Yes/No)

RIGHT TOTALS (MAXIMUM) **LEFT TOTALS** (MAXIMUM)

MOTOR SUBSCORES **SENSORY SUBSCORES**

UER + UEL = UEMS TOTAL LTR + LTL = LRTOTAL
 LER + LEL = LEMS TOTAL PPR + PPL = PPTOTAL
 MAX (25) (25) (50) MAX (50) (50) (112) MAX (50) (50) (112)

NEUROLOGICAL LEVELS **3. NEUROLOGICAL LEVEL OF INJURY (NLI)** **4. COMPLETE OR INCOMPLETE?** (In injuries with absent motor S4-5 sensory function in S4-5 only)
 1. SENSORY **5. ASIA IMPAIRMENT SCALE (AIS)** **6. ZONE OF PARTIAL PRESERVATION** **SENSORY** **MOTOR**

2. MOTOR **7. ZONE OF PARTIAL PRESERVATION** **SENSORY** **MOTOR**

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Spinal Cord Causes and Terminology

Traumatic Causes: motor vehicle accidents, falls, acts of violence and recreational sporting activities

Non-traumatic Causes: medical and surgical complications, spinal strokes, inflammation associated with infections or autoimmune or other disease processes and birth defects.

Possible Mechanisms of Injury:

- **Contusion:** bruising of the spinal cord which can occur when the cord is thrown hard against the vertebrae as in a whiplash injury
- **Compression:** pressure on the spinal cord which can be caused by a ruptured disc, broken vertebrae or tumor
- **Severed or lacerated:** a cut of the spinal cord commonly caused by a knife or bullet
- **Diseases and infections:** Multiple Sclerosis, Transverse Myelitis, Acute Flaccid Myelitis, Friedreich's Ataxia and Amyotrophic Lateral Sclerosis (ALS).
- **Birth defects:** Spinal Bifida

Paraplegia: loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord. Arm functioning is spared, but, depending on the level of injury, the trunk, legs, and pelvic organs may be involved.

Tetraplegia: loss of motor and/or sensory function in the cervical segments of the spinal cord. Tetraplegia results in impairment of function in the arms as well as in the trunk, legs, and pelvic organs.

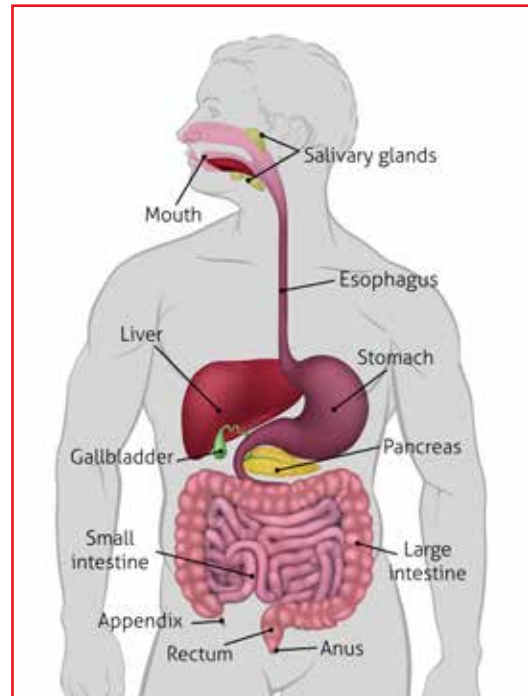
References and Resources

- NeuroRecovery Network for Spinal Cord Injury: christopherreeve.org/
- Spinal Cord Research Center, University of Louisville: kscirc.org
- Spinal Cord Research Center, University of Kentucky: mc.uky.edu/scobirc
- Spinal Cord Resource Center including research information: paralysis.org
- Classification of Spinal Injuries, ASIA scales: sci-info-pages.com/levels.html
- University of Alabama at Birmingham: spinalcord.uab.edu
- National Institute of Health: ninds.nih.gov/
- National Spinal Cord Injury Association: spinalcord.org

Chapter 2: Bowel Care

The digestive system consists of the mouth, pharynx, esophagus, stomach, small and large intestines, rectum, and anus. The digestive system provides two major functions: (1) food is broken down by mechanical (muscle activity) and chemical action allowing it and fluids to be absorbed as nutrients by the body and (2) undigested and unabsorbed material and bacteria (waste products) are passed through the digestive system and eventually excreted from the body.

As the bowel fills with stool, it stretches and triggers messages to the body. One message stimulates muscles to move the stool down through the bowel. Other messages let you know it is time to go to the bathroom. The muscle at the opening of the rectum, called sphincter, allows you to control the bowel movement.



Bowel Movement After Spinal Cord Injury

After spinal cord injury, messages that pass through the spinal cord from the bowel to the brain and messages from the brain to the bowel may be disrupted or lost completely. As such, you may not be able to feel when your bowels are full, nor be able to control when you will have a bowel movement. Depending on the level and severity of injury, you may experience what is called a **neurogenic bowel**. A neurogenic bowel describes impaired bowel function because of an injury to the brain, spinal cord and/or nerves from the spinal cord to the bowels. There are generally two types of neurogenic bowel dysfunctions that occur after a spinal cord injury.

- **Reflexic Bowel** also known as a spastic bowel results from an upper motor neuron injury at the level of T12 and above. This type of injury interrupts messages between the colon and the brain but the spinal cord still coordinates peristalsis and bowel reflexes. As stool builds up in the rectum, reflexes are triggered, and you will have a bowel movement without warning. Between bowel movements, your anal sphincter remains tight.
- **Areflexic Bowel** also known as a flaccid bowel results from a lower motor neuron injury at the level of L1 and below. This type of injury reduces peristalsis and reflexes that control the bowels, and your anal sphincter remains loose. As stool builds up in the rectum, due to the damage of the reflexes, stool cannot be emptied by itself.

Bowel Management Program

A bowel program is designed to help regain control of your bowel function after spinal cord injury to help improve quality of life. An effective bowel program will help empty your bowel on a regular basis, eliminate or minimize accidents and decrease complications such as diarrhea, constipation, and autonomic dysreflexia.

Reflexic Bowel

Bowel programs usually involve using a suppository with digital stimulation. A suppository is a medicine that is placed in the rectum to help trigger the muscles and nerves in the bowel. **Digital stimulation** relaxes and opens the anal sphincter to help eliminate the bowel.

Areflexic Bowel

Bowel programs generally involve **manual disimpaction** of the stool. Suppositories are generally not required because the response would be very sluggish. Management of this type of bowel may require more frequent emptying of the bowel.

Placement of Suppositories

Insert a well-lubricated gloved finger into the rectum and remove any stool that may interfere with inserting a suppository. After all stool is removed, insert a lubricated suppository through the anus and place it against the wall of the rectum. Be as gentle as possible when removing stool, placing suppositories, or performing digital stimulation as the tissue in and around the rectum and colon are delicate. You should wait approximately 15 to 30 minutes for the suppository to work prior to starting digital stimulation.

Performing Digital Stimulation

Digital stimulation is performed by placing a well-lubricated gloved finger approximately 1/2 to 1 inch into the rectum and gently rotated in a circular motion against the anal sphincter. This helps to relax the muscle and create an opening through which stool can pass. This relaxation will also help increase peristalsis.

Digital stimulation usually takes 20 seconds and should be done no longer than one minute at a time. Repeat digital stimulation every 5 to 10 minutes until you have a bowel movement.

Performing digital stimulation can trigger autonomic dysreflexia in some persons with an injury T6 and above. If this happens, you may need to apply lidocaine jelly into the rectum before you start your bowel program.

Successful Bowel Program Management

Each person's bowel program should be individualized to fit his or her needs. You and the rehab team will decide which bowel program works best, based on the type of spinal cord injury you have. There are certain things that you can do to make your bowel program more successful, including:

- **Timing of the bowel program.** For many, starting a bowel program 30 minutes after a meal or drinking warm liquids may help produce better results. This stimulates peristalsis which assists with pushing food through your digestive system to empty the bowel.
- **Consistency of the bowel program.** You may choose to do a morning or evening program after you return home. No matter which schedule is chosen, it is important to remember that the bowel program must be done at the same time each program day.
- **Positioning.** Sitting upright on a commode uses gravity to help move the stool down for easier evacuation. If you cannot tolerate an upright position, lay on your left side because that is where the bowel ends.
- **Keep the stool well formed.** Your stool should not be too soft or too hard. You may need to adjust your diet and fluid intake to change the softness of your stool. You should try to eat a well-balanced diet that is high in fiber which will help maintain a formed stool consistency. Drinking 8 to 10 glasses of water each day will help keep your stool from becoming too hard.
- **Stay active and exercise as much as possible.** Being active promotes better digestion of food and allows for better management of your bowel program.

Complications Associated with Neurogenic Bowel

► Constipation

Constipation is hard and infrequent stool that is difficult to pass. Constipation can be caused by many things including prolonged bed rest, lack of exercise, poor diet, and poor fluid intake. Some medication can cause constipation such as pain medications, iron, antacids, and some antidepressants. Lastly, not doing your bowel program consistently may increase your chance of being constipated.

Signs and symptoms of constipation

- Hard, loose, or watery stools
- Irregular bowel movements and/or accidents
- Swollen or hard stomach
- Loss of appetite
- Nausea and vomiting

Suggestions/solutions for constipation include:

- Eating a well-balanced diet which is high in fiber
- Adequate fluid intake of at least 8 to 10 glasses of water
- Exercise and staying active
- Maintain a consistent bowel program

► Diarrhea

Diarrhea is the increase in the frequency of bowel movements, usually three or more times a day, where stools are loose and watery.

Causes of diarrhea include:

- Eating foods that are spicy, high in fat content, or contains caffeine
- Certain medications, such as antibiotics
- Overuse of stool softeners or laxatives
- Stress

Suggestions/Solutions for diarrhea include:

- Avoid foods that can irritate your bowel
- Drink plenty of fluids. Diarrhea can cause you to become dehydrated
- Stop taking bowel medications until diarrhea stops
- If diarrhea lasts longer than 24 hours, consult your physician



Conclusion

In conclusion, bowel dysfunction after spinal cord injury should not prevent you from leading a healthy, active life. With a proper bowel management program, you should be able to achieve control of your bowels. The goal is to eliminate or minimize accidents and avoid the complications associated with constipation, impaction, diarrhea, and autonomic dysreflexia. This should, in turn, provide you with a sense of control and dignity around the sensitive issues of elimination.

References and Resources

- Bowel care
 - mageerehab.org
 - pva.org
 - sci.washington.edu/info/pamphlets/bowels_1.asp

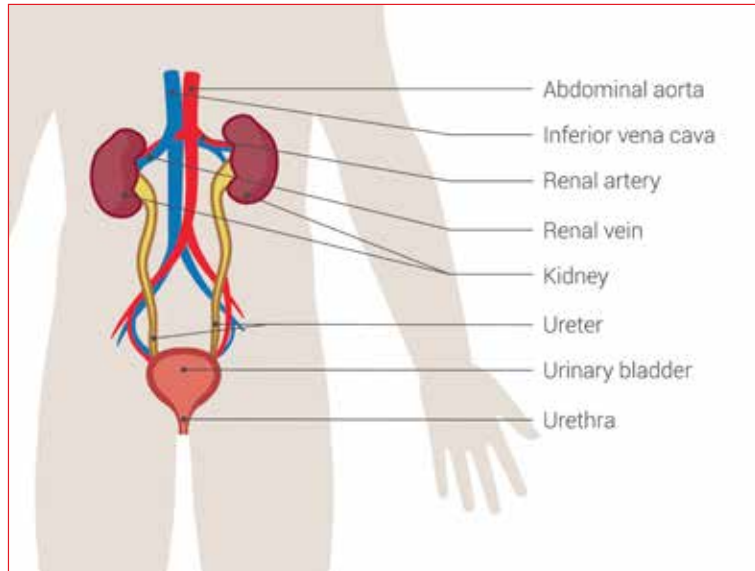
Chapter 3: Bladder Care

The Urinary System consists of the kidneys, ureters, bladder, sphincters, and the urethra. This system performs two major functions: (1) regulation of specific body chemicals, called electrolytes that are needed for your body to function properly and (2) removal of waste products and excess water from your blood. Your kidneys filter blood as it passes through by removing waste products and excess water, which creates urine. Once collected in the kidneys, urine leaves each kidney through a small tube, called a ureter, and drains into the bladder where urine is stored until it is released or eliminated from the body.

