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INTRODUCTION: THE PATIENT AND FAMILY HANDBOOK

This Handbook is designed to give you the information to better understand spinal cord injury and the tools needed to manage your health care needs successfully. Information is intended for you and your family because, those who love you, will often be involved in assisting you with your care needs while in the hospital, and in the home environment. As you read through the Handbook, your rehab team at Frazier is available to address your questions and provide you more information pertinent to your needs.

HANDBOOK CONTRIBUTORS

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A BRIEF NOTE ABOUT THE FOUNDER OF FRAZIER REHAB INSTITUTE

In her early 20’s, Amelia Brown of Louisville sustained a spinal injury in a car accident in the 1940’s. With no rehabilitation services in Louisville, she traveled to New York for treatment. After returning to Louisville, she married a physician, Dr. Harry Frazier. Believing Louisville needed its own rehabilitation facility, Mrs. Frazier founded the Frazier Institute of Physical Medicine and Rehabilitation in the early 1950s. Her son, Owsley Brown Frazier, served as Chairman of the Fund Raising Committee for Frazier’s new building, named the Frazier Rehab and Neuroscience Center, which opened in 2006.
**DISCLAIMER**

The information contained in this handbook should be used in accordance with the treatment plan prescribed by your physician and with the prior approval of your physician. You should not begin using any of the methods described in this publication until you have consulted your physician. Jewish Hospital & St. Mary’s HealthCare, Inc. D.B.A. Frazier Rehab Institute, its affiliates, associates, successors and assigns, as well as its trustees, officers, directors, agents and employees are not liable for any damages resulting from the use of this publication.

**GETTING STARTED**

**Education.**

The Frazier Spinal Cord Medicine Team has found that understanding spinal cord injury is essential to preparing individuals and families for discharge and future recovery needs. We invite you to take advantage of Frazier’s patient, family and caregiver educational opportunities to learn more about SCI and recovery. For example:

- Attend the Spinal Cord Injury Group held at 3:00 pm Mon-Fri
- Schedule Family Teaching Days with your case manager
- Attend Team and Family Meetings during in-patient admission
- Learn about Spinal Cord Injury through books, magazines, internet surfing

- As an inpatient, you will have a case manager assigned to your care for resources and information. As an outpatient, a case manager is available by calling the Spinal Cord Medicine Program phone number (502-582-7415).

**About Caregivers.**

A primary component of the Spinal Cord Medicine Program is caregiver education and teaching. Caregivers are often involved in decision making and coordinating recovery efforts. If you need to take time off from work to participate in the Spinal Cord Medicine Program, ask your employer about signing up for the Family Medical Leave Act (FMLA). FMLA allows you to take up to 12 weeks off from work all at once or intermittently, without jeopardizing your employment.

It is very important for caregivers to take good care of themselves by eating well, getting good rest and taking time out for themselves. The caregiver role will be more prominent after discharge and we want you to be prepared for the transition to home.

**Financial.**

Patients and family members should read the patient’s insurance policy and learn the vocabulary to better understand the benefits and limitations of the policy. For example, you need to know:

- What are the maximum lifetime benefits offered by your policy?
- What outpatient therapy benefits are covered?
• What are the benefits for the Durable Medical Equipment?
• Do you have an out of pocket maximum?
• Does the spinal cord injury survivor have short or long-term disability insurance benefits?
• Should we initiate an application for Social Security Disability?
Chapter 1: COMPREHENSIVE REHAB GOES FAR BEYOND THE REHAB CENTER

Spinal cord injury or impairment due to trauma, disease or congenital (at birth) conditions impacts the whole person - physically, emotionally and mentally. For those who have a spiritual belief, the impact can also be spiritual. The impact is keenly felt in the family also.

With emphasis placed on the whole person, Frazier Rehab Institute individualizes rehabilitation services for you and your family. Services are designed to:

- Stabilize you from a medical standpoint
- Provide state of the art therapies designed to get you moving again to achieve the highest level of independence possible
- Assist you and your family to deal with the psychological, vocational, relational (relations between you, friends and family), economic, academic, leisure and other life long care issues
- Provide you and your family the information and skills needed to maintain/enhance your health after discharge from the inpatient setting
- Provide a life long system of medical and rehabilitative care to maintain and enhance wellness
- Provide individualized assessment of your needs to determine the medical and rehabilitative services appropriate for you and your family.

YOUR SPINAL CORD MEDICINE TEAM AT FRAZIER REHAB INSTITUTE

Rehab Physicians, called Physiatrists, are specialty trained in physical medicine and rehabilitation with emphasis on spinal cord injury and impairment, brain injury, stroke, orthopedic care and other neuromuscular diseases. Your rehab doctor will manage and direct all medical and rehabilitative care provided to you while you are hospitalized and may follow you for years thereafter.

Care Coordinators are active with you and your family making plans for admission, communicating with your insurance company, and making preparations for discharge. After you leave the hospital, the care coordinator continues to serve as a resource person for you and your family.

Rehab Nurses provide a continuous link between you and your physician while delivering hands-on medical care and education to you and your family 24-hours-a-day, seven-days-a-week. After hospitalization, you will have access to Frazier's spinal cord nurse coordinator in the Spinal Cord Outpatient Clinic and by phone.

Physical Therapists focus on enhancing mobility, improving range of motion, maintaining optimal muscle strength and tone, and providing such specialized services as body weight assisted ambulation (Locomotor Training), functional electrical stimulation and aquatic therapy.

Occupational Therapists focus on developing self-care skills needed for activities of daily living, including work and school related activities, and driving incorporating the use of assistive technologies across many activities as appropriate.
Respiratory Therapists work to restore and/or maximizes lung function and health. They provide individualized care that may include: ventilator management and training to you and your family; and instruction of proper breathing techniques.

Speech and Language Pathologists focus on your speech and language skills, cognitive functioning and your ability to swallow safely. They provide treatment as needed.

Dietitians closely monitor your nutritional intake, make treatment recommendations and provide appropriate education to you and your family about your nutritional needs after injury.

Recreational Therapists involve you in numerous activities in and out of the hospital that are designed to teach community re-entry skills and enhance your quality of life over the life span.

Psychologists are involved with you and your family’s social and emotional adjustment to the injury/disease. Services are provided individually, to couples and to families, and through psycho-educational group sessions.

Peer Mentors are individuals with successful life experience living with spinal cord injury or impairment. Peer Mentors are involved in treatment planning and meet with you and your family as appropriate.

Other team members may include a vocational counselor, rehab engineer and teachers.

AFTER DISCHARGE FROM THE REHAB HOSPITAL

After discharge from the rehab hospital, you will likely be involved in some of Frazier Rehab Institute’s after hospitalization programs.

- Outpatient therapies
- Day Rehabilitation
- Spinal Cord Medicine Clinic
- Locomotor Training
- On-going Leisure, Recreational and Competitive Community Based Activities
- Aquatic Therapy
- Assistive Technology Lab
- Seating and Equipment Clinic
- Peer Mentors
- Driver's Evaluation
- Gait Analysis Lab
- Spinal Medicine Research Projects

YOU AND YOUR FAMILY ARE TEAM MEMBERS

Comprehensive rehab is defined as a process of teaching a person to live with their injury or spinal cord impairment in their own environment. This learning should begin soon after injury/disease and, for most, continues throughout a lifetime. Success cannot be achieved by the doctor working alone, or by any one therapist, or by any single community program, or only by you and your family. Success in rehab is the result of a team working in a coordinated and cooperative manner. You and your family, along with doctors, nurses and therapists, are all Team Members. Please share with us what your think, what your needs are and your questions. Learning to work together is important to your recovery.
Chapter 2: ANATOMY OF SPINAL CORD, FACTS AND FIGURES

KEY POINTS

- The spinal cord is the major neurological communication link between the brain and the body and has some independent neurological functions of its own.
- Damage to the spinal cord can result from various forms of trauma, interruption of blood supply, direct pressure or central nervous system diseases.
- Spinal cord nerve tissue either does not re-grow or heals very slowly (depending upon the tissue) but modern science is producing evidence that regeneration of spinal cord function could become a reality.
- The level of injury identifies the lowest place or section of the spinal cord where function is normal. Any damage to the spinal cord happens below the level of injury. Where damage has occurred to the spinal cord may or may not coincide with injury to the bony (skeletal) level of the spinal column. Therefore level of injury identifies a functional level.
- Incompleteness or Completeness of injury (functional deficit) are terms defined by whether or not nerve messages pass through the damaged spinal cord site (incomplete – partial passage; complete – no passage).

THE SPINAL CORD

The spinal cord is the largest and most complex single extension of the nervous system. It is made up of many specialized collections of nerve fibers that begin in the brain and extend down through the bony canal in the spinal column (commonly called the backbone) and out into the body. The cord itself is about a half inch in diameter and is soft and pliable but surprisingly strong. It is nourished by many small blood vessels that carry oxygen-rich blood and nutrients to its cells and connective tissue but this blood supply is very susceptible to damage or obstruction and is one of the spinal cord’s potential weaknesses. Because it is so complex in its neurological composition, a little damage could potentially create a great deal of functional interference and the communication the cord provides could either be halted altogether or become jumbled or confused creating havoc in bodily functions.

THE SPINAL COLUMN AND INJURY

Individual bones called vertebrae make up the spinal column. The vertebrae are stacked basically 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. The spinal column is comprised of 7 cervical (neck) vertebrae, 12 thoracic (chest and rib cage) vertebrae, 5 lumbar (lower back) vertebrae, and 5 fused sacral (tailbone) vertebrae. Therefore, there are 29 vertebrae in the spinal column.

The entire column of bones is held together by a complex system of ligaments, muscles, and tendons that provide stability of the column and at the same time use the column to support body movement. Between each of the vertebrae there is a tough,
fibrous disc, which acts like a hydraulic cushion, preventing the vertebrae from rubbing against one another and also protecting the spinal nerves that extend from the spinal cord to the rest of the body. One can readily see that anything that disrupts the integrity of the spinal column can result in injury to the spinal cord or its spinal nerves or both.

Spinal nerves are branches of the spinal cord that extend outward from the cord. Nerves that branch out from the neck or cervical region (C1 through T1) control muscles and sensory functions in the shoulders, arms, wrists, fingers and the large breathing muscle called the diaphragm.

Nerves that branch out from the trunk or thoracic area (T2 through T12) control muscle and sensory functions that lend balance to sitting and standing and enhance rib cage control to augment breathing and coughing.

Nerves that branch out from the lower back (L1 through L5) and tailbone (S1 through S5) control muscles and sensory functions of the lower extremities as well as control bowel, bladder and sexual functions.

The brain sends messages down the spinal cord to the motor nerves, which 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 affect the working of either the motor nerves or the sensory nerves or both.

In a complete spinal cord injury, nerve damage stops all messages from passing through the site where the injury occurred. In an incomplete spinal injury, some messages continue to pass through or around the injury site meaning that the spinal cord was not totally damaged. Immediately or shortly after injury, a person may appear to be a complete injury with no motor or sensory input below the level of the injury. However, after the swelling of the spinal cord goes down, some complete injuries are
re-classified as incomplete. After the swelling goes down in an incomplete injury, there may be significant improvement in motor and/or sensory function.

The spinal cord is kept alive by the flow of blood (through arteries) that carries oxygen and nutrients into the cells, and removes carbon dioxide and waste products (through veins). Swelling in the spinal cord can cause the flow of blood to be altered or stopped. Disruption in the flow of blood servicing the spinal cord can cause damage or death to spinal cord cells. Standard treatment for traumatic spinal cord injuries includes the administration of a steroid drug call methylprednisolone, which if given in the first few hours after injury, can decrease swelling in the spinal cord. Unfortunately, cells that die in the spinal cord are not replaced with new cells that serve the same purpose as the cells that died. However, scientific advancements in the future may prove otherwise. See Resources at end of the Chapter.