As the bladder fills with urine, sensory nerves send messages through the spinal cord to the brain. As this happens, you become aware of a full bladder and know it is time to use the bathroom.

When you decide to empty your bladder, your brain sends messages down your spinal cord to the bladder and the detrusor and sphincter muscles. **The detrusor muscles make up the walls of the bladder and helps push urine out of the bladder.** The sphincter muscles are located at the bottom of the bladder that act like a valve to hold urine in the bladder.

When it is time to urinate, the detrusor muscles contract (tighten) to push urine out of the bladder. At the same time, the sphincter muscles relax (open) which allows urine to flow out of the body through the urethra.



Bladder Function After Spinal Cord Injury

After spinal cord injury, messages that pass through the spinal cord from the bladder to the brain and messages from the brain to the bladder may be disrupted or lost completely. As such, you may not be able to feel when your bladder is full, nor be able to control when you will urinate. Depending on the level and severity of injury, you may experience what is called a **neurogenic bladder**. A neurogenic bladder describes impaired bladder function because of an injury to the brain, spinal cord and/or nerves from the spinal cord to the bladder. There are generally two types of neurogenic bladder dysfunctions that occur after a spinal cord injury.

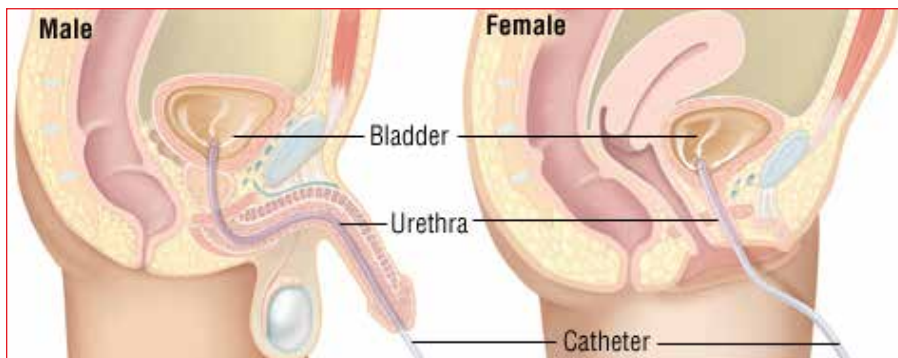
- **Reflexic Bladder** also known as a spastic bladder results from an upper motor neuron injury at the level of T12 and above. When your bladder fills with urine, a reflex automatically triggers the bladder to empty as the detrusor muscles contract. In this situation, you may not know when or if the bladder is emptying or if it has emptied completely.
- **Areflexic Bladder** also known as a flaccid bladder results from a lower motor neuron injury at the level of L1 and below. When your bladder fills with urine, because the reflexes of the detrusor muscles are diminished or absent, it may become distended (overfilled and over stretched). This means the bladder muscles do not push urine out of the bladder and can be damaged from overstretching.

Bladder Management

If your bladder does not work as it once did before injury, a bladder management program may be necessary. An effective bladder program will help you empty your bladder properly, avoid bladder accidents and minimize complications such as a urinary tract infection or autonomic dysreflexia. Your rehab team will help you establish a bladder program that works best for you.

Intermittent Catheterization (IC) also known as “in and out” catheterization, is the method most often recommended for bladder management. ICs are done typically every 4 to 6 hours by inserting a catheter through the urethra into the bladder, draining the bladder of urine and then removing the catheter. This management is healthier and urinary tract complications are less common. People who use this method must keep track of their fluid intake and be consistent with performing catheterizations.

Indwelling Catheterization is a method of bladder management where a catheter is inserted into the bladder and stays in place allowing for a continuous drainage of urine into a collection device (bedside drainage bag or leg bag). Indwelling catheters may be an option for those with limited hand function or have limited caregiver assistance. However, this method of bladder management has a higher risk for complications such as urinary tract infections and bladder or kidney stones. There are two basic types of indwelling catheters. Urethral indwelling catheters are inserted through the urethra and a suprapubic catheter is inserted through a surgical opening in the lower abdomen.



devasyahospital.com/wp-content/uploads/2018/12/nursing_care.jpg

Spontaneous Voids

Some patients experience spontaneous voids in between intermittent catheterizations which can be voluntary or involuntary. A voluntary spontaneous void means that the urination is under your control. An involuntary spontaneous void is not controlled, and the bladder begins to empty without notice. Depending on your level of injury, a spontaneous void may be caused by a reflex spasm of the bladder or from the overflow of a full bladder. Spontaneous voiding can also be a sign of a urinary tract infection.

How Much Fluid is Needed?

It is recommended that you drink about 2,000 to 2,400 ml of fluid a day. This is equivalent to approximately 8 to 10 cups of fluid a day. Your fluid intake is important in helping to keep your body functioning properly and minimizing complications such as dehydration and constipation.

Water is the ideal fluid for you to drink. Alcoholic beverages should be avoided, especially if you are taking medications. You may also need to space your fluid intake throughout the day instead of drinking large amounts at one time. Restricting your fluid intake before bedtime may help minimize how often you have to IC during the nighttime.

The amount of urine in the bladder between IC should not exceed 500ml. If you have more than this amount in your bladder at any one time, the bladder muscles can become overstretched and/or urine may back up into the kidneys possibly causing an infection. You may need to perform your ICs more often if you are getting out more than 500 ml of urine at one time.

Clean Technique Catheterization

The clean technique is performed as described below. Supplies needed include a catheter, washcloths or baby wipes, clean tray, and antiseptic soap.

- Wash your hands with soap and water or clean with hand sanitizer.
- Wash genital area thoroughly with a baby wipe or a damp washcloth and soap.
 - Males should clean from the tip to the base of the penis and females should clean from front to back.
- Position a collection tray between the legs. The end of the catheter that drains urine should be aimed toward the collection tray.
- Males need to hold the penis with one hand. Females need to spread the outer skin folds of the vagina using one hand.
- The catheter should be inserted with the free hand. Insert the catheter until urine flows, then advance the catheter about 1 to 2 inches further.
- When the stream of urine starts to a trickle, gently massage your abdomen. This type of massage is called the **credé maneuver**, and it helps to gently push any remaining urine from your bladder.
- Carefully remove catheter.
- Rinse genital area with a baby wipe or damp washcloth and soap.
- Wash your hands with soap and water.

Urinary Tract Infection

Urinary tract infections (UTI) are an ever-present concern for those with a spinal cord injury. The source of UTI is bacteria which are tiny, microscopic organisms that can quickly reproduce and multiply and can cause an infection. Unfortunately, UTIs do happen even when you do everything you can to prevent them.

▶ Signs and Symptoms of UTI

- Cloudy and/or foul-smelling urine
- Increase in mucous or sediment
- Increase in bladder or general spasms
- Pain or burning with urination
- Increase in frequency or incontinence
- Low back or flank pain
- Blood in urine
- Fever
- Nausea/vomiting
- Just not feeling well
- Autonomic dysreflexia

▶ Preventing Urinary Tract Infections

- Routinely and completely empty your bladder. When not emptied regularly, bacteria in the bladder may multiply and cause an infection. A clean catheter should be used each time you do an IC. For those using indwelling catheters, it is equally important to keep the tubing free of kinks and to drain the collection bag routinely.
- Proper position of drainage bags. If using an indwelling catheter that connects to a drainage bag, the bag should always remain below the bladder so urine will drain freely. Empty the drainage bag when it is half full. This helps prevent the backflow of urine and allows your bladder to continuously empty completely. Clean your drainage bag daily to prevent build-up of sediment that can interfere with proper drainage. Always clean with alcohol wipes before reattaching drainage bag to the catheter.
- Keep your skin clean. Wash the genital area with soap and water every day. Change your clothes if they become soiled and wash the genital area immediately after any urine or bowel accidents. Always wash your hands before and after providing bladder care.
- Follow up with your urologist. A urologist can also perform exams and procedures, make recommendations, or order tests to help better understand your bladder and how to manage it. Several tests are available to help monitor the health of your urinary system including renal ultrasounds, cystoscopies and urodynamics.

▶ Treatment of Urinary Tract Infection

If you suspect you have a UTI, you should call your doctor or healthcare provider as soon as possible. You may be asked to obtain a sample of your urine in a sterile specimen cup so it can be analyzed in a laboratory to determine if you have an infection and the specific bacteria causing the infection. The test that may be ordered is called a urinalysis with culture and sensitivity (UA C&S). Knowing the specific bacteria, your doctor can order the most appropriate antibiotic. If an antibiotic is prescribed, it is important to take it exactly and completely as prescribed.

References and Resources

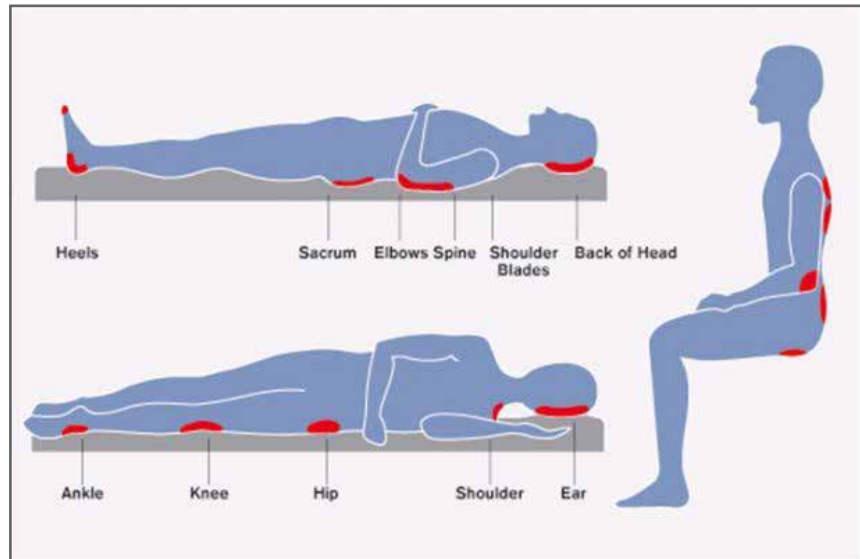
- Bladder Care
 - [nlm.nih.gov/medlineplus/ency/article/003981.htm](https://pubmed.ncbi.nlm.nih.gov/medlineplus/ency/article/003981.htm)
 - pva.org
 - spinalcord.uab.edu/show.asp?durki=21484

Chapter 4: Skin Care

The skin is the largest organ in the body which acts as a protective covering between a person and the environment and has several important functions. The primary function is to prevent harmful bacteria from entering your body and help prevent fluid loss. The skin also helps in the regulation of body temperature, both heating and cooling. Your skin also is an organ of sensation, including pain, touch, and pressure, as well as hot and cold temperature.

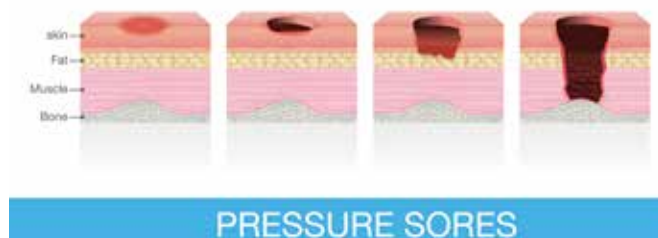
After spinal cord injury, the nerve cells in the sensory track of the spinal cord may be damaged, resulting in a decrease of sensation below your level of injury. The sensations of pain, touch, pressure, heat or cold may be altered, or lost, and skin injuries can occur quickly. One of the most common skin injuries is a **pressure ulcer**. A pressure ulcer is known by many names such as pressure sore, decubitus ulcer, ischemic ulcer, and bed or skin sore. No matter what name it is given, it is a serious problem that can take days, weeks, months, or even longer to heal.

You can develop a pressure ulcer when an area of the skin or underlying tissue does not get adequate blood flow due to prolonged pressures, and the skin or tissue begins to die. Most common areas for pressure ulcers are over bony prominences.