Other ways the spinal cord can be injured include:

- **Contusion** - bruising of the spinal cord which can occur when the cord is thrown hard against the vertebrae as in a whip lash 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 sometimes caused by a knife or bullet
- **Disease and infections** such as Multiple Sclerosis, Transverse Myelitis, Friedreich's Ataxia and Amyotrophic Lateral Sclerosis (ALS)
- **Birth defects** such as Spina Bifida where the spinal cord fails to develop normally early in pregnancy

Paraplegia refers to injury or impairment in the thoracic (T2 through T12); lumbar L1 through L5; or the sacral (S1 through S5) regions of the spine that affects functioning of the lower two extremities that being the legs. Tetraplegia, once called quadriplegia, refers to an injury or impairment in the cervical spine (C1 through T1) that affects all four limbs meaning both arms and legs.

Level of Injury refers to the lowest level where the spinal cord is functioning normally. Thus, a C5 injury would indicate that the spinal cord and all nerves at C5 and above are functioning normally. Thus, the injury to the spinal cord would be below C5.

### WHO GETS INJURED AND HOW

**Prevalence.**
In the United States, there are approximately 40 new cases of spinal cord injury per million or 11,000 new injuries each year. These figures do not include those who die at the scene of the accident. There are approximately 250,000 people in the United States living with spinal cord injury.

**Age and Sex.**
Spinal cord injuries occur most frequently in young adults. In the 1970’s most injured were between ages 16-30, average age was 28.7. Since 2000, the average age of
injury is 37.6 years. Approximately ten percent of all injuries were sustained by individuals over the age of 60. Approximately 80 percent of all injured are males.

**Cause.**

Motor vehicle accidents cause 47.5 percent of all spinal cord injuries; 22.9 percent are due to violence; 22.9 percent due to falls; 8.9 percent due to sports accidents; and 6.8 percent to other causes.

**Ethnic Groups.**

Among those injured, 62.9 percent were Caucasian; 14.2 percent were African American; 12.6 percent were Hispanic; and 2.5 percent were from other racial/ethnic groups.

**Level of Injury.**

Most frequent neurological category at discharge was incomplete tetraplegia (34.5 percent), followed by complete paraplegia (23.1 percent), complete tetraplegia (18.4 percent) and incomplete paraplegia (17.5 percent). Less than one percent experienced a full neurological recovery at discharge from the hospital. There has been a slight increase in the number of those with incomplete tetraplegia, a slight decrease in the number of those with complete tetraplegia and complete paraplegia.

**Mortality.**

Prior to new antibiotics in the 1950’s, those with spinal cord injury lived on average less than two years typically dying of urinary tract infections. Today, the leading cause of death is pneumonia followed by heart disease and sepsis, an infection spread throughout the body.

Those who became paraplegic in their 20’s and survived at least one year after injury, live an average of 46 more years compared to 58 years for the general population. Those with low level tetraplegia (C5 through C8) live an average of 41 years after injury; those with high level tetraplegia (C1 through C4) live an average of 38 years after injury.

**Length of Stay.**

National statistics indicate that average number days in the acute care hospital after injury is 19 days (2003). Average number of days in in-patient rehabilitation is about 45. Length of stays vary considerably in both the acute care and rehab settings depending upon medical complications, level of progress and many other issues.

**REFERENCES**

NeuroRecovery Network for Spinal Cord Injury -
http://www.christopherreeve.org/site/c.gelMLPOpGiF/b.1048729/k.6EF1/NeuroRecovery_Network.htm

Spinal Cord Research Center, University of Louisville - www.kscirc.org

Spinal Cord Brain Injury Research Center, University of Kentucky -
www.mc.uky.edu/scobirc

Spinal Cord Resource Center including research information - [www.paralysis.org](http://www.paralysis.org)

Classification of Spinal Injuries, ASIA scales - [www.sci-info-pages.com/levels.html](http://www.sci-info-pages.com/levels.html)

University of Alabama at Birmingham - [www.spinalcord.uab.edu](http://www.spinalcord.uab.edu)

National Spinal Cord Injury Association - [www.spinalcord.org](http://www.spinalcord.org)

### GLOSSARY

- **AMYOTROPHIC LATERAL SCLEROSIS (ALS)** - A progressive neurological disease affecting motor neurons that is considered fatal.

- **CERVICAL** - The neck region with 7 vertebrae and 8 spinal nerves.

- **COMPLETE SPINAL CORD INJURY** - An injury to the spinal cord where no neural signals are communicated past the level of injury, either from the brain to body parts below the injury or sensory signals from the lower body to the brain.

- **COMPRESSION** - Pressure on the spinal cord that can disrupt or stop the flow of information up and down the spinal cord.

- **CONTUSION** - A bruise on the spinal cord that can disrupt or stop the flow of information up and down the spinal cord.

- **DISC** - The cushion between each vertebrae of the spine that acts as a shock absorber.

- **FRIEDREICH’S ATAXIA** - A progressive disease affecting the nervous system impacting muscles used for movement, bowel and bladder control, speech and heart function.

- **INCOMPLETE SPINAL INJURY** - An injury to the spinal cord where some neural signals are communicated past the level of injury, either from the brain to body parts below the injury or sensory signals from the lower body to the brain.

- **LEVEL OF INJURY** - Refers to the lowest level where the spinal cord is functioning normally.

- **LUMBAR** - Refers to the low back region that includes five vertebrae between the thoracic and sacral regions.

- **MOTOR NERVES** - Nerves that carry information from the brain to muscles for muscles to contract, create movement.

- **MULTIPLE SCLEROSIS** - A disease that attacks the myelin, the insulator to nerve fibers, causing slowing or blockage of nerve signals.

- **SACRAL** - Refers to the lowest region of the spinal column sometimes called the tailbone.

- **SENSORY NERVES** - Nerves that carry information back to the brain related to hot, cold, touch, pain and pressure.

- **SEVERED** - Spinal cord partially or totally cut in two.
SPINA BIFIDA - During pregnancy, the spinal cord fails to develop normally which causes muscle weakness and/or paralysis after birth.

SPINAL COLUMN - also know as the spine or backbone contains 26 vertebrae or bones.

TETRAPLEGIA – Formally, quadriplegia. Refers to the loss of motor and/or sensory function in the arms, trunk and legs that is caused by injury or disease to the cervical (neck) segments of the spinal cord.

THORACIC - The region involving 12 vertebrae in the spine that runs from the shoulder to the lower ribs. This region is below the cervical region and above the lumbar region.

TRANSVERSE MYELITIS - Disorder caused by inflammation of the spinal cord often associated with infection though the cause is not fully known. It can result in muscle weakness and/or paralysis.

VERTEBRA - A single bone in the spinal column.
Chapter 3: 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. One, food is broken down by mechanical (muscle activity) and chemical action allowing it and fluids to be absorbed as nutrients by the body. Two, undigested and unabsorbed material and bacteria (waste products) are passed through the digestive system and eventually excreted from the body. These waste products move into the bowel which is last portion of the digestive system which consists of the small and large intestines, rectum and anus.

As the bowel fills with stool, it stretches, and normally 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**

Spinal cord injury can damage the nerves that allow you to control bowel movements. There are generally two types of neurogenic bowel dysfunction that occur. These are related to the level of spinal cord injury.

**Upper Motor Neuron Injury.** An upper motor neuron injury occurs above the L1-2 level and results in a reflexic bowel. In this type of injury, you do not receive messages telling you the bowel is full. The muscle that controls the opening and closing of the anus stays tight. As the bowel becomes full, it triggers a reflex, which automatically empties the bowel.

**Lower Motor Neuron Injury.** A lower motor neuron injury occurs below the L1-2. With a lower motor neuron injury the messages do not get to the spinal cord. Your reflexes do not function properly and the anal muscle remains relaxed. It is called a flaccid bowel.

**BOWEL MANAGEMENT PROGRAM**

The goals of an effective bowel program are to:

- Achieve control on a regular basis
- Eliminate or minimize accidents
- Decrease the complication associated with diarrhea, constipation impaction, autonomic dysreflexia. See chapter on Medical Concerns for more on autonomic dysreflexia.
- Provides the person with a sense of control and dignity around the sensitive issues of elimination.

There are certain things that you can do to make your bowel program successful. They include timing, regular physical activity, a balanced diet with an adequate fluid intake and digital stimulation. Your doctor may prescribe a medication to keep your stool soft and moving through your intestines. A suppository and digital stimulation may be needed to start your bowel program on a routine basis. The use of an enema is not advised as it can lead to bowel complications. However, when certain tests are ordered, you may be given enemas in preparation.

**Timing of the Bowel Program**

Frequency of the bowel program varies with each person. Your doctor may recommend a program be done every day or every other day. Never go longer than three days. After three days, fluid is absorbed from the fecal mass causing hard stool. The result is constipation or impaction.

It is important to consider a program that will meet the demands of your lifestyle. 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. Clinical experience shows that to have a bowel movement within 30 minutes of stimulation, the program must be done at the same time each program day.
For many, the best time to schedule a program is 15 to 30 minutes after the morning or evening meal. Eating stimulates peristalsis, a reflex that helps to move food through the digestive tract. Peristalsis begins with your first bite of food and its wave-like action continues to push food through your mouth, esophagus, stomach, small intestine, large intestine and into your colon. If the program cannot begin after a meal, a hot cup of coffee, tea or an evening snack may also cause this reflex.

**UPPER MOTOR NEURON INJURIES**

For upper motor neuron injuries, or injuries above the L₁-₂ level, bowel programs usually involve taking daily stool softeners and using a suppository with digital stimulation. Stool softeners are medicines that help prevent the stool from becoming too hard. A suppository is a bullet-shaped medicine that is placed in the rectum. This helps to trigger the muscles and nerves in the bowel to stimulate a bowel movement. Generally, Dulcolax suppositories are used first, with a progression to glycerin suppositories. You will learn what medicines work best for you. Some people will eventually not need to use suppositories (preferred, if possible) and stool softeners, and will only use digital stimulation. Digital stimulation is described below.

**Performing Digital Stimulation.**

Digital stimulation is performed when a well-lubricated gloved finger is gently placed 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 help increase peristalsis, the wave-like contractions that help move stool through the bowel.

Do this for about 30 seconds to one minute or longer if needed. Digital stimulation can be performed if a suppository has not been effective in emptying the bowel. You should wait approximately 30 minutes to see if the suppository will work. If the suppository is not working, perform digital stimulation. Digital stimulation can also be used without suppositories. Digital stimulation can be repeated about every 10 – 15 minutes up to a maximum of 4 times. The total time for a bowel program should not exceed one hour.

**Placement of Suppositories.**

Always wash your hands first and instruct others to do the same. Insert a well-lubricated gloved finger, and remove any stool near the rectum before inserting the suppository. This is called manual disimpaction. After all stool is removed, insert the suppository through the anus and place it against the wall of the rectum. Be as gentle as possible when placing suppositories, removing stool, or performing distal stimulation as the tissue in and around the rectum and colon are delicate.

**LOWER MOTOR NEURON INJURIES**

For lower motor neuron injuries, or injuries below the L₁-₂ level, bowel programs generally involve digital stimulation and manual removal (disimpaction) of the stool. Management of this type of bowel program may require more frequent attempts to empty the bowel.
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.