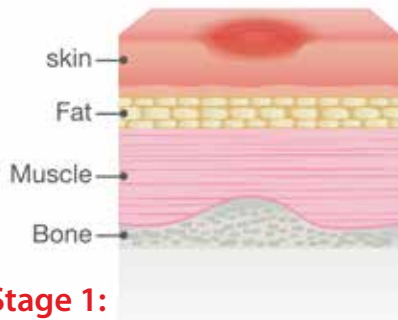


Risk Factors for Developing a Pressure Ulcer

- People with spinal cord injury spend a lot of time either in a wheelchair or in bed, this puts continuous pressure on the same parts of the body. If you do not perform pressure relief regularly and effectively you can damage your skin.
- Bowel and bladder accidents can further weaken the skin and cause skin to break down more easily.
- Spasticity and frequent or poor-quality transfers can cause shearing of the skin.



Stages of a Pressure Ulcer



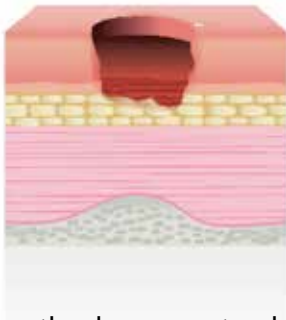
Stage 1:

Damage is limited to the top 2 layers of the skin. The skin is intact with a different color – pink or red in light skin; red, blue, or purple in darker skin. At this stage, the skin is not broken.



Stage 2:

Damage is limited to the top 2 layers of the skin. The sore may appear to be a scrape, blister, or small crater and the skin may be broken.



Stage 3:

At this stage, the damage extends through both layers of skin and the subcutaneous tissue all the way to, but not completely through, the deep fascia. This ulcer may appear as a deep crater and adjoining tissue may be damaged.



Stage 4:

The damage extends through all tissue layers and involves the muscle and bone and may extend to tendons and joints. Osteomyelitis or bone infection can be a serious complication associated with this type of pressure ulcer.

There are two other types of pressure injuries that do not fit into any of the four stages:

- Unstageable sores are covered in dead skin that is yellow, tan, green, or brown. The dead skin makes it hard to tell how deep the sore is.
- Deep tissue injury (DTI) is an injury that develops in the tissue deep below the skin. The area may be dark purple or maroon, and there may be a blood-filled blister. This type of injury can quickly become a stage III or IV.

Care and Treatment of Pressure Ulcers

At the first sign of a pressure ulcer, you must keep weight off the damaged area to promote healing. Depending on the severity, treatments can range from pressure relief, wound care to surgery. Your physician or a wound care specialist will determine the best treatment needed which may include cleaning and caring for the wound on a regular schedule. Cleaning helps to remove dead tissue or waste products from the wound so healing will be more successful.

Watch for signs of infection in the wound. These may include redness around the edges, warm skin, colored drainage, odor, or fever. An antibiotic may be prescribed if an infection is found. If a wound is bad enough, you may have to take time off work or limit your activities; however, this decreased activity level places you at higher risk for other complications such as respiratory compromise or infections. Stated briefly, you do not want a pressure ulcer; if you get one, it will take time to heal, and your overall health may be affected in a negative way.

Prevention of Skin Breakdown

▶ Pressure Relief is Essential

While in the wheelchair, pressure relief should be completed every 15 to 30 minutes depending on the level of injury and mechanism of relieving pressure. This allows your skin to be re-nourished by blood supplying oxygen and nutrients, thus preventing prolonged pressure in one area. While in bed, you should be repositioned at least every two hours. Also, try to keep bony areas from touching each other by using a pillow or foam.

▶ Always Utilize Proper Equipment

Proper cushions and mattresses help ensure proper positioning and help alleviate pressure by distributing the weight over larger areas of the body.

▶ Maintain Proper Skin Hygiene

Moisture weakens the skin and causes it to breakdown more easily so always keep your skin clean and dry. The buildup of sweat, dirt, and other waste products that can remain on the skin, make it more inviting for germs to invade the body. You should always wash and dry the skin immediately after any bowel or bladder accidents.

▶ Protect Your Skin

Because of impaired sensation after spinal cord injury, you should be mindful when it comes to protecting your skin such as:

- Heat can damage your skin and make pressure ulcers more likely. Be careful when it comes to exposure to heat such as time spent outdoors on hot, sunny days or heating pads. Always monitor the temperature of hot foods and liquids.
- You should avoid clothes and shoes that are too tight or has buttons or zippers that may place pressure on the skin.
- Take special precaution when performing transfers or participating in new activities or sports. Avoid movements or activities that may cut, scratch, or rub the skin.

▶ **Maintain Adequate Fluid Intake and a WELL-BALANCED Diet**

Work with a dietitian in planning meals that are high in protein, vitamins, and minerals. A balanced diet that includes fruits and vegetables as well as protein will help maintain healthy skin and will promote faster healing if problems occur. Drink at least 8 to 10 glasses of water each day to stay hydrated.

▶ **Avoid Smoking, Drugs, or Alcohol**

Smoking decreases oxygen to the skin and makes it more difficult for skin to heal. Drugs and alcohol can also damage your skin and can lead to other more serious health problems.

▶ **Skin Inspection**

Check your skin at least twice a day, usually once in the morning and once at bedtime. Carefully look for any changes in skin color or damage. Pay close attention to the bony areas which are more susceptible to breakdown.

References and Resources

- Pressure Ulcer: pva.org
- Skin Care: ChristopherReeve.org

Chapter 5: Medical Concerns

Autonomic Dysreflexia

Autonomic Dysreflexia (AD) is a medical emergency which can occur if your spinal cord injury is at the level of T6 and above. Autonomic dysreflexia is a dangerous rise in blood pressure which can develop suddenly, and if not treated promptly, it can lead to seizures, stroke, or death. Autonomic dysreflexia is an abnormal response to something that is painful or irritating below the level of injury. In a person with spinal cord injury at T6 and above, the blood pressure cannot be regulated because the message from the brain to dilate the blood vessels to lower the blood pressure cannot pass level of injury. The blood pressure may continue to rise until the cause, or the irritating stimulus is eliminated.

Causes of Autonomic Dysreflexia

Bladder

- Distended or overstretched bladder
- Kinked or clogged catheter tube
- Urinary tract infections
- Bladder or kidney stones
- Catherization

Bowel

- Constipation or impaction
- Digital stimulation
- Hemorrhoids

Skin Related Problems

- Constrictive clothing, shoes, or appliances
- Blisters, burns, sunburn, or frostbite
- Ingrown toenails
- Pressure ulcers

Reproductive

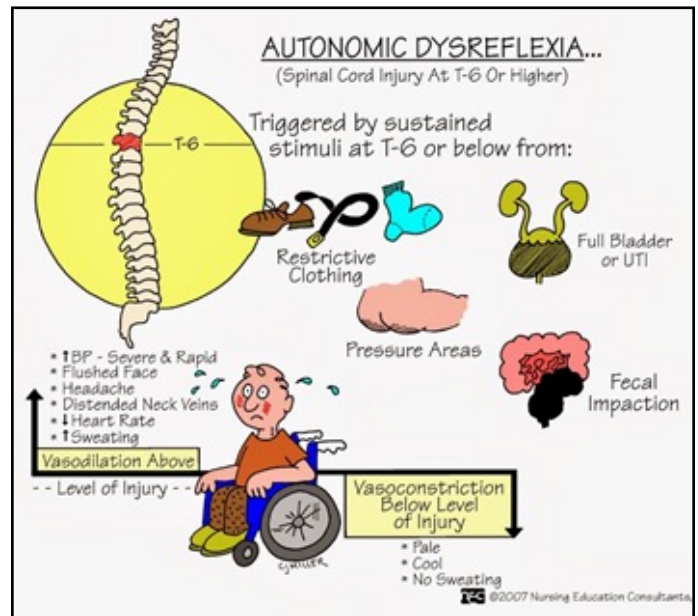
- Sexual intercourse
- Sexually transmitted infection (STI)
- Ejaculation
- Menstruation or Pregnancy

Other Sources

- Heterotopic ossification (HO)
- Deep vein thrombosis (DVT) or Pulmonary emboli (PE)
- Surgical or invasive procedures
- Bone fractures

Recognizing the Signs and Symptoms of Autonomic Dysreflexia

- Elevated blood pressure – systolic blood pressure 20-40 mm HG above baseline
- Bradycardia (low heart rate)
- Pounding headache
- Sweating above the level of injury
- Goosebumps above the level of injury
- Flushing above the level of injury
- Blurred vision or spots
- Nasal congestion
- Feeling anxious
- Silent autonomic dysreflexia – minimal or no symptoms, despite a significantly elevated blood pressure



Treatment for Autonomic Dysreflexia

- Immediately sit up in an upright position
- Monitor blood pressure and heart rate frequently
- Loosen any clothing, shoes or constrictive device
- Check bladder for distention – most common cause
 - Catheterize with lidocaine jelly (if immediately available)
 - Check for kinks and proper drainage with indwelling catheters
- Check bowels for fecal impaction
- Perform a skin check for bruises or abrasions

Medications for Autonomic Dysreflexia

Quick action and troubleshooting will usually resolve autonomic dysreflexia. However, if the offending trigger or stimulus cannot be identified and removed, it may be necessary to utilize medications that has a rapid onset and short duration while the causes are being investigated. They generally include:

- Nitroglycerin paste
- Nifedipine bite and swallow

These are general guidelines, and you should consult your physician before using blood pressure medications to control the symptoms associated with autonomic dysreflexia.

Prevention of Autonomic Dysreflexia

- Maintain a regular and consistent bladder and bowel program.
- Frequent pressure relief in the wheelchair and bed. Perform wheelchair pressure relief at least every 15 to 30 minutes and change positions in the bed at least every 2 hours.
- Protect your skin. Dress appropriately to prevent sunburns or frostbite.

Deep Vein Thrombus

Deep Vein Thrombus (DVT) is a blood clot that block the flow of blood in a blood vessel. This generally occurs in the veins of the lower leg and thigh, but can occur in any large vein, including blood vessels in the pelvis and arms. The blood clot or thrombus can cause circulation problems, pain, and other serious complications.

Risk Factors

After a spinal cord injury, due to decreased mobility, you can develop certain conditions like slower blood flow and damaged veins which make it more likely to develop a clot.

Signs and Symptoms

A clot in your arm or leg can cause:

- Pain
- Swelling
- Warmth
- Blue-purple skin color

A clot in your lungs can cause:

- Difficulty breathing
- Chest pain, especially when taking a deep breath
- Coughing up blood
- A fast heartbeat

Prevention

- Stay as active as possible. Perform daily range of motion exercises.
- Minimize swelling by elevating legs or wear compressive stockings.
- Check your legs for signs of DVT's daily.
- Take blood thinner if ordered by your physician.

Diagnosis and Treatment

- Call your physician or go to the emergency room immediately.
- A Doppler ultrasound may be ordered to identify a DVT.
- Stay in bed with the affected leg elevated and in a straight position.
- Do not rub or massage affected leg.
- Remove tight shoes and clothing.
- You may be placed on a blood thinner.

Heterotopic Ossification (HO)

Heterotopic Ossification (HO) is the development of new bone in soft tissue where bone is not normally found. This may occur anywhere in the body but is most frequently found around the joints or long bones of the hips, knees, shoulders, and elbows. The highest risk period for the occurrence of HO is 3 to 12 weeks after spinal cord injury. Because the cause is currently unknown, preventive measures are limited. The primary problems associated with HO include decreased mobility and range of motion and may predispose the individual to skin breakdown and contractures.

Signs and Symptoms

- Warmth, swelling, and redness over the affected area
- Decreased range of motion
- Fever
- Increased spasticity
- Joint pain, muscle pain
- Autonomic dysreflexia

Diagnosis

- X-ray (may not detect early stages)
- Triple phase bone scan
- Ultrasound
- Blood tests

Treatment

- Gentle range of motion of the joints.
- Medications to slow down or stop the abnormal growth of bone
- Radiation has been used in some cases to stop the growth of bone
- Surgery to remove if HO severely affects movement or causes extreme pain

Orthostatic Hypotension

Orthostatic Hypotension (OH) is a sudden drop in blood pressure that occurs with positional changes. When your blood pressure drops, there is a temporary decrease of blood flow to your brain, which can make you feel dizzy or lightheaded and can sometimes lead you to faint. Low blood pressure is common in people with a spinal cord injury, especially if your level of injury is at T6 or above, because arteries do not get messages from the brain to constrict and keep the blood pressure regulated at a normal level. This leads the blood to collect in the veins and arteries of the legs and feet instead of being pumped back to the heart.

Signs and Symptoms

- Lightheadedness or dizziness
- Blurred or spotted vision
- Pale face or numbness around the face
- Syncope (passing out)

Prevention

- Make gradual positional changes.
- Wear compression stockings and/or an abdominal binder. These will help prevent pooling of blood in arteries and help pump the blood back to your heart.
- Drink plenty of water throughout the day.
- If your blood pressure drops too low and causes you to faint, your caregiver should lay you down and elevate your legs. If you are in a wheelchair, your caregiver should tilt your wheelchair backwards to lower your head and raise your feet.
- You may also be prescribed medications to help keep your blood pressure more level.

Spasticity

Spasticity is an uncontrolled, involuntary movement of the muscles that is common after a spinal cord injury. Spasticity can affect the arms, legs, and torso and can be triggered by just about anything. Spasticity presents differently from person to person and may come in many forms including: involuntary bending or straightening of limbs, jerking, or twitching of muscles or muscle tightness.

Common Triggers

- Moving or stretching your arms or legs
- Any irritation to the skin, such as in-grown toenails, pressure sores, or tight clothing
- Urinary tract infection or full bladder
- Constipation or hemorrhoids
- Fractures or DVT

Advantages of Spasticity

Spasticity is not always harmful and there are some benefits including:

- Helps promote circulation of blood. It assists in pumping fluid and blood out of the veins, which may help decrease edema and deep vein thrombosis.
- May be used to improve some functional activities such as transfers or walking with braces.
- Increase in spasticity can serve as a warning signal to identify pain or problems in areas where there is no sensation.

Disadvantages of Spasticity

- May interfere with certain activities like safe transfers, driving or sleeping.
- Can cause skin damage from rubbing, shearing, or scraping.
- Can result in loss of range of motion in your joints (contractures).
- Spasticity in the chest muscles can make it difficult to take a deep breath.
- Spasticity can cause pain.

Management of Spasticity

If spasticity becomes a problem and interferes with activities of daily living, you should discuss treatment options with your physician.

- Regular stretching and exercises to maintain flexibility and reduce muscle tightness.
- Orthoses, braces, or progressive casting to provide continuous muscle stretching.
- Oral medications: baclofen, dantrolene, tizanidine, diazepam.
- Botulinum toxin injection is used to target specific muscle groups.
- Intrathecal baclofen pump: Surgically implanted device that delivers continuous medication directly into the spinal canal. This treatment is recommended when all other treatments have been tried and failed.

References and Resources

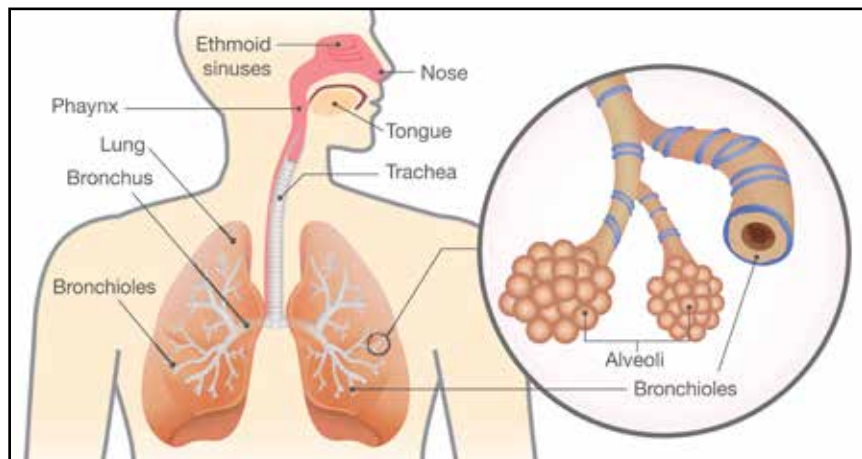
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- Spasticity:
 - emedicine.com/orthoped/topic425.htm
 - msktc.org/sci/factsheets/spasticity

Chapter 6: Lung Care

Spinal cord injury may make it more difficult to breathe air in and out, cough and keep your lungs healthy and free of infection. How well your lungs work after injury will be influenced by the level of your injury. Your recovery will also be affected if you were a smoker, have been exposed to environmental intoxicants or had asthma or other lung diseases.

Normal Anatomy and Physiology

The Respiratory system includes the nose, trachea and lungs. The normal respiratory cycle of inhalation (breathing in) and exhalation (breathing out) occurs at a rate of 12 to 16 times per minute. The nose and mouth warm, humidify and filter the air you breathe. The air breathed in goes through the voice box (larynx) into the windpipe (trachea), and then through the air passages (bronchi) leading to the air sacs (alveoli). It is in the air sacs that oxygen enters the blood



stream and carbon dioxide leaves the blood stream as you exhale. Oxygen is needed for all cells in your body to work. Carbon dioxide is a waste product. The heart sits between the lungs. The oxygenated blood (hemoglobin) goes to the heart where it is pumped to all parts of the body.

The windpipe (trachea) and air passages (bronchi) are simple passageways by which the oxygen you breathe gets into the air sacs. Located in these passageways are tiny hair like structures (cilia) and mucus (phlegm) that help clean the lungs of the dirt and pollution in the air you breathe. It is important to keep this mucus thin in order for the cilia to remove the dirt and clear secretions (mucus) from the lungs.

Your lungs are surrounded by the rib cage and muscles. The major muscle that moves air in and out of the lungs is called the diaphragm. Other muscles which help the diaphragm are the chest muscles, neck, shoulder muscles, and abdominal muscles.

During inspiration, the muscles contract and make the chest cage larger and air is pulled into the lungs. The diaphragm and chest muscles do most of the work. The neck and shoulder muscles also help. During expiration, the muscles relax and air flows out of the lungs. Expiration is usually passive as muscles relax. However, during forceful exhalation, as in a cough, the diaphragm and the abdominal muscles are active.

All breathing muscles are controlled by the brain which sends and receives messages from the spinal cord which in turn is connected to individual nerves that serve the breathing muscles. The brain sends signals to inhale and to exhale 24 hours a day. The brain also monitors oxygen and carbon dioxide levels in the blood and sends messages to the muscles via these nerve routes to tell the muscles to speed up and breathe more deeply or slow down and breathe more shallowly.

Level of Injury and Respiratory Function

Injury to the spinal cord can weaken or paralyze some or all of the muscles needed for you to breathe on your own. The level and extent of your spinal cord injury or impairment will determine how well your respiratory system will function.

- C1-2-Respiratory muscle function lost; breathing muscles paralyzed. Mechanical ventilator/respirator needed for breathing along with tracheostomy to remove secretions due to ineffective cough
- C3-May have diaphragm muscle paralysis. Intercostal muscles ineffective, & unable to take as deep of breath. Typically poor cough, therefore tracheostomy may be needed
- C4-Diaphragm should be working but not the intercostal muscles, therefore deep breathing techniques very important. Cough still weak
- C5-T5-Abdominal muscles paralyzed & varying levels of chest muscle function therefore important to take deep breaths. Cough will be impaired
- T6-T12-Should be able to take a deep breath, but cough may still be impaired
- L1-S5-Breathing muscles should not be affected

*Patients with incomplete impairment/injury may or may not find the specific descriptions listed on the levels accurate for themselves.

Impaired Respiratory Muscle Assistance

▶ Ventilator – Respirator

You may require temporary ventilator assistance while your body heals. However, when spinal cord injury results in paralysis of the diaphragm, a ventilator may be needed on a permanent basis. If so, your pulmonary rehab team will educate you and your family about how to manage a ventilator in the home setting.

▶ Tracheostomy

A tracheostomy is an opening in the windpipe (trachea) into which a metal or plastic tube is placed to allow management of the airway. This may be required for several reasons in the spinal cord injured patient.

- When ventilator support, a respirator, is needed due to weakened or paralyzed respiratory muscles, the tracheostomy allows air to flow from the ventilator to the patient's airway and lungs by-passing the nose or mouth.
- A tracheostomy may also be required if coughing is ineffective and secretions accumulate in the lungs causing poor gas exchange and infection.

Breathing Retraining

Since spinal cord injury may paralyze or impair some of your muscles used for breathing, it is important to strengthen the existing muscles so they can take over some of the lost function. Your pulmonary rehab team will show you various exercises to help you strengthen the working muscles that you have.

Breath stacking is a technique where you take three deep breaths in and hold the air for three seconds and exhale slowly. Some people prefer to use an incentive spirometer, a device to help with deep breathing. This prevents the small air sacs in your lungs from collapsing. You can get into the habit by doing three sets of 10 in the morning, afternoon, and evening.

The Threshold Inspiratory Muscle trainer and Expiratory Muscle Trainer are devices that consist of a spring-loaded valve, mouth piece, and nose clip. They are used to increase the strength and endurance of your respiratory muscles. Just as walking and jogging increase the strength and endurance of certain muscle groups, these muscle trainers strengthen the respiratory muscles. This is done by placing a constant workload on these muscles during inspiration or expiration. The actual amount of resistance and length of time used will be prescribed by one of your pulmonary rehab therapists.

Pulmonary Hygiene

Pulmonary hygiene refers to the removal of secretions which is needed to maintain your lungs' ability to get air into and out of your bronchial tubes and air sacs.

Nebulized medications can be inhaled either through your mouth or tracheostomy tube to help open your air passages. Often, positive pressure and vibration is used to inflate the lungs using a machine called a Cough Assist. A mechanical percussor may also be used to help clear the congestion. Use of saline instillation, humidification and respiratory muscle training may also be used. Treatments are usually two to four times a day depending on the amount of congestion. It's important to remember that controlled coughing should follow each treatment. Sometimes, the cough may not be productive for an hour or two after the session.

Coughing

Coughing is an automatic reflex that causes air to be forcefully expelled to rid the lungs of secretions and foreign substances. In order for a cough to be effective, muscles of the chest, abdomen and the diaphragm need to work in perfect harmony. This very important cleaning mechanism of the lungs is often impaired after spinal cord injury. When some of these muscles are weakened or paralyzed, certain practices can be used to improve the cough.

One technique used is assistive (quad) coughing. This technique is similar to the Heimlich maneuver and is very important to understand if your cough is impaired. The lower palm of your caregiver's hand is placed on the upper abdomen, two or three fingers below the center of the rib cage. Take a slow deep breath and cough. As you cough, your caregiver abruptly pushes the abdomen in and upward. If your arms and

hands are strong enough you can improve your cough by performing this technique yourself. If you have stomach discomfort you can modify the technique by having your caregiver place his or her hands on your outer chest, below ribs, maintaining contact during inspiration. As you cough, the chest wall is abruptly compressed without losing hand contact.

In addition to effective coughing, there are several other things which can be helpful to keep the lungs clear. Drinking the proper amount of fluids, especially water, will make the mucus in the lungs thinner and easier to cough up. Frequent changes in position prevent the pooling of secretions in the lungs and most optimal breathing. You should turn or be turned at least every two hours while in bed. Position changes while out of bed can be done through use of the reclining mechanism on some wheelchairs, lean-overs, or wheelchair pushups.

Warning Signs of Respiratory Problems

Breathing problems are one of the most common reasons for hospitalization during and after rehab.

CALL YOUR DOCTOR IF:

- Increased shortness of breath
- Changes in sputum color, amount or consistency, increased wheezing
- Fever greater than 38.3° C (100° F)
- Signs of dehydration (sticky sputum, dry tongue, dry skin, dark urine)
- Unusual fatigue
- Behavior changes, difficult to arouse
- Headaches, confusion
- Decrease in pulmonary functions (vital capacity) or deep breathing ability.