**SUCCESSFUL BOWEL PROGRAM MANAGEMENT**

There are several key components to a successful bowel program. They are as follows:

- Keep a Regular Schedule. You can train your bowels by following a routine schedule, and coordinate your bowel program with prior bowel habits and current life-style. Perform bowel programs at the same time every day. The best time to schedule a bowel program is 15-30 minutes after a meal. This stimulates a natural reflex in the body that will assist in emptying the bowel.

- Try Performing Your Bowel Program in an Upright Position. If possible, transfer to a padded toilet or bedside commode. Gravity helps move the stool down into the rectum for easier evacuation. Avoid the use of a bedpan; it may cause damage to your skin. If you cannot tolerate an upright position, lay on your left side because the bowel ends on the left side. If the program cannot begin after a meal, a warm beverage, or snack can cause this reflex.

- Keep the Stool Well Formed. Your stool should not be too soft or too hard. You may need to adjust your stool softness and diet. You should try to maintain a well balanced diet that is high in fiber. This will help maintain a formed stool consistency that allows for a successful bowel program. Fiber is found in fresh fruits, vegetables, and whole grain breads and cereals. Try to limit spicy foods and junk foods. Try to drink 8 – 10 glasses of water each day. Following these suggestions will help keep his will help keep your stool from becoming too hard which will help avoid constipation.

- Stay Active and Exercise as Much as Possible. Being active promotes better digestion of food and allows for better management of your bowel program.

- Provide for Privacy. Privacy will help you relax, allowing for a more successful bowel program.

**COMPLICATIONS ASSOCIATED WITH A BOWEL PROGRAM**

**Constipation**

Constipation is hard and infrequent stool that is difficult to pass. Constipation can be caused by prolonged bed rest, not drinking enough fluids or not eating a well balanced diet that is rich in fiber. Some medication can cause constipation such as pain medications, iron and antacids. To prevent constipation, your doctor may recommend you take a stool softener on a regular basis. Lastly, not doing your bowel program on schedule may increase your chance of being constipated. Signs and symptoms of constipation include:

- Straining to move bowels
- Hard, loose, or watery stools
- Irregular bowel movements
- Swollen or hard stomach
- Loss of appetite
- Nausea and vomiting
- Suggestions/solutions for constipation include:
  - Adequate fluid intake of at least 8 to 10 glasses of water
  - Eating a well-balanced diet which is high in fiber
  - Exercise and staying active
  - Maintain a scheduled bowel program
  - Take stool softeners as needed

**Diarrhea**

Diarrhea is the increase in the frequency of bowel movements where stools are usually loose and watery with bowel movements at least a couple times a day and usually more.

Causes of diarrhea include:
- Eating foods that are spicy, high in fat content, or contain caffeine (poor diet)
- Certain medications, such as antibiotics
- Over use of stool softeners or laxatives
- Stress
- Medical problems, like the flu

Suggestions/Solutions for Diarrhea include:
- Not taking any laxatives or routine stool softeners until the diarrhea stops.
- Adjust your stool softener dose after an episode of diarrhea is over.
- Stop eating foods that upset your stomach or that disagree with you.
- Drink plenty of fluids. Diarrhea can cause you to become dehydrated.
- If diarrhea lasts longer than 24 hours, consult your physician.

**Autonomic Dysreflexia**

Autonomic dysreflexia is a medical emergency that can be caused by the body’s response to a painful stimulus. Autonomic dysreflexia can occur in persons with spinal cord injury at, or above the T6 level. The painful stimulus causes an over-reaction of the sympathetic nervous system, which is characterized by an immediate rise in blood pressure.

Autonomic dysreflexia can be triggered by hemorrhoids, rough digital stimulation, pressure on the skin, or a full bowel can trigger autonomic dysreflexia. It is important to maintain a regular bowel program as you attempt to prevent triggering autonomic dysreflexia. Your doctor may suggest you try anesthetic ointments when performing digital stimulation. See chapter on Medical Concerns for more on autonomic dysreflexia.

**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 without the use of laxatives and enemas. 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.

**RESOURCES AND REFERENCES**


Bowel care - [http://www.mageerehab.org](http://www.mageerehab.org)

**GLOSSARY**

AUTONOMIC DYSREFLEXIA - An emergent, potentially dangerous condition associated with a spinal cord injury patient whose level of injury is T₆ or above. This condition is usually related to a noxious stimulus that is not sensed or felt by the individual due to the neural impulses blocked in the spinal cord due to the injury. During an episode of autonomic dysreflexia, the blood pressure can become very high and can cause stroke if not treated appropriately.

CONSTIPATION - Difficulty having a bowel movement, typically related to inactivity, dehydration and/or narcotic medications. It is important to maintain regular bowel movements to prevent constipation. Routine use of stool softeners and/or suppositories can also help prevent constipation.

DIARRHEA - Loose and watery stool usually associated with multiple bowel movements.

DIGITAL STIMULATION - Rotating a finger in the rectal vault to assist with bowel elimination by gently stretching the “ring” of anal muscle.

FLACCID BOWEL - This results when reflexes are not working properly. The anal muscles remain relaxed and do not normally push stool out through the anus.

LOWER MOTOR NEURON INJURY - Injury to nerves that originate in the spinal cord and travel out to the body (nerves below L₁₋₂) and can cause non-reflexic or flaccid bowel and bladder, and, for males, loss of reflexogenic erection.

MANUAL DISIMPACTION - Using a finger to manually remove stool from the rectum.

PERISTALSIS - Wave-like muscle contractions that help move food through the digestive tract.

RECTUM - Area between the end of the colon and the anus.

REFLEXIC BOWEL - When the bowel becomes full, it triggers a reflex that automatically empties the bowel.

SPHINCTER - Round, donut shaped muscle that constricts an opening. For example, the sphincter when closed, keeps stool in the rectum; when the sphincter is relaxed, stool can be passed.

STOOL SOFTENERS - Medications that are used to keep the stool soft as it moves through the digestive tract making elimination easier.
UPPER MOTOR NEURON INJURY - Injury to the long nerve cells within the spinal cord that communicate with the brain. Reflexes usually remain functional and allow for reflexic bowel, bladder and reflexogenic erections for males.
Chapter 4: BLADDER CARE

THE URINARY SYSTEM

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 two 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.

NORMAL BLADDER FUNCTION BEFORE SPINAL CORD INJURY

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 help push urine out of the bladder. The sphincters are round, donut shaped muscles 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 and control because of injury to the brain, spinal cord and/or nerves from the spinal cord to the bladder. A neurogenic bladder, in relation to spinal cord injury, is classified in one of two ways:

**Reflex Bladder.**

Also known as a spastic or upper motor neuron (UMN) bladder, a reflex bladder can occur when the injury is above the L1-2 level. If your injury is above L1-2, 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.

**Non-reflex Bladder.**

Also known as a flaccid or lower motor neuron (LMN) bladder, a non-reflex bladder can occur when the injury is L1-2 or below. If your injury is below L1-2, and your bladder fills with urine, it may become distended (overfilled and over stretched) because the reflexes of the detrusor muscles are diminished or absent. This means the bladder muscles do not push urine out of the bladder. These muscles can be damaged from overstretching. Additionally, the urine can then back up through the ureters into the kidneys.

The sphincter muscles may also be affected after injury to the spinal cord. Dyssynergia occurs when the sphincter muscles do not relax when the bladder contracts thus preventing urine from flowing properly.

**BLADDER PROGRAMS**

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 prevent complications such as infections and/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. IC’s are typically done every 4 to 6 hours around the clock by using a small flexible tube called a catheter. You, your caregiver and/or your nurse insert the catheter through an opening called the meatus (located at the tip of the penis for males and above the vaginal opening for females). The catheter is passed through the urethra until it enters the bladder. Once the catheter is in the bladder, urine
will flow until the bladder is empty. When the urine stream stops, the catheter is slowly removed. At this point, the catheter will either be thrown away or cleaned for reuse. The frequency (how often) you will need to do IC’s will vary from person to person.

A Foley catheter is another method of bladder management. A Foley catheter is an indwelling catheter that remains in the bladder 24 hours each day and allows the bladder to drain continuously into a collection device (bedside drainage bag or leg bag). The Foley is inserted as described above for intermittent catheterization. Once it is inserted into the bladder, a small balloon at the end of the Foley catheter is filled with sterile water and holds it securely in the bladder. To remove a Foley, the normal saline (salt water) is emptied from the balloon using a syringe and the Foley is pulled out. Unless contraindicated, indwelling catheters will be removed within 72 hours of admission.

A supra pubic catheter is another type of indwelling catheter that may also be used for bladder management. This type of catheter is similar to the Foley but requires surgery for placement. A small opening is created in the abdomen by a surgeon and a catheter is inserted into the bladder through this opening. The catheter continuously drains urine from the bladder into a collection device (bedside drainage bag or leg bag). The Foley catheter and supra pubic catheter are effective in draining the bladder, but the risk of infection and other complications are higher for indwelling catheters than intermittent catheterizations. Thus, intermittent catheterizations (IC’s) are usually recommended.

**SPONTANEOUS VOIDS**

Some patients experience spontaneous voids 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 will begin to empty without notice, possibly causing you to wet yourself (bladder “accident”). 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 urinary tract infection. There are several different brands of incontinence devices available and can be purchased at a local drug store/pharmacy or the Internet. Males may benefit from wearing an external catheter device. These external catheters are often referred to as Texas or condom catheters. They fit on the penis much like a condom and have an adhesive on the inside to hold them in place. A bedside drainage bag or leg bag is attached to the end of the external catheter so that urine may flow freely while keeping you dry. Females may wear external protection in the form of an incontinence pad or brief.

**HOW MUCH FLUID IS NEEDED**

It is recommended that you drink between 2000 and 2400ml(cc) of fluid a day (unless you have been told otherwise by your doctor). This is equivalent to approximately 8 to 10 (8oz) glasses of fluid a day. This may sound like a large amount but you probably drank close to that amount before your injury. Your fluid intake is important in helping keep your body functioning properly and minimizing complications such as dehydration and constipation.
Water is the ideal fluid for you to drink. However, you may still drink other fluids such as juices, soft drinks, coffee and tea in moderation. It is suggested that you switch to caffeine-free drinks if possible because caffeine stimulates the production of urine. Drinking caffeinated drinks may cause your bladder to become distended (overfilled) before your scheduled catheterization. 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 possibly minimize how often you have to catheterize (IC) during the nighttime.

The amount of urine in the bladder during any 4-hour period should not exceed 400-500ml (cc) or 10 oz. If you have more than 400-500ml (cc) in your bladder at any one time, the bladder muscles can become damaged (overstretched) and/or urine may back up into the kidneys possibly causing an infection. You will need to perform your IC’s more often (increase the frequency) if you are getting out more than 400-500ml (cc) or urine at one time. If you have an indwelling catheter and drink large amounts of fluid, the drainage device will need to be emptied more often. Keep in mind that ice, ice cream, applesauce, sherbet, Jell-o and soup are also considered fluids. Alcoholic beverages should be avoided, especially if you are taking medications. It is very dangerous to mix alcohol or other drugs with over the counter medications or medications prescribed by your doctor.

Keeping a daily journal or diary comparing your daily fluid intake and urine output may help you and your rehab team to develop a successful bladder management program. In general, your urine output should be about equal to the fluid that you take in during the day.