You should obtain the pneumonia, Covid and flu vaccines. If you smoke or vape anything, you should make efforts to stop. It is important for you to monitor and be aware of all aspects of your respiratory system and ask for help when needed.

References and Resources

- Lung Care: health.yahoo.com/ency/healthwise/ug2580/ug2927

Chapter 7: Cognition, Communication, and Swallowing

Cognition and Communication

Injuries or illnesses affecting the brain can cause problems with memory, problem solving or planning, and speaking. Impaired speech, though, can also be caused by other conditions of the spinal cord or respiratory system. Speech and voice can be hard to produce because the muscles of the chest, throat, mouth, and face are weak, paralyzed and/or uncoordinated. A person with any of these problems may not produce speech or voice that can be heard or understood.

Swallowing

Swallowing problems (dysphagia) occur with some illnesses and injuries. For example, if you have had neck surgery performed as a result of the spinal cord injury, you may feel like food and/or liquid is getting stuck in your throat when you swallow. Special tests and imaging can be performed to determine if you are swallowing correctly and keeping food/fluids from getting into your lungs.

After injury or illness, the first step toward eating and drinking may be tube feedings through the nose to the stomach (nasogastric tube), or through the abdominal wall directly to the stomach (gastric tube). Regular, thin liquids often cause difficulties for you if you have swallowing problems. Thin liquids may be more likely to fall into the lungs instead of the esophagus (food tube). Liquids that have been thickened may be offered to you. Softer or pureed foods may be recommended also.

Preventing Pneumonia

If you have swallowing problems that cause saliva, liquids or food to enter the lungs, you are at risk for getting aspiration pneumonia (an infection in the lungs). **Good oral hygiene is one of the best ways to prevent this type of pneumonia.** Another pneumonia preventive measure is ensuring you are carefully fed if you are unable to feed yourself. Meals that are fed too quickly or bites that are too large can cause food to go into your lungs. Sitting upright at a 90 degree angle while eating/drinking will also help prevent food/liquid from going into your lungs. If a swallowing problem is present, your chances of avoiding pneumonia are also better when you are out of bed and active.

Frazier Rehab Institute pioneered the Frazier Water Protocol (FWP) that permits people who have difficulty swallowing thin liquids to: (1) have water between meals (30 minutes after a meal) or (2) have water anytime if receiving nutrition via tube feedings, even though the water might enter the lungs. Aggressive oral care, including brushing of teeth/tongue, is required. The FWP is a safe practice because our bodies are composed of more than 60% of water and water that enters the lungs is quickly absorbed into the bloodstream without harmful effect, **as long as good oral care has been completed.** All rehabilitation team members offer patients water and assist them to drink water when help is needed.

Chapter 8: Self Care and Activities of Daily Living

After sustaining a spinal cord injury (SCI), you may find it difficult to manage your self-care. In the rehab setting, self-care activities are referred to as activities of daily living or ADLs. Some of the most common ADLs are:

- Dressing
- Bathing
- Toileting (including bowel & bladder management)
- Grooming and Hygiene
- Feeding

Your occupational therapist (OT) will help you develop skills needed to complete your ADLs as independently as possible. It may be necessary to use different techniques and adaptive equipment to perform your ADLs. These devices are used to assist you with completing daily self care tasks. The amount of assistance you may need to perform ADLs varies from person to person depending on your level of injury, current strength and range of motion, and overall prior level of function.

▶ Upper Body Dressing

Upper body dressing (UBD) includes putting on and taking off any clothing items from the waist up. If sitting balance is impaired, it may be safer/easier to sit in a wheelchair or complete from bed level. Additional factors are also considered including hand function and arm movement/strength. If needed, adapted clothing, adaptive equipment, and/or orthoses may be used to increase independence with UBD.

▶ Lower Body Dressing

Lower body dressing (LBD) includes putting on and taking off any clothing item from the waist down. When dressing the lower body, you may find it helpful to use a combination of different techniques and adaptive devices. The most common position for performing LBD is circle sitting or long sitting. These positions allow you to reach your legs/feet, from a more stable surface to assist with balance. Some of the most common pieces of adaptive devices used during dressing include:

- Dressing sticks
- Reachers
- Long-handled shoe horns
- Button hooks
- Elastic shoe laces
- Sock aids
- Leg straps

▶ Bathing

Initially, you will most likely sponge bathe from bed. Once you are medically stable and cleared for showering by the doctor, your occupational therapist will help you learn to shower safely. You may use some of the following equipment/devices to assist with safety and completion of your bath:

- Tub Transfer Bench
- Transfer board
- Shower chair (with tilt/recline feature)
- Universal-cuffs or other orthoses to assist with holding items
- Wash mitt
- Hand-held shower
- Long handled sponge
- Grab bars
- Thermometer

▶ Toileting

Toileting includes the ability to pull down clothing in preparation for elimination, cleaning of the perineal area and pulling clothing up after completion. Toileting is unique for each person. Your OT will help develop a specialized toileting program for patients/caregivers for the discharge environment. A person with SCI is sometimes able to independently complete the process with the correct technique and needed equipment. Examples include:

- Leaning on one elbow to raise a hip and pull down clothing from side to side
- Drop-arm bedside commode for safe transfers
- Toilet aid to reach perineal area

▶ Grooming and Hygiene

Grooming tasks include brushing teeth, washing face, combing hair, shaving and applying make-up. For a person with a SCI, grooming may be more difficult. If sitting balance is impaired it may be safer/easier to sit in a chair/wheelchair to complete. Necessary adaptive equipment and orthotics may include:

- Universal-cuff to hold toothbrush, razor, make-up, etc.
- ADL wrist orthosis to stabilize wrist
- Wash mitt
- Long handled brush
- Lap tray
- Built-up handles

▶ Feeding

Feeding, like upper body dressing and grooming, may be more difficult following a SCI. There are several orthoses and pieces of adaptive equipment available to assist with this process. These items include:

- Universal-cuff to hold utensils
- ADL orthosis to stabilize wrist
- Non-skid bowl
- Plate guard
- Scoop dish
- Adaptive utensils
- Long straw
- Mobile arm supports

As soon as you are able to swallow safely, your occupational therapist will begin working with you to promote self-feeding. This may include strengthening/positioning regimens to increase tolerance for ADL's.

▶ Kitchen and Homemaking Skills

After injury, you may need to try some new ways to cook and clean. You may practice doing these activities from a wheelchair level. There are several types of equipment and modified techniques that may help you become more independent in these areas. Your OT will work with you to discover the techniques that will enable you to be successful.

References and Resources

- Trombly, C. (1995). Occupational Therapy for Physical Dysfunction (4th Ed.). Baltimore: Williams & Williams.
- Adaptive Equipment
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Chapter 9: Nutrition

After spinal cord injury, changes take place in your body that can affect weight, muscle and bone mass, digestion, and general health. Understanding these changes and staying well-nourished are essential to all stages of recovery.

Soon After Injury

During the first several weeks after injury, calories for maintaining weight will likely increase because of the energy your body will need as it tries to heal. At the same time, your appetite and food intake may decrease because of pain, stress, illness, limited mobility, restricted diet, hospital environment or other challenges. If your body is burning more calories than it takes in, weight loss will occur. If this loss is too rapid it is often due to muscle loss in addition to fat loss. Inability to use muscles due to injury also contributes to muscle breakdown. As a rule, the higher the level of spinal cord impairment, the greater the weakness or paralysis, and therefore more “muscle disuse” results. To minimize fast weight loss and muscle shrinkage, dietary changes can be made like adding snacks and specialized shakes to meet your needs. If food intake continues to fall short of daily goals, alternative-feeding methods (tube feedings) can temporarily be used to assure that nutrition needs are met.

Once Medically Stable

Once you are out of the acute or crisis phase, about one or two months after injury, your appetite and food intake will likely improve, old eating habits will return, and weight and protein loss usually stop. With limited physical activity and disuse of certain muscles from spinal cord impairment often permanent changes in body composition occur. Lost muscle is replaced in part by fat, water and connective tissue, which burn fewer calories than muscles. Therefore, you will need fewer calories to maintain weight as compared to pre-injury.

Ideal Body Weight After Injury

After spinal cord injury, one’s ideal body weight is typically lower. This is true as most individuals with injury are not as physically active as they once were, there is a decrease in muscle mass in affected muscle groups, so less calories are needed to be healthy and maintain weight. The ideal body weight is adjusted downward for those with paraplegia by 5-10% and for those with tetraplegia by 10-15%.

FOR EXAMPLE:

- A 5’8” man now has paraplegia. His pre-injury ideal body weight would be 154 lbs. His adjusted ideal weight range would be between 138-146 lbs.
- A 5’5” women with tetraplegia would have a pre-injury ideal body weight of 125 lbs. Her new adjusted ideal body weight range would be 106-113 lbs.

Health Issues and Nutrition

► Skin Health

Because of increased pressure on some parts of the body due to decreased movement, there is a greater chance for skin breakdown. This is compounded by decreased sensation, blood flow and muscle mass. When a person is underweight, insufficient padding over bony areas makes skin breakdown more likely. Obesity also poses a problem since more weight means there is more pressure being placed on some parts of the body. Blood delivers oxygen and nutrients to the cells to allow healing, but blood does not flow as easily through fat mass often delaying healing. Keeping a healthy weight can help prevent skin problems.

► Bowel Function

After injury, bowel function slows down and you may become constipated due to decreased physical activity, reduced trunk-muscle tone, or medications (like iron or pain medications).

Dietary fiber is one way to help resolve problems with bowel function. Fiber absorbs water in the intestine to help form soft, easy-to-pass stools. Since it absorbs water, it is important to consume adequate amounts of water (8-10 cups a day). Keep in mind that some intestinal disorders may need modified amounts of fiber and should be discussed with your dietitian to determine specific needs.



► Gastroesophageal Reflux Disease

After spinal cord injury, your stomach may empty more slowly. This can cause reflux or heartburn. Limit high fat foods and other irritants such as caffeine-containing beverages, mint, carbonated beverages, citrus, or tomato products. Ways to eat that can prevent heartburn include: eat small, frequent meals instead of a few large ones; sit upright and avoiding slouching forward while eating; avoid lying flat after meals and consider elevating the head of the bed while sleeping; avoid late night snacking or eating dinner too close to bedtime; avoid smoking; and wear comfortable clothing.

► Bladder Function

Adequate fluid intake is required for a good bladder and bowel program as well as important for kidney function, regulating body temperature, skin integrity, and overall health. Water is the best source of fluid. It is best to avoid high calorie regular sodas or other sugary beverages. To limit added sugars from beverages look for no-added-sugar juices, sugar-free iced tea, flavored waters. Caution with caffeine-containing drinks which have diuretic effects that may complicate a bladder program and interfere with medications. Alcohol is best avoided as it does not mix well with many medications, is high in calories, can increase fat in your bloodstream, and puts you at risk for bowel or bladder accidents. As stated in the chapter on bladder health, drinking fluids throughout the day instead of large amounts at one time is best.

▶ Cardiac Disease

Limited activity coupled with changes in body composition can contribute to heart disease. It is also well known that diet plays a key role in controlling blood glucose, cholesterol, triglycerides and blood pressure.

▶ Osteoporosis

Osteoporosis, or thinning of the bones, can occur when physical activity is reduced. Bones are more apt to break when they lose their density. Calcium plays an important role in the development of healthy bones and teeth, muscle flexion and nerve reaction, as well as influences heart function and blood clotting. With your doctor's approval, calcium supplementation with added vitamin D, which helps with absorption, is often recommended to treat bone loss. This is because calcium that is resorbed from your bones in the paralyzed part of the body may reach high levels in your bloodstream, causing nausea, kidney stones and bone formation disorders. If this occurs, your doctor may restrict calcium in your diet.

Weight Management After Injury

After spinal cord injury, extra weight can cause problems with your breathing, overall health, self-help skills, mobility, and transfers. Being overweight or obese can also increase your risk factors for chronic diseases like heart disease, arthritis, stroke, and diabetes. Weight management through exercise programs can benefit endurance, stress levels, functional status and overall health. Keep in mind that drastic weight changes can impact how your custom built durable medical equipment fits you. Improperly fitting equipment is less efficient and can put you at risk for pressure injuries.

Due to individual health variances, national guidelines on weight management for people with spinal cord impairment do not exist. If weight loss is desired, it is recommended to lose no more than 1-2 pounds per week.

Guidelines for Heart Healthy Eating

- Limit total fat intake while significantly decreasing saturated fat (usually from animals) and trans-fats (some processed foods) as well as limiting cholesterol containing foods.
- Choose unsaturated fats such as olive oil or canola oil.
- Increase intake of whole-grain products, fruits and vegetables.
- Limit sodium from salt and salty foods to control high blood pressure.
- Maintain a healthy body weight with regular exercise.

Food Preparation Tips for Following a Heart-Healthy Diet

- Trim all fat from meat and remove poultry skin before cooking.
- Cut out fatty foods and use less fat and oil in food preparation.
- Broil, roast, steam, bake or grill food on rack allowing fat to drip away.
- Remove fat from soups and gravies using a skimmer or refrigerate the food in advance allowing the fat to harden at the surface for easy separation.
- Minimize animal fat, hydrogenated oils, and tropical oils (palm and coconut oils)
- Try non-salt spices and herbs for added flavor, especially when fat is reduced.

Reading the Food Label



EAT SMART

WITH FOOD NUTRITION LABELS

The Nutrition Facts label can help you make healthier choices.

Use it! Here's what to look for:

| Nutrition Facts | |
|-------------------------------|----------------------|
| 8 servings per container | |
| Serving size | 2/3 cup (55g) |
| Amount per serving | |
| Calories | 230 |
| % Daily Value* | |
| Total Fat 8g | 10% |
| Saturated Fat 1g | 5% |
| Trans Fat 0g | |
| Cholesterol 0mg | 0% |
| Sodium 160mg | 7% |
| Total Carbohydrate 37g | 13% |
| Dietary Fiber 4g | 14% |
| Total Sugars 12g | |
| Includes 10g Added Sugars | 20% |
| Protein 3g | |
| Vitamin D 2mcg | 10% |
| Calcium 260mg | 20% |
| Iron 8mg | 45% |
| Potassium 235mg | 6% |

* The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.

Start with serving information.

This will tell you the size of a single serving and how many servings are in the package.

Check total calories.

Do the math to know how many calories you're really getting if you eat the whole package.

Limit certain nutrients.

Compare labels when possible and choose options with lower amounts of added sugars, sodium and saturated fat and no trans fat.

Get enough of beneficial nutrients.

Eat foods with nutrients your body needs, like calcium, dietary fiber, iron, potassium and Vitamin D.

Understand % Daily Value.

- The % Daily Value (DV) tells you the percentage of each nutrient in a single serving in terms of the daily recommended amount.
- To consume less of a nutrient (such as saturated fat or sodium), choose foods with a lower % DV (5% or less).
- To consume more of a nutrient (such as fiber or potassium), choose foods with a higher % DV (20% or more).

For more tips and tricks on eating smart, visit heart.org/HealthyForGood

EAT SMART MOVE MORE BE WELL

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Healthful Meal Planning

Maintaining a balanced diet is especially important after a SCI. Use the following graphic as a guide.

Small Changes Matter.
Start Simple
With MyPlate Today.

MyPlate.gov

Healthy eating is important at every stage of life.

Make half your plate fruits & vegetables.

Focus on whole fruits. → **Fruits** (apple, banana, grapes)

Make half your grains whole grains. → **Grains** (bread, rice, pasta)

Vary your veggies. → **Vegetables** (broccoli, carrots, spinach)

Vary your protein routine. → **Protein** (fish, chicken, beans)

Move to low-fat or fat-free dairy milk or yogurt (or lactose-free dairy or fortified soy versions). → **Dairy** (milk, yogurt)

Limit (sugar, fat, sodium) → Choose foods and beverages with less added sugars, saturated fat, and sodium.

The benefits add up over time, bite by bite.

References and Resources

- choosemyplate.gov
- dietaryguidelines.gov
- eatright.org
- heart.org
- heart.org/en/healthy-living/healthy-eating/eat-smart/nutrition-basics/making-the-most-of-the-nutrition-facts-label
- lapbandsurgery.com/nutrition-101-fiber

Chapter 10: Mobility and Range of Motion

Range of motion is the amount of movement you have at a particular joint. Range of motion exercises should be done every day to:

- Prevent joints from getting stuck
- Improve posture, balance and transfers
- Improve ability to perform daily activities (dressing, grooming, hygiene)
- Prevent pressure ulcers

Your therapist will instruct you in the most appropriate exercises for your needs.

Range of Motion

Range of motion exercises can be performed at different levels. Passive range of motion (PROM) is performed when you are unable to move a body part for yourself. A therapist or caregiver can move the body part for you. It is also possible for you to do your own passive self-range of motion exercises (self ROM) by using body parts that work to move other body parts. Active Assistive Range of Motion (AAROM) is performed when you are able to partially move a body part, but are unable to move it through the full range of motion. In this case, the therapist or a caregiver can help you complete the movement. Active range of motion (AROM) is performed when you are able to move a body part independently through full range. It is important to understand that these exercises will not make paralyzed muscles work again. They will, however, help to make daily activities easier to accomplish.

You may be thinking to yourself, “I have never been flexible, so why do I need to be now?” The answer to that is normal flexibility helped you to do functional activities before your spinal cord impairment. Now, increased flexibility and increased range of motion may be needed in some parts of the body to sit up, dress, or for transferring. It is important to let your physician know if you notice a decrease in your range of motion as this can be a sign of heterotrophic ossifications (HO). (*See Chapter 5 for HO review*).

Avoid Overstretching

When doing range of motion exercises, it is important to avoid over-stretching the muscles and ligaments on the back of your neck, fingers and trunk. Overstretching can lead to decreased function with tenodesis or with functional sitting balance and transfers. Tenodesis is the ability to passively flex the fingers for a grasping movement by actively extending the wrist.

Transfers

Transfers may be used to help you get from bed to wheelchair or one place to another.

- Before attempting a transfer yourself, it is important to learn to do transfers safely.
- Your therapist will teach you the best type of transfer for you to use.

Guidelines for Performing Safe Transfers

▶ Independent Transfers

- Lock brakes and stabilize all surfaces including a bed prior to transferring.
- Remove arm rests, leg rests and any other objects in your way prior to transferring.
- Wear non-skid footwear: ALWAYS.
- To reduce the risk of skin breakdown, focus on lifting and shifting during the transfer to prevent any shearing.
- A transfer board may need to be used during a transfer if the surfaces are far apart or if you need to take rest breaks during the transfer. Make sure the board is positioned under your buttock/hip and firmly on the surface to which you are transferring. If transferring in or out of a power wheelchair make sure it is turned off during the transfer.
- If transferring to a bedside commode it is safest to have the commode up against a wall or other sturdy surface so it will not tip over. Make sure you have adjusted the commode height to provide a level surface and have your feet on the floor.
- Before transferring into a bath tub adjust the height of the tub bench or chair to provide a level surface transfer but to also have your feet on the floor.

▶ Assisted Transfers

- If you are unable to maintain your balance or stability during the transfer, or if you do not have the strength to complete a transfer, you will need to have a caregiver, nurse, or therapist help you.
- You should be able to direct your caregiver with step by step instructions on the safest transfer. Floor based lift, over the shoulder or over the hip
- If you have any bracing, make sure the caregiver does not pull, tug or hold onto the bracing at any time during the transfer.
- A caregiver training day is expected of all patients and their caregivers to attend to learn how to assist with transfers.

References and Resources

- Duesterhaus Minor, MA and Duesterhaus S. Patient Care Skills. 4th ed. Stamford, CT: Appleton and Lange; 1999.
- Mobility: spinalcordcenter.org/manual/index.html
- Getting Moving after SCI (Video): sci.washington.edu/info/forums/reports/exercise_2013.asp

Chapter 11: Seating and Assistive Technology

Wheelchairs and Cushions

- Most patients with SCI will need a wheelchair and cushion after rehab.
- There are many different types of wheelchairs and cushions.
- It is very important to get a chair that best fits your needs and lifestyle.
- Cushions are not a substitute for performing regular pressure relief.
- A therapist trained in seating and positioning will help you decide which chair and cushion are right for you.

At Frazier you will have the opportunity to try various chairs, cushions, seating, and positioning options. Trying out different equipment will help you understand what you do and do not like, and what works best for you and your lifestyle. You will work with a therapist with advanced training in seating and positioning to determine which chair is best for you.

When deciding what wheelchair is best for you, it is important to consider the following:

- Will you be using the chair mostly indoors or outdoors, on level ground, on uneven surfaces, for work, for play or for athletic competition?
- How much time will you spend in the chair each day?
- How will you transfer in and out of the chair?
- Will you be independent using your wheelchair?
- How wide are the doors and hallways at home, work or school?
- Can you transport the chair in your vehicle?
- Do you expect any growth spurts or changes in your body size?
- Do you feel comfortable with a chair that can be adjustable?
- How long will you need the chair?

Wheelchairs are designed to last for five years at which time, a new evaluation is required to obtain a new wheelchair. Over the course of that 5-year period, a new evaluation may be required to make changes to your wheelchair to accommodate any changes in posture, skin integrity issues/wounds, changes in weight or function. It is recommended that you are seen in the seating clinic each year for reassessment.

Manual Wheelchairs

Manual wheelchairs can provide independence in the home and community for someone who is strong enough to propel the chair. These wheelchairs are generally lightweight and can be broken down to fit inside a vehicle or into the trunk. Manual wheelchairs consist of **two main frame designs and multiple different components**.



▶ Folding Frame

The frame is the main part of the chair to which all other parts are attached. The folding frame folds in the middle (like the letter X) so it fits into a vehicle. It is slightly heavier than a rigid frame and you lose some power when pushing the wheelchair because the chair has more movable parts. The more active user is likely to damage a number of moving parts on this frame.



▶ Rigid Frame




This type of frame is stronger, lighter and has few moving parts so there is less chance for breakdowns. It does not fold in the middle, instead, the rear wheels pop off and the back folds down. This type of chair may require more storage space in the vehicle but it is lighter weight and easier for some people to manage on their own. This frame is more durable than a folding frame chair, and less energy is lost when pushing the chair due to its rigid nature.

Wheelchairs come in a variety of sizes and configurations. Each wheelchair is custom tailored to best fit the needs of the wheelchair user. The goal is to configure the lightest weight and best performing wheelchair possible. Accessories/Components can be removed as skill levels increase. It is important to master higher level skills including wheelies for community mobility. These skills can be addressed as part of outpatient therapy.

Power Wheelchairs

A power wheelchair is a battery-powered wheelchair that increases independence in the home and community. A power wheelchair may be recommended for someone who is unable to propel a manual wheelchair efficiently, independently perform pressure relief, or positioning needs are too great for a manual wheelchair.

Power chairs easily weigh over 400 pounds and cannot be broken down into small pieces to fit into a car so consideration needs to be given to how the user and his or her power wheelchair will be transported from one location to another. Some people will use a privately owned van with a lift while others will opt for fixed route or paratransit public transportation, i.e., a bus or van with a lift. Many people also purchase a manual wheelchair in addition to their power chair in case the chair breaks down and requires repair. Power wheelchairs come in **three different drive configurations**.

| Front Wheel Drive | Mid Wheel Drive | Rear Wheel Drive |
|--|--|--|
|  |  |  |
| Permobil F5 <i>Photo from Permobilus.com</i> | Quantum Mobility Q6 Edge3.0 <i>Photo from Quantumrehab.com</i> | Sunrise Medical P222 <i>Photo from Sunrisemedical.com</i> |

Power Assist Options

Power assist devices are a component that can be added onto a manual wheelchair. Power assist is designed to assist with shoulder preservation by minimizing propulsion strokes. It can be helpful with long distance propulsion of navigating uphill inclines. If power assist is appropriate, it will be discussed during the wheelchair consult. Insurance funding may not be available initially and the power assist may need to be added later. **There are two main types of power assist; an external clamp on device or wheels with a built-in motor that are push rim activated.**

Wheelchair Cushions

- Maximize sitting tolerance
- Maximize sitting balance and posture
- Provide some pressure relief (The cushion is not a substitute for performing pressure relief)
- Distribute your weight more appropriately between your buttocks and thighs

Seating and Positioning Clinic

At Frazier's Seating and Positioning Clinic, you can try out new chairs, seating and positioning options. A referral or order from your physician is needed and the visit and any recommended equipment changes should be paid for by your health insurance.