**CLEAN TECHNIQUE CATHETERIZATION**

Because hospital environments are known to have many types of bacteria, all intermittent catheterizations (IC’s) are performed by using a sterile technique. The sterile catheterization kit, which usually contains a collection tray, catheter, betadyne swabs, gloves, drapes and water-based lubricant, is thrown away after one use. However, some of the catheters (such as red rubber catheters) from these types of kits can be saved, cleaned and reused in the home. In the home environment, it is not necessary to use the sterile kit/technique for catheterizations. Instead, patients and families typically use what is called the clean technique. Using clean technique, gloves do not have to be worn, the genital area does not have to be swabbed/cleaned with betadyne ointment and the catheters can be cleaned for reuse. The clean technique is much more cost-effective as well as somewhat simpler to perform. If your bladder management program consists of catheterizations, you and your family/caregivers will be taught the clean technique prior to going home from the hospital.

The clean technique is performed as described below. Supplies needed include a clean catheter, water-based lubricant (such as K-Y Jelly), washcloths or baby wipes, clean tray and antiseptic soap.

- If in bed, lie on your back or side and raise the head of bed enough to see what you are doing. A mirror may be helpful in the beginning to help you see and become familiar with your genital area, especially for females. Females
should lie on their back with legs in “frog-like” position if in the bed. With practice, catheterizations may also be performed in a seated position on the toilet, bedside commode or in your wheelchair.

- Wash your hands with soap and water or a gel-type 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.
- Apply lubricating jelly to tip of catheter and position tray between legs. The end of the catheter that drains urine should be aimed toward the toilet or collection tray so that you do not make a mess.
- Males should hold the penis with one hand. Females need to expose the meatus by spreading the outer skin folds of the vagina with a forefinger and middle finger of the same hand. The hand that touches the genital area is now considered “dirty”.
- The catheter should be inserted with the other hand, the “clean” hand with the end of the catheter that drains urine pointed toward the collection tray or toilet. Insert the catheter until urine flows. Then, advance (push in) the catheter about 1-2 inches further.
- When the stream of urine starts to a trickle, gently massage your abdomen. This type of massage is called the Crede’ maneuver and it helps to gently push any remaining urine from your bladder. Continue the Crede’ maneuver as you slowly remove the catheter from your urethra. Do not remove the catheter until the bladder is completely empty. You will know that the bladder is empty when urine is no longer flowing out of the catheter.
- Place the used catheter in a storage container or bag to be cleaned later.
- Inspect your urine. Urine volumes should not exceed 400-500ml (cc). Note the color, volume (amount in ml or cc) and if there is an odor or sediment (small particles floating in urine) present. If your urine has a strong odor or contains sediment, see section on urinary tract infections below.
- Rinse genital area or perineum with a baby wipe or damp washcloth and soap.
- Wash your hands when finished!

CLEANING CATHETERS AND DRAINAGE DEVICES, ONCE USED AT HOME

Most insurance companies now cover the cost of single use catheters for home use. If reusing catheters at home, they need to be cleaned before being used again. It is a fairly simple process that could be done daily or even multiple times a day if needed. Most people choose to collect several used catheters before the cleaning process is started. Proper cleaning of catheters is described below:

- After using a catheter, wash the inside and outside of the catheter with antibacterial soap and water. Make sure to rinse well with water and drain the inside of the catheter by holding upright until water no longer drops out.
- Dry the catheter thoroughly by laying on a clean towel.
• When completely dry, you may store the catheters in a self-sealing plastic bag (Ziploc), a paper bag or plastic container. Some individuals prefer to wrap each catheter in aluminum foil as well.
• Always inspect each catheter after cleaning. Throw away any catheter that becomes brittle, cracked or does not drain well.
• After the cleaning/drying/inspection process is completed, the catheters may be reused.
• If you have frequent urinary tract infections (see below), or if you currently have a urinary tract infection, you may want to use the following additional steps when cleaning your catheters:
  • Thoroughly clean and rinse catheters as directed above.
  • Place several catheters in large pan of water, cover and boil for 15-20 minutes. Before boiling several catheters at once, you may try boiling one or two catheters to make sure that damage does not occur to the particular type of catheter you are using.
  • Drain the catheters and allow them to cool and dry completely on a clean towel.
• The catheters are now ready for reuse and may be stored as directed above.
• Urinary collection devices such as leg bags and bedside drainage bags should be cleaned at least once a day or when disconnected from your catheter. In order to properly clean the collection device, you will need antibacterial soap, water, white vinegar and a clean towel. The cleaning procedure is as follows:
  • Empty any urine from the collection device.
  • Wash the inside and outside of the drainage bag with soap and water. Make sure to rinse well with water.
  • Drain/empty bag.
  • Mix a solution consisting of 2 parts white vinegar to 3 parts water which is equivalent to one cup of vinegar to one & one-half cups of water.
  • Pour the vinegar solution into the drainage bag making sure the solution is also in the tubing.
  • Agitate or swish the solution around in the bag and tubing for at least 30 seconds.
  • Drain/empty bag completely.
  • Lay on clean towel to air dry.

Using a diluted bleach solution is equally effective in cleaning these collection devices. However, bleach may be irritating to the skin and/or respiratory tract (due to the fumes) and can also remove color from clothing. Thus, a vinegar solution is often preferred.

Your collection devices should be discarded after approximately one month of use (or sooner if they are no longer functioning appropriately) and be replaced with a new one at that time.
Chapter 4: Bladder Care

**URINARY TRACT INFECTION**

Urinary tract infections (UTI’s) are an ever-present concern for those with spinal cord injury. The source of UTI’s is bacteria which are tiny, microscopic organisms that can quickly reproduce and multiply. Bacteria in the bladder and kidneys can cause disease and infection.

**PREVENTING URINARY TRACT INFECTION**

You can drastically cut the risk of UTI by preventing the spread of bacteria into the bladder. There are several things you can do to help yourself avoid a UTI.

**Maintain a healthy fluid intake.**

Drinking the proper amounts of fluid helps to wash out bacteria and other waste products from the bladder. Water is the beverage of choice. Other beverages with sugar and caffeine are acceptable in moderation. Generally, it is recommended that you drink approximately 2000-2400cc daily which is equivalent to 8-10 (8 oz) glasses of liquid per day or about 2 quarts. For persons with a Foley catheter or supra pubic catheter, it is recommended you increase your fluid intake to about 3 quarts per day.

**Routinely and completely empty your bladder on a regular basis.**

It is very important that your bladder is emptied on a regular basis. When not emptied regularly, bacteria in the bladder may multiply and cause a urinary tract infection. Additionally, the bladder muscle may be damaged due to overstretching (overfilled bladder) and cause urine to backflow into the kidneys which, in turn, may lead to kidney infection and other health problems. Maintain your regular catheterization schedule as recommended by your healthcare provider but keep in mind that adjustments may be necessary. Extra catheterizations may be needed if you drink more than usual in the heat of the summer, at a social gathering or for medical reasons. Remember, the ideal amount for each intermittent catheterization should be under 400-500cc. A sterile or 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.

**Keep your skin clean.**

Good hygiene helps prevent infection. 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 accident. This helps decrease the number of bacteria that remain on the skin. Always wash your hands before and after providing bladder care and instruct any caregivers to do the same. Hand washing is the number one way to prevent the spread of bacteria and infection.

**Proper position of drainage bag.**

If using a catheter (indwelling or external) that connects to a drainage bag, the bag should always remain below the bladder so urine will drain freely. Empty the drainage bag at least every four hours or when the bag is about half full. This helps prevent the backflow of urine and allows your bladder to continuously empty completely.
Maintain your urinary products or appliances by regular washing and inspection.

Clean your drainage bag every day as described above. Sediment in the urine can collect in tubing and connectors making it more difficult for urine to drain and easier for bacteria to spread. Always put a cap over the end of the tubing that connects directly to your catheter when the bag is not in use and use an alcohol wipe to clean this end before reattaching it to your catheter.

Have regular urology checkups.

It is highly recommended that you have a complete medical checkup at least yearly. Your rehab physician or primary care physician will perform necessary urologic exams and order any other tests needed. You may also be seen by a urologist who is a physician who specializes in bladder care. 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. A renal scan or ultrasound may help identify whether the kidneys are functioning properly. An x-ray of the abdomen may be ordered to help detect any kidney or bladder stones. For those with indwelling catheters, cystoscopic evaluations may be ordered allowing the doctor to see inside the urethra and bladder. Recent research is showing a small increase in the risk of bladder cancer among individuals who have been using indwelling catheters for long periods of time.

**SIGNS AND SYMPTOMS OF URINARY TRACT INFECTION**

Unfortunately, UTIs do happen even when you and/or your caregivers do everything you can to prevent them. As such, you need to know the signs and symptoms of a UTI which usually include one or more of the following:

- Cloudy and/or foul smelling urine
- Increase in mucous strands or sediment
- Blood in urine
- Pain or burning with urination
- Increase in bladder spasms
- Increase in frequency of urination or urinary incontinence
- Increase in residual urine
- Low back or flank pain
- Elevated temperature/fever
- Chills, nausea and/or vomiting

**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 the 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 how the doctor recommended in order to kill the bacteria completely.
CONCLUSION

In conclusion, successful bladder management can be achieved in persons with spinal cord injury. The keys to a healthy urinary system are: taking all the proper steps to care for your skin, bladder and kidneys; performing your bladder program routinely; taking steps to prevent UTI; and getting necessary treatment if a UTI develops.

REFERENCES AND RESOURCES

Bladder Care -
http://www.harborhospital.org/body.cfm?xyzpdqabc=0&id=555628&action=detail&AEProductID=Adam2004_1&AEArticleID=003981
Bladder care - http://www.urologyhealth.org

GLOSSARY

AUTONOMIC DYSREFLEXIA - An emergent, potentially dangerous condition associated with a spinal cord injury patient whose level of injury is T6 or above. This condition is usually related to a noxious stimulus that is not sensed or felt by the individual due to the neural impulses blocked in the spinal cord due to the injury. During an episode of autonomic dysreflexia, the blood pressure can become very high and can cause stroke if not treated appropriately.

BLADDER - As urine flows from the kidneys, it is collected in the bladder prior to urine leaving the body.

CREDE’ MANEUVER - Gently press on the lower abdomen just above the pubic bone to either initiate a bladder contraction. This procedure helps to empty the bladder of urine, or helps the bladder completely empty once a bladder contraction has started.

DETRUSOR MUSCLES – Bladder muscles that contract (squeeze) when time to urinate and then relax to allow your bladder to fill with urine.

DYSSYNERGIA - A condition when the bladder muscles contract to push urine out but the sphincter muscles do not relax and inhibit the normal flow of urine from the bladder.

FOLEY CATHETER - Sometimes called an indwelling catheter, remains in the bladder for extended periods of time allowing the bladder to drain continuously.

KIDNEYS - As blood circulates through a pair of kidneys, it screens out waste products from the blood and creates urine.

LOWER MOTOR NEURON BLADDER – See Non-reflex Bladder.

INTERMITTENT CATHETERIZATION - A procedure used to empty the bladder of urine using a catheter at scheduled times. Once the bladder is empty, the catheter is removed.

MEATUS – See Urinary Meatus
NEUROGENIC BLADDER - Impaired bladder function and control due to injury to the central or peripheral nervous system, as in persons with spinal cord injury.

NON-REFLEX BLADDER - Absence or limited reflex of the bladder muscles that usually contract when the bladder starts to fill with urine.

PERINEUM - For males the space between the scrotum and anus; for females the space between the vulva and the anus.

REFLEX BLADDER - As the bladder fills with urine, a reflex is triggered to cause the bladder muscles to relax and push urine from the bladder.