A "Final Fit" is recommended to insure optimal fit of the wheelchair at delivery. During this appointment, the therapist and complex rehab supplier will re-educate on functions and features of the wheelchair. Additional appointments may also be required for modifications due to changes in weight, presence of wounds, and change in medical health. Please contact the physician to initiate the referral process.

Assistive Technology

Those with limited mobility in the upper body may be concerned about how to use digital technology including phone, tablets and TVs. These issues and many more can be addressed in the Assistive Technology Resource Center (ATRC) at Frazier which is available to both inpatients and outpatients. When you are evaluated in the Clinic, you will learn about and be given the opportunity to try and use various pieces of assistive technology that may help you be more independent in your home, work or school environments.

In the ATRC, you may be introduced to technologies that allow you to operate room lights, TVs, radios, fans, small appliances and smart phones. Simple switches, with or without mouth sticks, or voice to text and voice-controlled technology or touch pads may be used to access equipment. Many items available for commercial use can be helpful with the transition home. Smart home technology from Google, Amazon and Samsung are a few examples of this reasonably priced and available technology to facilitate independence. A "Smart Room" is available to trial some commercially available smart home features. Recommendations can be individualized based upon needs.

References and Resources

- Lange, M and Minkle, J. Seating and Wheeled Mobility: A Clinical Resource Guide. Slack Incorporated; 2017.
- Christopher and Dana Reeve Foundation: christopherreeve.org
- Daily Life When Using a Wheelchair: wheelchairnet.org
- Equipment Database: abledata.com
- Users First: usersfirst.org
- Wheelchairs and Accessories
 - sportaid.com
 - pimpmychair.com
- Wheelchair Reviews: wheelchairjunkie.com

Chapter 12: Bracing and Orthoses

When muscle function is lost or impaired, changes occur that may damage muscles, joint structures and soft tissues. These changes can result in muscle overstretching, muscles getting stuck in one position, joint stiffness, joint misalignment, soft tissue tightening and joint instability. These changes can be minimized with range of motion exercises, positioning, casting and splinting or bracing. Braces and orthoses can serve the following purposes:

- Protect a weak body part such as the hand or arm from damage.
- Support and keep a body part from moving while healing.
- Maintain normal alignment of the body part to reduce stiffness and prevent the part from getting stuck.
- Provide support to weak muscles to facilitate function.
- Provide comfort and reduce pain.
- Minimize or reduce any deformity of joints.

Your therapists and physician will recommend, prescribe and provide the appropriate orthoses based on your needs. The therapist will also provide education regarding the reasons for the use of the orthosis, how to use and care for the orthosis, as well as any precautions for using the orthosis. The following orthoses are most commonly used for individuals with spinal cord injury.

► Upper Extremity Orthoses



Resting Hand Orthosis

This is an orthosis that keeps the hand in a position that supports the wrist and hand to reduce the risk of joints getting stuck in one position. It is commonly used in the beginning phases of rehab to protect weak or immobile hands.



Wrist Cock up Orthosis

This orthosis supports the wrist in a bent back position for better hand use.



Universal Cuff

The universal cuff (U-cuff) is a hand-based orthosis that holds ADL items for self-care tasks. It is commonly used by individuals who do not have hand function but do have wrist control.

▶ Lower Extremity Braces



Bracing can also be used on the legs to improve function especially in a standing position. The most common brace used for the leg is the **Ankle Foot Orthosis (AFO)**. This brace is placed into the shoe and comes up the back of the lower leg and straps around the calf. It is used to help keep the foot from resting in a dropped down position and to help prevent the toes from dragging during walking. It is usually used for someone with no control or very weak control of the ankle.

There are multiple other bracing options for individuals who are learning to walk. These specialty braces are most frequently used in the outpatient therapy setting. Your physical therapist can discuss bracing options with you when appropriate.

Skin Inspection with Bracing

When wearing a brace, it is very important to perform skin inspection frequently to check your skin for areas of irritation or breakdown. Often the plastic or straps on the brace can rub the skin especially over bony areas. The therapist will recommend a wearing schedule as the brace is introduced. Skin inspection is extremely important as you may not be able to feel the areas as you did before.

References and Resources

- Christopher and Dana Reeve Foundation: christopherreeve.org
- sci.washington.edu/info/forums/reports/Arm%20and%20hand%20function%20slides.pdf

Chapter 13: Home Modifications

Soon after spinal cord injury, you may find that some changes need to be made at home to make it more accessible for bathing, toileting, transfers and movement into and out of the house using a wheelchair or walker. While each person with a spinal cord injury is unique, there are several basic rules and measurements standard for wheelchair users. Below you will find basic measurements and minimum space requirements for each room of your home based on a standard sized adult wheelchair using the Americans with Disabilities Act (ADA) Standards for Accessible Design. The measurements on your wheelchair will depend on its size and style. Please mention any concerns about doorway width, stair height or bathroom access to the therapist.

If possible, it is recommended that a caregiver video or photograph the living spaces and entrance into your home to allow for the therapist to make recommendations. Measurements for doorways and hallways along with bathroom, bedroom and kitchen layouts are beneficial for the therapist to be able to assist with planning the transition home.

Home Accessibility – General Topics

- To create more space, remove all unnecessary furniture and rugs.
- Hallways require minimum 32" width in order to turn into doorways using a wheelchair.
- Kick plates floor level on doors or protective panels on drywall will protect from repetitive use damage.
- Couches, beds and lounge chairs should be as level as possible with the wheelchair to facilitate safe transfers.
- Wall mounted outlets are more accessible if they are no lower than 15 inches above the floor. Light switches, alarm systems, towel racks and thermostats mounted 3 to 4 feet from floor level is typically recommended.
- Swing Clear or Off-set door hinges take the thickness of the door out of the door width. This gives an extra 1-1.5" in the doorway.
- Window locks should be within reach from the wheelchair.
- Clothing rods placed no higher than 50 inches from the floor are helpful. Some people choose to install adjustable rods in closets to increase storage and accessibility.
- There are lift devices available that can assist with transferring into the bed or wheelchair for those who need a lot of assistance with moving from one surface to another. The therapist will help determine if a lift is needed for safe functional transfers.
- Power door openers, push code door locks, and replacing round door knobs with lever-style handles can assist with easy home entry.

▶ Kitchen and Bathroom

Consult multiple ADA Certified contractors for kitchen and bathroom remodels. Visit showrooms or view previously completed projects to determine which features best suit your needs. Additional tips are listed below.

- Counter tops need to be placed to allow for rolling under without thighs touching the under-surface to minimize risk of injury.
- Continuous countertops with built in stovetops are ideal. Electric stoves are recommended to avoid clothing catching fire when reaching across burners.
- Allow for as much knee space under the sinks and countertops as possible. You may consider removing existing cabinets to create this space.
- Keeping the space below the sink open will allow someone at a wheelchair level to pull up under the sink for better access. The piping should be located as far back as possible and insulated to avoid leg burns when the pipes are hot.
- Other modifications include installing turntable corner cabinets, heat resistant countertops, pull-out trays, adjustable shelves and mounted mirrors above the stove to monitor items on the back burner.
- If space is limited, a drop arm bedside commode may be used to complete toileting.
- Bathtubs with a handheld shower is recommended for bathing safety. Single handle faucet controls are helpful. Remember hot and cold sensation may be impaired and a means to test water temperature may be needed.
- Roll-in showers should be sloped to allow for proper drainage. Curtains are recommended in place of glass door and thresholds to facilitate safe transfers.
- Grab bars should be placed in the shower/tub area and near the toilet. Be sure to anchor all grab bars securely to wall studs. You may wish to have a professional install grab bars to ensure safety. Do not use towel bars/racks as grab bars, as they are not designed to support body weight.
- A tub/shower chair is recommended. Your occupational therapist will practice using different models to assist with selecting the model that is right for you.

► Ramps

Ramps are often needed to allow a person to enter the home level and should be constructed using proper guidelines so entry into the home is safe. A ramp is not needed when there is access to an entryway at ground level. Below is a list of general guidelines for proper ramp construction:

- The maximum incline or slope for a ramp is 1:1 meaning for every 1 inch of total height in step(s), 1 foot of ramp length is required. For example, a two-step entry that is 14 inches tall would require 14 feet of ramp.
- Ramps should be a minimum of 36 inches wide. If the ramp must be longer than 30 feet, a landing or level area should be considered, and ramps should have non-skid surfaces for safety.
- Landings are required at both the top and bottom of the ramp. The landings should be at least as wide as the ramp and have 60 inches of clearance in all directions.
- Handrails should be installed 34-38 inches above the floor of the ramp on both sides if the ramp has a rise of greater than 6 inches.
- Start on sidewalk or pavement and end it with a level landing at the home's entry.
- Ramps should have a barrier edging on both sides of the ramped surface to minimize risk of wheels accidentally driving off the edge of the ramp.

If there is not sufficient room to build a ramp long enough to meet the above specifications, alternate means of accessing the home such as a vertical porch lift will be needed.

References and Resources

- Americans With Disability Act Accessibility Guidelines: [access-board.gov/guidelines-and-standards](https://www.access-board.gov/guidelines-and-standards)
- Home Modification
 - [infinitec.org/manual/index.html](https://www.infinitec.org/manual/index.html)
 - mhfa.state.mn.us/homes/access
- The Ramp Project: [accessnorth.net/cilnm/ramp.pdf](https://www.accessnorth.net/cilnm/ramp.pdf)
- Building a Ramp: [wikihow.com/Build-a-Wheelchair-Ramp](https://www.wikihow.com/Build-a-Wheelchair-Ramp)

Chapter 14: Emotional Adjustment after Spinal Cord Injury

What is adjustment?

Everyone experiences changes in life. Adjustment is how one adapts to, or becomes used to, a new situation. Having a spinal cord injury (SCI) is a new and challenging situation that can affect almost every aspect of our life. After a SCI, the initial adjustment may be difficult. Over time, most people adjust well and continue to adjust to ongoing changes.

How do people adjust to SCI?

Everyone has different expectations for what life will look like after an injury. It may be feeling happy, doing meaningful and enjoyable activities. It may be preventing stress, depression, or anxiety. It may be any combination of these, or something else. Most people will adjust by setting and meeting their own expectations for life after injury. Like most life-changing events, it takes time to adjust to a new “normal.” People with injuries often express that it feels as though they are doing things for the first time as they learn how to do activities differently. These feelings often go away over time as you become familiar with these new ways of completing activities and adjust them to best fit your daily needs.

- After injury, personality and the way that you adjust to life changes does not usually change.
- You may feel “different” in your body, especially in the early weeks and months after injury. This feeling usually fades over time as you become more comfortable with your self-image, learning how to manage self-care, and gaining a better understanding of your body.
- You may adjust personal values to better align with what is most important to your life after injury.

Adjusting Well

While there is not one way to adjust to life after injury, people who adjust well:

- Do not experience clinical depression or if they were depressed soon after injury, they begin to feel better within a few weeks.
- Have an effective coping strategy. These can include:
 - A “fighting spirit.” This is when you use available resources to overcome challenges and setbacks.
 - Viewing injury as a challenge and seeing the potential for growth, this may include making meaning of the injury.
 - Acknowledging or accepting that the injury happened and learning how to move forward with the new “normal.”
- Are resilient, meaning they bounce back when faced with difficulties and challenges. People who are resilient:
 - Seek purpose and meaning.
 - Connect support networks. This may be family, friends, faith, and other community members.
 - Use resources to improve their experience.
- Stay flexible. Setbacks can happen and are common, but you can adjust your plan to reach your goals.

- Solve problems. Try this approach:
 - What is the problem?
 - What possible solutions are there?
 - Choose the solution you think will work the best.
 - Try the solution.
- If it doesn't work, try another solution.