SPHINCTERS - A round, donut shaped muscle that constricts an opening. For example, the sphincter when closed, keeps stool in the rectum; when the sphincter is relaxed, stool is passed.

SUPRA PUBIC CATHETER - During surgery, a catheter is inserted through the abdominal wall into the bladder which allows continuous drainage of the bladder.

UPPER MOTOR NEURON BLADDER - See Reflex Bladder.

URETERS - Urine draining from the kidneys is passed through two small tubes called ureters into the bladder.

URETHRA - A tube that allows urine to pass from the bladder to outside the body. For males, semen is ejaculated through the urethra.

URINARY MEATUS - Opening of the urethra on the body surface where urine is excreted. It is located at the tip of the penis on males and above the vaginal opening on females.

URINARY TRACT INFECTION – This is a bacterial or fungal infection that occurs in the kidneys, ureters or urinary bladder.
Chapter 5: SKIN CARE

The skin is a protective covering that acts as a barrier 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 liquid and water 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 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 without you knowing they have occurred. One of the most common skin injuries is a decubitus ulcer. A decubitus ulcer is known by many names such as pressure sore, 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 decubitus ulcer when an area of the skin or underlying tissue does not get adequate blood flow and the skin or tissue dies. Specifically, a decubitus ulcer may develop when you are sitting in your wheelchair for a long period of time. Continuous pressure from your pelvic bones pressing down into your buttock muscles prevents blood from flowing freely in that area which can cause your skin to breakdown. However, if pressure from the pelvic bones is relieved periodically, blood begins to flow again and the skin can stay healthy.

RISK FACTORS FOR DEVELOPING A DECUBITUS ULCER.

After spinal cord injury, you are at greater risk for developing a decubitus ulcer or pressure sore. It is estimated that up to 80% of individuals with a spinal cord injury will develop a pressure sore during their lifetime, with up to 30% having more than one episode. This increased chance occurs for several reasons:

You can place a great deal of pressure on your skin because you may not be able to move as you once did. 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. The moisture from accidents is very irritating to the skin.

Spasticity and frequent transfers can cause shearing of the skin.

STAGES OF A PRESSURE SORE.

The most common sign of a developing pressure sore is the appearance of a reddened area on the skin. Normally, this reddened area will clear within 30 minutes after pressure is relieved from this area. If the redness does not clear, a pressure sore has begun to form. A person with darker skin may see a change in their skin color. This area may become light, dry, flaky or ashy. There are four stages of pressure sore.
Stage 1:
Damage is limited to the top 2 layers of the skin. These are the epidermal and dermal layers. At this stage, the skin is not broken, but the redness does not turn white when touched.

Stage 2:
The skin is slightly broken. The sore appears to be an abrasion, blister or small crater. At this stage, the damage extends into the 3rd layer or subcutaneous tissue.
Stage 3:
At this stage, the damage extends through all layers of the skin and into the muscle. This ulcer may appear as a deep crater and adjoining tissue may be damaged.

Stage 4:
In this stage, damage extends through all tissues and involves the bone and joint structures. Osteomyelitis or bone infection can be a serious complication associated with this type of pressure ulcer.

**CARE AND TREATMENT OF PRESSURE SORES.**
If you happen to see signs of a decubitus ulcer or pressure sore as described above, remove all pressure from this area and call your physician.
Once you have a decubitus ulcer or pressure sore, you must keep weight off the damaged area to promote healing. Treatments range from pressure relief, extended bed rest, medication and surgery. Your physician will determine the best treatment needed which may also include cleaning and dressing the pressure sore on a regular schedule. Cleaning helps to remove dead tissue or waste products from the sore so healing will be more successful. Always remember to wash your hands and instruct others to do the same when providing care to the sore.

Watch for signs of infection in the sore. These may include redness around the edge, warm skin, colored drainage, odor, or an elevated temperature. You may be prescribed antibiotics if an infection develops. 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 don’t want a pressure sore; 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 at least every 20-30 minutes. This allows your skin to be re-nourished by blood flow supplying oxygen and nutrients, thus preventing prolonged pressure in one area. While in bed, you should be turned at least every 2 hours. If your injury is at the C4 level or higher, you may need assistance to perform pressure relief. At C5 or C6 levels, you may be able to lean forward or side-to-side for regular pressure relief when in a wheelchair. At the C7 level, you may be able to perform wheelchair push-ups. For more on various pressure relief techniques, see the Chapter on Mobility.

**Always Utilize Proper Equipment When in a Seated Position or Lying Down.**

Your rehab team will make recommendations to assist you in obtaining proper wheelchair cushions, mattresses, and any other pressure relieving or protective 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.**

Always keep your skin clean and dry. Moisture weakens the skin and causes it to breakdown more easily. The buildup of sweat, dirt, and other waste products, that are allowed to remain on the skin, make it more inviting for germs to invade the body. Wash and dry the skin right away after any bowel or bladder accidents. Change clothes when wet. Avoid heat from the sun, very hot water, kitchen appliances or an open fire. Try using lotion instead of powder on your skin. Spinal cord injury affects the normal control of blood vessels. Thus, the body doesn’t regulate skin temperature as well and burns or frostbite can occur more easily.

**Protect Your Skin.**

Avoid movements or activities that cut, scratch, or rub the skin. Avoid clothes and shoes that are too loose and too tight fitting. Avoid clothes with thick seams, buttons, or
zippers that place pressure on the skin. Avoid slumping or slouching when seated in your wheelchair. Bad sitting posture places direct pressure on the sacrum (tailbone). Take special caution when performing transfers or participating in new activities or sports. Make sure any adaptive equipment or splints fit properly.

**Maintain Adequate Fluid Intake and a Well Balanced Diet.**

Work with a dietician in planning meals that are high in protein, vitamins, and minerals. This will help maintain healthy skin and will promote faster healing if problems occur. Drink at least 8-10 glasses of water each day. Try to avoid caffeinated drinks and alcohol.

**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. These are the areas that are more susceptible to breakdown. These areas include the sacrum or tailbone, heels, hips and base of the buttocks.

In conclusion, almost all decubitus ulcers and pressure sores are preventable. The key is to maintain healthy skin, which is a life-long process. Know what to look for, know how to direct others in proper skin care, know when to limit your activities and know when to consult your physician. Maintaining healthy skin should be an everyday event and should not prevent you from leading an active healthy life.

**RESOURCES**

Skin care - [http://www.paralysis.org/site/c.erMJUOxFmH/b.1306547/k.F280/Skin_Care.htm](http://www.paralysis.org/site/c.erMJUOxFmH/b.1306547/k.F280/Skin_Care.htm)

**GLOSSARY**

**DECUBITUS ULCER** - A breakdown in the skin that starts as a red spot and can easily progress to a break in the skin that can deepen all the way down to the bone if not properly treated. Ulcers are often caused by unrelieved pressure while lying in bed without turning or sitting in a chair in one position. Sometimes called a pressure sore.

**PRESSURE RELIEF** - The act of taking weight off a part of the body that has sustained pressure for a long period of time.

**PRESSURE SORE** - See decubitus ulcer.
Chapter 6: MEDICAL CONCERNS

AUTONOMIC DYSREFLEXIA

Autonomic dysreflexia, also known as dysreflexia, is a medical emergency which can occur if your spinal cord injury is at the T₆ level or above. Autonomic dysreflexia can develop suddenly, and if not treated promptly, it can lead to seizures, stroke or death.

Autonomic dysreflexia occurs when an irritating stimulus happens in the body below the level of spinal cord injury. This produces a mass body response leading to constriction or narrowing of the blood vessels and an immediate increase in blood pressure. In a person with a spinal cord injury T₆ and above, the blood pressure cannot be regulated because the message from the brain to dilate (open up) the blood vessels and lower blood pressure cannot pass down the spinal cord past the level of injury. The blood pressure may continue to rise until the cause or the irritating stimulus is eliminated.

Causes of Autonomic Dysreflexia.

Autonomic dysreflexia is triggered by something painful or uncomfortable often associated with bladder or bowel problems. Common triggers are identified below.

**Bladder**
- Distended or overstretched bladder
- Kinked or clogged catheter tube
- Urinary tract infections
- Spasms
- Overfilled collection bag

**Bowel**
- Constipation or impaction
- Stretching of the rectum during improper digital stimulation
- Excess gas causing distention of the bowel

**Skin Related Problems**
- Pressure on skin for prolonged periods of time (tight jeans, too tight shoes, wrinkles in linens or clothes)
- Pressure sore (another reason to prevent skin breakdown)
- Burns, cuts, abrasions

**Sexuality Activity**
- Over stimulation during sexual activity
- Menstrual cramps and labor pains can also be a source of dysreflexia in the female.

**Other Sources**
- Heterotopic ossification (HO)
• Bone fractures
• Abdominal conditions such as ulcers, colitis, and peritonitis

Signs and Symptoms of Autonomic Dysreflexia.

There are many danger signals that may alert you to the onset of dysreflexia and they may vary from one episode to another. The most common and obvious symptom is onset of a sudden severe and pounding headache. This is caused by the rise in blood pressure. Other signs and symptoms may include:

• Vision changes such as blurring, seeing spots and narrowing of vision
• Nasal congestion or stuffiness
• Flushing or splotching of the face, neck or chest above the level of injury
• Goose bumps or excessive sweating above the level of injury
• Slow heart rate

Treatment for Autonomic Dysreflexia.

Autonomic dysreflexia represents a significant and imminent threat and will not go away until the cause has been eliminated. Treatment should begin quickly to prevent complications.

The first appropriate response is for you to remain calm and get into a comfortable position. If in bed, raise the head of the bed or sit up. This will help to lower your blood pressure. If in a wheelchair perform a pressure relief. The cause of the autonomic dysreflexia may be in one of the areas described below.

**Bladder.**

If your bladder management program is intermittent catheterization, you may need to drain your bladder by performing a straight cath. This should be done slowly to prevent bladder spasms. You may wish to use an anesthetic lubricant when inserting the catheter. If you have an indwelling catheter, empty the leg or bed bag if full. Check to make sure the drain tube is not kinked or clogged.

**Bowel.**

Check your bowels. If autonomic dysreflexia occurs during digital stimulation, stop until symptoms stop. Consider using an anesthetic lubricant prescribed by your physician. If the bowel is full, remove the stool. This should be done as gently as possible and an anesthetic lubricant may be needed.

**Skin.**

Check your skin for any problems. Loosen clothing and remove stocking, socks and shoes. Check for any potential source of noxious stimulus and remove it. Look for skin breakdown, blisters and infections. Check for ingrown toenails.

**Medications for Autonomic Dysreflexia.**

Quick action and trouble-shooting will usually resolve autonomic dysreflexia. However, if the offending trigger or stimulus cannot be identified and removed, it may be necessary to utilize medications. They generally include:
• Clonidine, 0.1 to 0.2 mg by mouth -- the drug of choice
• Procardia, 10 mg under the tongue or by mouth
• Nitroglycerin, 1/150 under the tongue or 1/2 inch topical paste, which can be removed upon resolution of dysreflexia
• Hydralazine, 10 to 20 mg by shot into the muscle or vein
• 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.**

With proper precautions you should be able to prevent or reduce the number of autonomic dysreflexia episodes. These include:

• Frequent pressure relief in the wheelchair and bed. Perform wheelchair pressure relief at least every 20-30 minutes and change positions in the bed at least every 2 hours.

• Avoid becoming sunburned and protect your skin with sunscreen when outdoors. Because your sensation is impaired, you may not realize when your skin is being burned. Always test water temperature to avoid being burned by hot water. Dress appropriately in cold weather to prevent frostbite. The skin below the level of spinal cord injury is more susceptible to frostbite than skin above the level of injury.

• Maintain a regular bowel and bladder program. Always have proper supplies available. These may include cath kits, gloves, anesthetic lubricants, and urinary supplies.

• Discuss with your doctor the need to have a prescription for blood pressure medicine available for the treatment of autonomic dysreflexia.

**Conclusion.**

Remember, autonomic dysreflexia is an emergency situation that can occur in anyone that has suffered a spinal cord injury at the T₆ level and above. Become familiar with the causes, signs, symptoms and treatment of autonomic dysreflexia and make sure those close to you understand these as well. Quick assessment and action may prevent the complications associated with autonomic dysreflexia.

**DEEP VEIN THROMBUS**

Deep vein thrombus (DVT) occurs when a blood clot develops in one of the large deep veins of the body. 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 more serious complications. For example, a piece of the clot can break off, travel through the blood stream and lodge in the lungs. This is called a pulmonary embolus, and can be life threatening. The most serious complications occur when the clot lodges in the brain, heart or lungs.
Risk Factors.

After spinal cord injury, you are at a greater risk for developing DVT’s because blood can remain or pool in the leg veins and lower trunk due to paralysis and decreased mobility. Normally, the actions of the muscles help keep blood moving, but after a spinal cord injury, this action may be limited or lost. Other possible risk factors include:

- Prolonged bed rest
- Abnormal blood clotting
- Major injury
- Surgery, especially to the hips or knees

Signs and Symptoms

Redness, swelling and increased warmth occur along the path of the vein. This is due to inflammation of the lining of the vein during the initial formation of DVT.

Pain, tenderness and skin color changes may occur in the affected extremity. This is caused by a reduction of blood flow as the clot or thrombus enlarges.

Low-grade fever. There may be a slight increase in temperature without any signs of infection.

Prevention

- Drink plenty of fluids, preferably water (6-8 glasses each day).
- Stay as active as possible. Perform daily range of motion exercises.
- Check your legs for signs of DVT’s on a daily basis.
- Minimize swelling by elevating legs or wear compressive stockings if ordered by your physician.
- Take anticoagulants if ordered by your physician.

Treatment

- Call your physician immediately if you think a DVT is present.
- Stay in bed with the affected leg elevated and in a straight position.
- Do not rub or massage affected leg. Do not exercise your affected leg as this may cause a piece of the clot to break free and travel to other areas of the body.
- Increase your fluid intake.
- Remove tight shoes and clothing.
- Take prescribed medicine, if ordered. You may be placed on anticoagulant medications.

**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 most frequently is found around the joints or long bones of the hips, knees, shoulders, and elbows. In individuals with spinal cord injury, HO may begin below the level of injury. The highest risk period for the occurrence of HO is soon after injury.
Chapter 6: Medical Concerns

Early signs and symptoms of HO include swelling, erythema, redness, and warmth over the area. If only a small amount of bone is forming, you may not notice any clinical signs or symptoms. In later stages of HO development, you will notice limitations in joint movement and pain with range of motion exercises.

The primary problems associated with HO include decreased mobility and range of motion, and may predispose the individual to skin breakdown and contractures. This may in turn interfere with your ability to perform normal activities of daily living and may ultimately decrease your independence. Diagnosis is based on clinical assessments of signs and symptoms, lab tests, x-rays and bone scans.

Management of Heterotropic Ossification.

Management generally involves therapy, medications, and/or surgical intervention. The role of therapy is to prevent ankylosis (freezing or fixation of the joint due to fusion of bones). This is done through gentle range of motion exercises. The drug of choice is Didronel. This does not prevent HO from forming during the initial inflammatory process, but helps to inhibit new bone formation. Certain drugs like Ibuprofen can be used for inflammation. Surgery is indicated only when HO interferes with self-care and mobility. Occasionally, radiation therapy can be used to minimize HO.

Summary.

Heterotropic Ossification generally occurs soon after spinal cord injury and consists of the formation of new bone in soft tissues where it is not normally found. You should be alert to the signs and symptoms of HO and contact your physician immediately if these become present. Initial symptoms include swelling, redness, and warmth over the area. Later symptoms include decreased range of motion. While there is no cure, quick and early intervention can minimize the possible problems caused by HO.

ORTHOSTATIC HYPOTENSION

Orthostatic hypotension is a sudden drop in blood pressure that occurs when you change positions. It often happens to those with spinal cord injury when you sit up or get up out of bed too fast. This may lead to dizziness or fainting.

Most people with spinal cord injury have a daily blood pressure that is lower than that of the general public because arteries do not get messages from the brain to constrict and keep the blood pressure regulated at a higher level. After injury when you sit up with your legs down or when you stand up, your blood pressure may drop even lower than is typical for you. This happens because the blood tends to collect or pool in the veins and arteries of the legs and feet instead of being pumped back to the heart. This lower blood pressure decreases the amount of blood reaching the brain and may cause dizziness or fainting.

Preventing Orthostatic Hypotension

- Before getting out of bed, raise the head of the bed for at least 15 to 20 seconds.
- Sit up slowly.
- Wear compressive stockings and an abdominal binder, if ordered. These will help prevent pooling of blood in arteries and help pump the blood back to your heart.
Chapter 6: Medical Concerns

- Move slowly, moving too fast may cause dizziness or make it worse.
- Drink one or two glasses of fluids prior to getting up.
- If you become extremely light-headed and faint, your family or caregivers should know to lie you down and elevate your legs above the level of your heart. If you are sitting in a wheelchair, have your family member or caregiver tilt your wheelchair backward lowering your head and raising your feet.
- If you continue to have problems with dizziness or fainting, consult your physician.

**SPASTICITY**

Spasticity is uncontrolled muscle activity. Spasticity usually begins a few weeks after spinal cord injury and may continue over the life span. Spasms can affect the arms, legs and/or trunk. Sometimes muscles in spasm will cause the limb to quickly jump and release several times before stopping. Some spasms will cause a muscle to contract and hold an arm, leg or other body part in one position for many seconds before releasing. Any spasms you may have will likely change over time.

Spasticity can be triggered by many things including bladder or kidney infections, skin breakdown, pressure sores and putting on clothes. Spasticity is stronger for individuals who do not perform range of motion exercises regularly, making the muscles and joints tight.

**Advantages of Spasticity.**

There are some benefits to spasticity. They include:

- Increases in spasticity can serve as a warning signal to identify pain or problems in areas where there is no sensation. For example, an increase in spasticity can be a warning sign to developing a urinary tract infection or skin breakdown.
- Spasticity helps promote circulation of blood. It assists in pumping fluid and blood out of the veins, which may help decrease edema and DVT's.
- Spasticity may be used to improve some functional activities such as performing transfers or walking with braces.

**Disadvantages of Spasticity.**

The disadvantages of spasticity can include:

- Spasticity may interfere with certain activities like sleeping, driving, sex and walking with braces.
- Spasticity can cause skin damage through friction, shearing or scraping, and/or hitting solid objects.
- Spasticity can limit joint movement and increase the risk of a contracture (a tight, limited joint movement).
- Spasticity can cause pain.

**Preventing Spasticity.**

There are some ways to help control and prevent some of the complications associated with spasticity.
Performing daily range of motion exercises.
Avoid certain body positions and fast movement, which may trigger spasticity.
Try taking a warm bath or shower. Always remember to test the water to make sure it is not too hot.

Treatment Options.
If spasticity becomes a problem and interferes with activities of daily living, you should discuss treatment options with your physician. Certain medications (Baclofen, Valium, Zanaflex or Dantrium) can be used. These medications act as muscle relaxers to help decrease spasticity. Injections of specific medication into muscle or nerves can help reduce spasticity (Botox or Flanol).

A Baclofen Pump Implantation is a surgically implanted programmable pump that delivers Baclofen directly into the fluid surrounding the spinal cord. This is indicated in cases where severe spasticity is present and oral medicines have not been successful in controlling spasticity or cause intolerable side effects.

Surgery may be indicated in severe cases of spasticity. This may be indicated in cases where other treatment options have failed.

REFERENCES AND RESOURCES
Autonomic dysreflexia - http://calder.med.miami.edu/pointis/automatic.html
Heterotopic ossification - http://www.emedicine.com/pmr/topic52.htm

GLOSSARY
AUTONOMIC DYSREFLEXIA - An emergent, potentially dangerous condition associated with a spinal cord injury patient whose level of injury is T6 or above. This condition is usually related to a noxious stimulus that is not sensed or felt by the individual due to the neural impulses blocked in the spinal cord due to the injury. During an episode of autonomic dysreflexia, the blood pressure can become very and can cause stroke if not treated appropriately.

COLITIS - Inflammation of the colon.

DEEP VEIN THROMBUS - Occurs when a blood clot develops in one of the large deep veins of the body. 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.

DIGITAL STIMULATION - Rotating a finger in the rectal vault to assist with bowel elimination.
EMBOLUS - Debris or other foreign object transported by the blood and can include blood clots, pieces of bone, or air bubbles. Debris can move from one place in the body to another such as the heart, lungs or brain and cause serious injury.

HETEROTOPIC OSSIFICATION - Growth of bone tissue in locations where it should not be found. This condition can cause joints to become stiff and limit movement.

ORTHOSTATIC HYPOTENSION – the sudden drop in blood pressure that occurs when you change body position that leads to dizziness or fainting. It often happens to those with spinal cord injury when sitting up or getting up out of bed too fast.

PERITONITIS - Inflammation of the abdominal cavity.

SPASTICITY - A state of increased muscle tone and excessive response that often occurs when a muscle is stretched. It can cause an arm or leg to feel tight and be difficult to move.

ULCER – An opening, sore or wound in the skin/tissue.
Chapter 7: LUNG CARE

Spinal cord injury and impairment 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 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 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.

These air passages and air sacs together make up the lung. See the illustration below. The right side of the lung has three lobes and the left side of the lung has two lobes. The heart sits between the lungs. After the blood picks up oxygen in the lungs and gets rid of the carbon dioxide, the blood goes to the heart where it is pumped to all parts of the body.

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. Moving air in and out of the lungs is like a bellows:

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.

**PATHOLOGY**

Injury to the spinal cord can weaken or paralyze some or all of the muscles needed for you to breathe on your own. How well you breathe is affected by the condition of your lungs before injury and by the level and extent of your injury.

Breathing complications may occur for the following reasons:

- The loss of abdominal and chest wall muscles may reduce your ability to cough and clear secretions.
- If secretions remain in the airways and air sacs, the oxygen cannot get into the air sacs.
- A weak diaphragm can also fatigue or tire out easily.
- Without your breathing muscles moving properly, the tiny air sacs, called alveoli, may collapse.
- Injury may cause the chest muscles and the diaphragm to work against each other resulting in inefficient work.
- The end result of muscle paralysis is: change in rate, depth and rhythm of respirations (breathing); impaired removal of secretions; and abnormal oxygen and carbon dioxide levels in the blood.
LEVEL OF INJURY AND RESPIRATORY FUNCTION

The level and extent of your spinal cord injury or impairment will determine how well your respiratory system will function.

S5 through L1.
If you have a complete spinal cord injury between S5 and L1, your breathing muscles will not be affected and you will have the ability to breathe as you did before injury.

T12 through T6 Level of Injury.
If you have a complete spinal cord injury between T12 and T6:
- The abdominal muscles will be weakened or paralyzed.
- Your ability to cough will be impaired.
- Alternative or augmented cough techniques will be needed.