Difficulties with Adjustment

► Depression

- For most people, a SCI will be associated with negative emotional reactions. It is normal to have good days and bad days after a SCI. However, for some, depression may develop or worsen weeks or months after a SCI.
- Depression is more common in patients with a SCI as compared to the general population, with about one in five people (20%) with SCI experiencing depression (Model Systems Knowledge Translation Center, 2010).
- Depression is characterized by significant depressed mood or loss of interest in enjoyable activities most days during a two-week period. Some people experience feelings of hopelessness, worthlessness, emptiness, or guilt.
- Thoughts of suicide are a symptom of depression that should not be ignored. People with SCI are at higher risk of suicide than the general population (Cao et al., 2014). Risk factors specific to individuals with SCI include: first six years after SCI, level of injury, and prior history of mental health issues.
- If you experience thoughts of suicide, wanting to harm yourself, or wishing you were dead, reach out for help.
 - If it is a life-threatening emergency call 911 or have someone take you to the nearest emergency department.
 - National Suicide Prevention Lifeline: 800-273-TALK (8255)
 - Hope Now Hotline: 502-589-4313
 - Crisis Text Line: Text "HOME" to 741-741

► Anxiety

- Anxiety is a normal reaction to physical changes and day-to-day experiences related to a SCI and subsequent functional deficits.
- Anxiety becomes a cause for concern when the worry, fear, or panic is excessive, difficult to control, and interfering with ability to function.
- Anxiety is more common in patients with SCI than compared to the general population. Estimates suggest self-reported experiences of anxiety occur in 15-30% of patients with SCI (Le & Dorstyn, 2016).
- If you are experiencing symptoms of anxiety, inform your rehab team or physician.

▶ Substance Abuse

- Abusing alcohol and other drugs can cause significant challenges and difficulties, in addition to SCI. For example, when under the influence of alcohol or drugs, pressure relief and other self-care can be ignored. The likelihood of injury from falls or hitting objects while in a wheelchair is increased. Substance abuse can impact nutritional status, bowel and bladder function is often negatively affected, respiratory function is threatened, and overall memory and judgment become impaired.
- Research suggests that people with SCI are at highest risk of substance abuse compared to individuals without SCI (Graupensprger et al., 2019).
- If you are currently struggling with substance abuse, or have in the past, inform your rehab team or physician so that you can receive help in a confidential and professional manner.

How Families Can Help

When a loved one is hurt or injured, families often come together quickly. Family members drop, or put on hold, important parts of their lives such as school, work, and community activities. Family members often stop taking care of themselves in order to care for the loved one. Perhaps most difficult for families is their inability to fix the SCI and return their loved one to life as it was before. Families can do a great deal that is helpful, which makes a difference even though it may not seem so at the time.

- Relate to your loved one as you did in the past.
- Practice being a good listener.
- Encourage the expression of feeling.
- Reinforce independence.
- Learn about SCI and impairment.
- Attend and participate in caregiver education while at Frazier.
- Join a spinal cord advocacy/support group.

▶ Family Members Struggle Too

At Frazier, we believe an injury does not just happen to the one who is hospitalized but rather it happens to the entire family. Most everyone struggles trying to deal with many thoughts and emotions that accompany having a family member with a SCI. Understandably, most want to care for their loved one first and themselves, second. Nonetheless, it is important for you and other family members to take care of your physical and psychological health so you can be strong and helpful to your loved one over the long term.

► Caregivers

During inpatient rehabilitation, family members will often be asked to learn how to do hands-on care for their loved one. This may involve activities of daily living (bathing, dressing, feeding), transfers from bed to wheelchair, specific medical care (wound dressing, tube feedings), procedures for skin protection (pressure relief), and bowel/bladder management (catheterization). The level and severity of your loved one's injury will determine the type and amount of care needed in the home environment and the amount of time required to provide care each day.

Family members, now caregivers, provide an invaluable service to their loved one. Nonetheless it may put many strains on the caregiver's time, finances, physical and emotional health, leisure time, and social relationships with others, including the loved one. Caregivers are advised to learn to give yourself permission to care for yourself, learn how to do it well, and do it regularly.

References and Resources

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Chapter 15: Sexuality after Spinal Cord Injury

Sexuality is a multi-faceted and central aspect to the identity of an individual. Sexuality is what guides our desire to bond with others. This bond can be achieved through love, affection, and intimacy. Loss of muscle control, sense of touch, and sexual reflexes often occur after spinal cord injury (SCI). How this loss affects arousal, orgasm, and fertility depends on your level of injury and whether the injury was complete or incomplete. After a SCI, your desire for sex may be low. But, the desire will likely increase with time as you learn to manage self-care and better understand your body after injury. If not, speak with your doctor to determine if any medications may be interfering with sexual desire.

SCI may also impact how you think and feel about yourself. Some people with SCI may not feel desirable. Loss of movement or sensation does not affect your level of desirability. Understanding your body and feeling comfortable with yourself and your identity is likely to help you to feel more desirable and want to express your sexuality.

Intimacy

Intimacy is the process in which partners, because of sharing personal and private thoughts and feelings, come to feel understood, appreciated, and cared for by one another. Intimacy can include feelings of closeness, love, marriage, privacy, physical engagement (by touching or standing very close to another), or sexual activity. After a SCI, it is possible that your view of intimacy will change and evolve over time. For some, post-injury intimacy may be more focused on physical displays of affection, for example through touch and intercourse. For others, post-injury intimacy may focus on maintaining connections, deepening emotional intimacy, and closeness. Intimacy after SCI requires open and honest communication with partners. Having a supportive partner is important for developing and maintaining a stable, intimate relationship.

Females

▶ Menstrual Cycle

- Often there is a pause in your menstrual cycle after initial injury. If your period does not return after the first few months contact your doctor. During this time and following, it is possible to become pregnant.

▶ Contraception

- Prior to starting/resuming any birth control pill, your physician should be consulted. Generally, condoms are the preferred method of birth control. Birth control pills are often not recommended due to the increased risk of developing a blood clot. Due to lack of sensation, intrauterine devices are usually not recommended since warning signs of complications can go unnoticed.

▶ Pregnancy

- Having a SCI does not affect your ability to naturally become pregnant, carry, and deliver a baby. Women with all levels of injury have had children after injury, and it may be possible that you should be able to become pregnant if you choose.

- Risk for secondary conditions related to SCI may increase as you progress through pregnancy. Therefore, it is important to take steps to prevent secondary conditions if you can and to manage them if they develop. You are at risk of autonomic dysreflexia (AD) at any time if your injury is T6 or above. (*AD is discussed in the Chapter on Medical Concerns.*) Have a plan in place with your physician on how to manage AD if it develops. Other potential secondary conditions include urinary tract infections, pressure ulcers, bowel changes (constipation or diarrhea), and muscle spasms.
- Full-term pregnancy is 39-40 weeks, but it is best to start watching for signs of labor at 28 weeks. Women with paraplegia can learn how to check for labor by feeling the uterus. Women with quadriplegia can talk with their obstetrician (OB) about a contraction monitor for home use. Women with an injury at level T10 or above may not feel labor pain; whereas women with injuries below T10 may feel the uterus contracting.
- It is advised that your OB consult with your rehab physician to fully understand spinal cord issues that could affect your pregnancy.

▶ **Maintaining Sexual Health**

- Sexual health needs do not change as a result of SCI. For women, this includes continued yearly gynecologic exams, PAP tests, monthly self-breast examinations, and mammograms when appropriate.
- Because of the injury to the spine, the vaginal area may not become lubricated as it once did. Secondly, it may be discovered that there may be little or no sensation in that area. If one or both of these changes exist, a woman is encouraged to use some type of lubricant during intercourse to prevent injury during intercourse. Having your partner perform oral sex may help increase vaginal lubrication. Another option is a water-based lubricant. Vaseline or other oil-based products are not recommended because they tend to remain in the vaginal area for a long time and can lead to infection.

Males

▶ **Erectile Dysfunction**

- Men with SCI may have difficulties with erectile dysfunction, which may include difficulties getting an erection, maintaining an erection, or both. There are two types of erections which usually work together. A reflexogenic erection occurs with direct stimulation of the penis or internal stimulation, such as a full bladder. A psychogenic erection occurs with sensory input, such as thinking sexual thoughts, sights, smells, or sounds. These thoughts/feelings send signals from the brain down the spinal cord and stimulate the genitals, which produces an erection. When the spinal cord is injured, the messages from the brain may not get through thus preventing a psychogenic erection. The spinal cord damage, though, does not prevent a male from being sexually aroused.

▶ **Erectile Management**

- There are several ways in which erectile dysfunction can be treated. You will need to discuss treatment options with your doctor to make a choice that is suitable for both you and your partner.
- Oral medications are generally taken 30-60 minutes before engaging in sexual activity. These medications do not automatically produce an erection. Rather, they allow an erection to occur after physical and psychological stimulation. Priapism is when an erection lasts longer than 4 hours and is a possible side effect of these medications. Priapism is considered a medical emergency.

- Other erection aids include urethral suppositories which are directly inserted into the penis to create an erection. Some medications are injectable. A tension ring or a vacuum device are other options.

▶ Ejaculation Function

- Ejaculation occurs when semen is expelled from the urethra and is coordinated by the brain relaying messages to the spinal cord to stimulate erection and ejaculation. After SCI, input to and from the brain does not usually occur. SCI may make it difficult to respond to sexual stimulation and to ejaculate in a “normal” way.
- After injury, some men have what are called retrograde ejaculations. During ejaculation, semen enters the bladder rather than exiting through the penis. This does not cause problems to the individual, but fertilization/pregnancy won’t occur.

▶ Fertility

- Successful ejaculation is the process where semen, which contains sperm from the male, is released out the end of the penis. Sperm is needed to achieve fertilization of the female’s egg causing a pregnancy. Following SCI, males who have erections may not ejaculate during intercourse. If not, alternative methods may be used to induce ejaculation. Masturbation stimulates the penis with greater intensity than intercourse. Masturbation may be done by hand or using a hand-held vibrator. Another method, called electro ejaculation, places a probe in the rectum and uses electrical stimulation to produce an ejaculation. Once sperm is collected following ejaculation, it can be used to fertilize an egg.

▶ Maintaining Sexual Health

- Your sexual needs do not change as a result of your SCI. For men, this includes continued self-testicular examinations and prostate checks.

Ability to Orgasm

Orgasm is a reflex response from the nervous system that feels good and relaxes you. Most people with SCI can still have orgasms.

Women may not have a clitoral or vaginal orgasm as they previously did because of the SCI. However, women do report having orgasm-like experiences following stimulation of the body where sensation remains. Males with complete spinal cord injuries typically do not have an orgasm during intercourse. Some males with complete injuries do report orgasm-like experiences when areas of the body that still have feeling are stimulated. It is through exploration that you may find such sensitive areas of your body.

Safe Sex

You need to practice safe sex if you want to prevent pregnancy. Condoms are considered the best choice for both men and women. Condoms are also highly effective in reducing the transmission of sexually transmitted infections and diseases.

Bowel and Bladder Management

Prior to any sexual activity, males and females who do not have control of bowel and bladder are encouraged to empty the bowel and bladder. If done, the chance of having an accident during sexual activity is greatly reduced. Should an accident occur, it is not harmful physically. Most couples find that bowel and bladder issues are a challenge that need to be discussed openly, so that if an accident occurs, they have a plan established. After clean-up, many couples simply resume sexual activity.

It is not necessary to remove an indwelling catheter prior to sexual activity. For males, it is recommended that a condom be placed over the penis prior to intercourse. When this is done, the catheter is held relatively secure inside the condom. With females, the catheter is often taped to the leg or abdomen during intercourse. It is important to understand that the catheter is not placed in the vagina. Rather it is placed in the urethra, the outlet for urine, which is in front of the vagina.

References and Resources

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 - mskctc.org/sites/default/files/SCI-SexFunction-Sp-508.pdf (en Español)
- Pregnancy and Women with Spinal Cord Injury:
 - mskctc.org/sites/default/files/SCI-and-Pregnancy-508.pdf
 - mskctc.org/sites/default/files/SCI-Pregnancy-Sp-508.pdf (en Español)
- Sex, Love, and Intimacy After Spinal Cord Injury: sexualitysci.org/
- Parenting after SCI: lookingglass.org/



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