T5 through C5 Level of Injury.
If you have a complete spinal cord injury between T5 and C5:
- The abdominal muscles will be paralyzed and varying levels of chest muscle function will be lost.
- The ability to take a deep breath independently and to cough will be lost.
- Deep breathing techniques will be needed to prevent air sac collapse.
- You will need to learn alternative and augmented cough techniques.

C4 Level of Injury.
- If you have a complete spinal cord injury at the C4 level:
  - All breathing muscles except the diaphragm will be paralyzed.
  - Normal respiratory pattern may be reversed.
  - The ability to take a deep breath and to cough independently will be lost.
  - Deep breathing techniques will be needed to prevent air sac collapse.
  - You will need to learn alternative and augmented cough techniques.
  - A tracheostomy may be needed to allow secretions to be suctioned with a catheter.

C3 Level of Injury.
If you have a complete spinal cord injury at the C3 level, all items listed under Levels of Injury above apply here. In addition:
- There may be one-sided or two-sided impairment or paralysis to the diaphragm.
- The ability to take a deep breath with alternative techniques may be lost.
- Mechanical ventilator, sometimes called a respirator, may be needed to assist with breathing.

C2 and C1 Level of Injury.
If you have a complete spinal cord injury at the C2 or C1 level, all items listed under Levels of Injury above apply. In addition:
- All respiratory muscle function will be lost; all breathing muscles are paralyzed.
• Full time mechanical ventilation or respirator will be required.
• Tracheostomy to remove secretions will be required.

If you have an incomplete spinal cord injury, the descriptions above may or may not be accurate to your situation. Your respiratory therapist and others on the rehab team will help you understand how your injury has affected your ability to breathe and how best to keep your lungs healthy and breathing muscles strong.

Oxygen Delivery Systems.
Immediately after injury, it is common to need additional oxygen to raise the level of oxygen in your blood. One common method is to deliver oxygen through a tube or nasal prong directly into the nose. If needed, a mask with a bag may be used to provide higher concentrations of oxygen. If you have a tracheostomy, oxygen may be given to you with a special trach-mask or T-piece connector. In the event that a mechanical ventilator is used, oxygen is then delivered by the machine.

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 rehab team will educate you and your family about how to manage a ventilator in the home setting.

Diagnostic Testing
Your doctor and respiratory therapists may use several methods to fully assess your respiratory function. Many of these tests can be done bedside.

For example:
• Direct observation and listening to the movement of air in your chest.
• Chest X-rays.
• Bronchoscopy done by looking into your air passages with a special scope.
• Electrical muscle testing.
• Arterial blood tests to measure oxygen and carbon dioxide levels
• Pulmonary function tests and oximetry testing measures oxygen in the blood performed with a finger sensor.

PULMONARY HYGIENE
Pulmonary hygiene refers to the removal of secretions needed to maintain your lungs' ability to get air into and out of air sacs. Many patients need a combination of daily treatments for successful maintenance. These treatments may include use of a manual resuscitator, saline instillation, humidification and respiratory muscle training. Secondly, to maintain opened air passages (bronchi), you may require nebulized medications which are inhaled either through your mouth or tracheostomy tube. Other treatments, described in details below, include positioning, positive pressure, coughing, postural drainage, percussion and vibration.
Positioning.
Frequent changes in position prevent the pooling of secretions in the lungs. 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.

Positive Pressure.
On occasion, positive pressure is used to inflate the lungs periodically either by a manual resuscitator (ambu bag) or with a special machine. Treatments are usually three or four times a day.

Coughing.
Coughing is an automatic reflex that causes air to be forcefully expelled from the lungs 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 techniques must be used to improve the cough.

These techniques include assistive (quad) coughing, the cascade cough, huff cough, end expiratory cough and sustained maximal inspiration as described below. In addition to effective coughing, other things need to be done to keep the lungs clear. Drinking the proper amount of fluids will make the mucus in the lungs thin and easier to cough up. Frequent turning and re-positioning will also assist in removing mucus from the lungs. Medications may also be used in improving airway clearance.

Augmented (Quad) Cough
When your abdominal muscles are paralyzed, your caregiver’s hand is placed on the upper abdomen, two or three fingers below the center of the rib cage, while the other hand is placed on your shoulder. Take a slow deep breath and cough. As you cough, your caregiver abruptly pushes the abdomen in and upward.

When your abdominal muscles are weak or fatigue easily, have your caregiver place his or her hands on your outer chest, maintaining contact during inspiration. As you cough, the chest wall is abruptly compressed without losing hand contact.

Cascade Cough
- Take a deep, slow breath.
- Cough successfully three or four times on same inhalation.
- Inhale slowly and repeat.

Huff Cough
- Same as above, except say “huff” while coughing. Instead of a cough noise, there is a huff noise.
- Especially good if you gag when coughing.
- May need to be followed with cascade cough.
End Expiratory Cough

- Take several deep inhalations (slow).
- On the third or forth breath exhale half your air, then cough.
- Follow with cascade cough.

Postural Draining/Percussion and Vibration.

If coughing alone is ineffective in keeping your lungs clear of mucus, a technique called postural drainage may be used. Just as the name implies, postural drainage helps different sections of your lung drain by changing posture or position. This usually means turning onto sides, back, and, if possible, the stomach. The positions used will depend upon which area of the lung requires drainage. This technique allows gravity to move the mucus into the airway where it is more easily coughed out. Your nurse or therapist will instruct you as to which position or positions will help drain your lungs.

Frequently, percussion and vibration are added to postural drainage. This combination is referred to as the ketchup bottle technique. When pouring ketchup out of a bottle, you turn it over (postural drainage), if it doesn’t come out you pound the end of the bottle (percussion) and shake it (vibration). Just like with the ketchup bottle, these techniques help to move mucus from the smaller to larger airways, where it is more easily coughed out.

Percussion is also called cupping. This is done by cupping the hands and gently but firmly striking the chest in a rapid rhythmic fashion. The area to be percussed will be shown to you by your nurse or therapist. This should create a hollow not slapping sound if done correctly. A thin towel or sheet should be used next to the skin.

Percussion may be followed by vibration. This is done with flat, not cupped, hands on the chest. The arms of the person administering the treatment are locked. As the patient, you are instructed to take a deep breath and breathe out slowly. As you exhale, hands are placed over the appropriate area and a vibration is generated from the shoulder and upper arm. This should create a fine vibration on your chest wall which is also being compressed during the entire exhalation. This technique is repeated at least 3 times followed by coughing.

A mechanical precursor may also be used in place of this manual technique. Several methods may be tried and the one that yields the best results for you will be continued. 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.

Respiratory Muscle Training

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 rehab team will show you various exercises to help you strengthen the working muscles that you have. In addition, your respiratory therapist may have you do additional exercises.
**Breath Stacking/Incentive Spirometer.**

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. You should perform deep breathing exercises at least 80 to 100 times per day. This prevents some of the small air sacs in your lungs from collapsing.

**Breathing Retraining.**

The Threshold Inspiratory Muscle Trainer and Therapep 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 by conditioning. 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 team members. As your muscles get stronger, the workload and time will be increased. These exercises need to be done faithfully, and ideally, at the same time each day. The goal is 15 minutes, twice a day.

**Diaphragmatic Weights.**

The diaphragm is a large muscle that is located under your lungs and in normal conditions performs about 60% - 80% of the work associated with breathing. When the spinal cord is injured, some of the chest and abdominal muscles may be paralyzed. When this happens, it is important to make the most of the diaphragm because it may be doing all the work of breathing. To do this, weights may be placed over the diaphragm, which is located just under the ribs and above the belly button. During inspiration, you should see the weight rise, and with expiration, it will fall. The amount of time and weight needed will be recommended by your therapist. It will be increased as your muscles gain strength. This is another form of conditioning exercise which needs to be done regularly.

**Respiratory Care**

*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.

There are two basic types of tracheostomy tubes, cuffed and uncuffed. A cuffed tube is used when a closed system is needed, such as when a patient is on a ventilator or when a patient has swallowing difficulties and food or secretions enter the lungs by
mistake. Extra care needs to be taken with a cuffed tracheostomy tube because the potential exists for the inflated cuff to cause too much pressure on the lining of the airway. Your nurse or therapist will instruct you on how to inflate and deflate the cuff and watch for potential problems. An uncuffed tracheostomy tube is used if the patient’s primary problem is secretion removal.

**Communicating with a Tracheostomy Tube.**

When a trach tube is in place, your ability to talk will be affected but various methods will be provided to help you communicate. From the beginning you may communicate through lip reading or writing. If the trach tube is cuffless, you may be instructed to simply place your finger over the opening during exhalation to speak. With a trach tube plugged, you can exhale air around the tube, up through your vocal cords (voice box) and speak. Often trach tubes are reduced to the smallest size needed and plugged.

**Passy Muir Speaking Valve.**

In the event that the tube cannot be plugged or a cuffed tube is needed for mechanical ventilation, a special valve is used to help you to speak. The Passy Muir Speaking valve allows you to inhale through the trach tube but allows you to exhale through your normal voice box and upper airway. The rehab staff will instruct you in the proper use of this valve. You must remember to:

- Deflate cuff prior to using valve if trach tube has a cuff.
- Clean valve daily with liquid ivory soap, rinse well and air dry.
- Discard when valve no longer functions or at least every other month.

**Talking Tracheostomy Tubes.**

If you are ventilator dependent, various trach tubes are available which permit you to have the cuff inflated while providing a way to speak. An additional port, along with a secondary air flow source, shunts air above the cuff through your vocal cords, thus allowing you to speak. The ports on this cuff must be kept open to allow air to flow. This is done through irrigating the ports with saline every 1-2 hours.

**WARNING SIGNS OF RESPIRATORY PROBLEMS**

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

Many of these changes will need treatment and help from your doctor. For example, if the sputum is yellow, then antibiotics may be ordered. Further diagnostic tests may be ordered such as a chest X-ray or arterial blood gases. Preventing respiratory infections is important. You should obtain both the pneumonia and flu vaccines. If you smoke, you
should make efforts to stop smoking. 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

GLOSSARY
ALVEOLI - Air sacks in the lung where oxygen enters the blood and waste products leave the blood.

AUGMENTED COUGH - Technique for coughing which improves cough or makes the cough more effective.

BRONCHI - Air passages in the lungs that lead to the small alveoli.

CILIA - Hair like structures in the bronchi that move in a wave like fashion to remove pollutants from the lungs.

DIAPHRAGM - Large breathing muscle attached to the bottom of the lungs and helps pull air into the lungs.

INCENTIVE SPIROMETER - Device used to encourage deep breathing.

LARYNX - Voice Box.

MANUAL RESUSCITATOR - Device which allows increased amount of air or oxygen to be given to lungs.

MUCUS -- Viscid fluid secreted by the mucous membranes and glands.

PASSY MUIR SPEAKING VALVE - Valve placed at the end of a tracheostomy tube that allows a person to speak and be heard.

PHLEGM - Thick mucus.

POSTURAL DRAINING - To help drain the lungs, the patient is placed in a specific posture (head below feet while lying in bed).

QUAD COUGHING - A cough that is assisted by pressing down and up on upper abdominal muscles to increase the productiveness of the cough. This technique is often helpful for persons with quadriplegia or tetraplegia who cannot cough on their own.

RESPIRATOR - Breathing machine.

THRESHOLD INSPIRATORY MUSCLE TRAINER – A spring loaded device used to work expiratory muscles to improve coughing.

TRACHEA - Wind pipe carrying air to and from the lungs.

TRACHEOSTOMY - Opening in the throat, through trachea which allows a tube to be inserted.
Chapter 8: COGNITION, COMMUNICATION AND SWALLOWING

After spinal cord injury or disease, you may experience difficulty thinking, speaking, understanding, reading, writing and/or swallowing. If this is true, a Speech Language Pathologist (SLP) may work with you in some or all of these areas.

COGNITION AND COMMUNICATION

Thinking skills (cognition) may be impaired when an injury or illness affects the brain. The SLP may have you do exercises and activities to improve thinking and offer strategies to compensate for problem areas such as memory, problem solving or planning.

Injuries or illnesses affecting the brain can also cause speaking problems. Impaired speech, though, can be caused by other conditions of the spinal cord or the 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.

Speech is produced by the mechanical action of certain muscles. Additionally, an important part of speech is the message. The message that is spoken comes from our ability to use language. The words we use to communicate are part of our language. Partial or complete loss of language may occur when the brain is damaged from illness or trauma. When language is impaired, a person may have problems finding words or putting words together to express thoughts. A person with language impairment is likely to have some difficulty understanding other peoples’ spoken words. Problems with language can also be found with a person’s ability to understand written words when reading or ability to write words. The SLP is trained to work with all of these communication problems.

With help of the SLP, some patients will regain their communication abilities. Other patients will be trained to use alternative forms of communication to get their message across to listeners. Methods of alternative communication include low tech and high tech options. Advancements in computers have led to the development of devices that give a speaking voice to patients who have the language to communicate but lack the mechanical ability to speak.

A key feature of successful rehabilitation is collaboration amongst team members, for example between a SLP and Respiratory Therapist. Collaborating team members work with patients without voice who have tracheostomy (trach) tubes and/or are on ventilators. Their goal is to safely achieve voice that can be heard by applying a speaking valve.

SWALLOWING

Swallowing problems (dysphagia) occur with some illnesses and injuries. The SLP can perform swallowing tests at the bedside or in the fluoroscopy suite in the Medical Imaging (X-ray) Department. The bedside test may involve the SLP watching you eat and drink a variety of foods and liquids. Some bedside tests may involve looking down in the throat with a fiberoptic scope while you swallow. The swallowing test in the
fluoroscopy suite is a moving X-ray that also allows the SLP to view swallowing inside your body recorded on video tape. These tests provide the SLP and medical team with results that lead to a plan for improving swallowing and maintaining nutrition.

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. It is our goal for you to be able to eat and drink as normally and quickly as possible. The SLP will help you achieve these safe-swallowing goals through exercises, swallow practice and compensations as well as changes in your diet.

**Preventing Pneumonia**

If you have swallowing problems that cause saliva, liquids or food to enter the lungs, you are at risk for getting pneumonia. Good oral hygiene is one of the best ways to prevent pneumonia because bacteria in the mouth that is not cleaned either by you or your caregiver can mix with saliva resulting in an infection causing 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. If a swallowing problem is present, your chances of avoiding pneumonia are also better when you are out of bed and active.

**Staying Hydrated**

Our bodies need eight to ten cups of fluid per day to stay hydrated. There are a variety of medical conditions that place people at risk for dehydration. Dehydration can lead to medical complications including: changes in drug effects, infections, poor wound healing, pressure sores, decreased urine volume, urinary tract infections, confusion, lethargy, constipation, altered cardiac function, acute kidney failure, weakness and declining nutritional intake. The likelihood of dehydration can also increase if you have a tendency to avoid drinking unappealing thickened liquids.

Frazier Rehab Institute pioneered the Frazier Water Protocol that permits people who have difficulty swallowing thin liquids to: (1) have water between meals or (2) have water anytime if receiving nutrition via tube feedings, even though the water might enter the lungs. This is a safe practice because our bodies are composed of more than 65% water and water that enters the lungs is quickly absorbed into the bloodstream without harmful effect. The Frazier Water Protocol has gained wide acceptance internationally but is not practiced in all health care settings.

The SLP watches patients swallow water and progresses therapy based on demonstrated improvements. Patients express great satisfaction with being able to drink water as thirst is quenched and quality of life is enhanced. All rehabilitation team members offer patients water and assist them to drink water when help is needed.
QUALITY OF LIFE

Injury and illness often change yours and your family’s life. Common daily functions such as speaking and swallowing, that are usually taken for granted before hospitalization, might present a great challenge for you and your family now. The goals of the SLP are aimed at improving your quality of life by helping you achieve the greatest outcomes possible.

RESOURCES
Swallowing - http://www.emedicine.com/pmr/topic152.htm

GLOSSARY

DEHYDRATION - Excessive loss of water.
DYSPHAGIA - Difficulty swallowing.
GASTRIC TUBE - Feeding tube surgically implanted through the abdominal wall into the stomach.
NASOGASTRIC TUBE - Feeding tube from nose to the stomach.
PNEUMONIA - Infection in the lungs
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 keeping well nourished are essential to all stages of recovery. There is much truth in the saying “You are what you eat.”

SOON AFTER INJURY

Your nutritional needs may increase at the same time that appetite decreases. 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 deal with stress, fever, infection, and/or surgical or wound healing. At the same time, your appetite and food intake may decrease because of pain, emotional stress, illness, limited mobility, restricted diet, hospital environment or other challenges. Simply stated, if your body burns more calories than it takes in, you will lose weight, often times quite rapidly. Quick weight loss results in muscle loss, additional to fat loss.

Inability to use muscles due to injury also contributes to muscle breakdown. Loss of muscle in the lower limbs can be notable for those with paraplegia and tetraplegia. As a rule, the higher the level of spinal cord impairment, the greater the weakness or paralysis, and therefore more “muscle disuse” results. Consequently, more muscle is lost in the arms and upper trunk in people with tetraplegia than with paraplegia.

To minimize fast weight loss and muscle shrinkage, dietary changes can be made. These include adding snacks and special shakes formulated 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.

Just as the extent of injury varies from person to person, so do nutrient requirements. A registered dietitian can meet with you, establish nutrition goals and help devise ways for you to meet them.

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. As old eating habits return, weight and protein loss usually stop. With limited physical activity and disuse of certain muscles that come with spinal cord impairment, permanent changes in body composition occur. Lost muscle is replaced in part by fat, water and connective tissue, which burn fewer calories than do muscles. Therefore, you will need fewer calories to maintain weight as compared to pre-injury. Because muscle weighs more than non-muscle mass, you may look and feel heavier if you return to your usual weight. Some people struggle to prevent excess weight gain starting a few months after injury. For muscular athletes with spinal cord injury, calorie needs will not need to decrease as much since muscle burns many calories.

IDEAL BODY WEIGHT AFTER INJURY

After spinal cord injury/disability, one’s ideal body weight changes, i.e., ideal body weight is typically lower. This is true as most individuals with injury/disability are not as
physically active as they once were, need less calories daily to be healthy and avoid weight gain, and because the muscle mass in muscles groups that are paralyzed is smaller and weigh less. The ideal body weight is adjusted downward for those with paraplegia by 5-10% and for those with tetraplegia by 10-15%. (See Ideal Body Weight Charts for Men and Women at end of Chapter.)

**HEALTH ISSUES AND NUTRITION - FOOD FOR THOUGHT**

**Skin Health - It’s More Than Just Skin Deep.**

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 fat has poor blood circulation. Blood delivers oxygen and nutrients to the cells to allow healing. Keeping a healthy weight can help prevent skin problems.

Nutrient rich foods should be selected to attain and maintain a healthy weight for managing skin problems. The diet should include foods rich in vitamins, especially vitamins A and C, and minerals, especially zinc and iron, along with ample calories, protein and fluids. For more on skin, see Skin Care Chapter.

**Bowel Function - Roughing It Up With Fiber.**

After injury, bowel function slows down and you may become constipated due to decreased physical activity, reduced trunk-muscle tone, iron pills and/or pain medications. Constipation means fewer bowel movements or small, hard stools. It can be managed by diet that may lessen your need for stool softeners and laxatives.

Dietary fiber is one way to help resolve problems with bowel function. Fiber comes from food in the plant kingdom. It is the part of the plant that remains undigested and unabsorbed as it passes through your intestines. Fiber absorbs water in the intestine. This helps in the formation of soft, easy-to-pass stools. It may be helpful to eat foods with fiber many times during the day to aid your bowel program. Certain types of fiber can also resolve diarrhea, as it helps to form stools. If you have diverticulosis or other intestinal disorders, the high-fiber diet may need to be modified. Your dietitian can direct you in selecting the best high fiber foods to meet your specific needs.

There are two basic categories of fiber. Insoluble fiber, referred to as roughage, includes structural parts of plants such as vegetable skins and the outer covering of grains called bran. This type of fiber causes waste products to pass through the intestine faster. Soluble fibers are substances that dissolve in water to form gels, and help in the formation of soft stools. Included here are oats, barley and citrus fruits. Other good sources of fiber include baked potatoes with the skin, carrots, oranges, greens, berries and bran cereals.
Simply Healthy, High-Fiber Snacks

- Apple wedges with peanut butter
- Whole-grain crackers and roasted pepper hummus
- Low-fat cereal with skim milk, topped with berries
- Carrots dipped in salsa
- Celery sticks dipped in low-fat pimento-cheese
- Air-popped popcorn sprinkled with parmesan cheese

It is best to choose a wide variety of unprocessed plant foods including vegetables, fruits, nuts, legumes and whole-grain products when planning your menu. Prunes have especially good laxative properties.

Fifteen grams of fiber is the average daily intake for most Americans. Your goal, due to spinal cord impairment, may be closer to 35 grams, noting that individual needs may vary. An average serving of fruit or vegetables provides two to three grams of fiber, while legumes, dried beans and whole grains may contain more. Food labels list the grams of dietary fiber per serving. Refer to these labels when planning your meals.

Since fiber must absorb water in order to be effective, and because your fiber intake may increase, fluid intake should also be increased by about two cups per day (total 8-10 cups daily on average) as compared to before injury. Too little fluid along with a high-fiber diet can actually make constipation worse.

Sample Menu.

The following sample menu shows how small changes can make a big difference in increasing the fiber content in a single meal. Compare these two menus.

<table>
<thead>
<tr>
<th></th>
<th>Fiber Content</th>
<th></th>
<th>Fiber Content</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4 oz. chicken breast</td>
<td>0 grams</td>
<td>4 oz. chicken breast</td>
<td>0 grams</td>
<td></td>
</tr>
<tr>
<td>1/2 cup mashed potatoes</td>
<td>1.5 grams</td>
<td>Small baked potato w/ skin</td>
<td>4.0 grams</td>
<td></td>
</tr>
<tr>
<td>1/2 cup mac &amp; cheese</td>
<td>0 grams</td>
<td>1/2 cup broccoli &amp; cheese</td>
<td>4.4 grams</td>
<td></td>
</tr>
<tr>
<td>1 dinner roll</td>
<td>0 grams</td>
<td>1 whole wheat roll</td>
<td>2.0 grams</td>
<td></td>
</tr>
<tr>
<td>1/2 cup applesauce</td>
<td>2.0 grams</td>
<td>1 medium apple with peel</td>
<td>4.5 grams</td>
<td></td>
</tr>
<tr>
<td>1 cup iced tea</td>
<td>0 grams</td>
<td>1 cup iced tea</td>
<td>0 grams</td>
<td></td>
</tr>
<tr>
<td><strong>Total fiber:</strong></td>
<td><strong>3.5 grams</strong></td>
<td><strong>Total fiber:</strong></td>
<td><strong>14.9 grams</strong></td>
<td></td>
</tr>
</tbody>
</table>

If you stand to benefit from adding more fiber to your diet, do so gradually to allow your body to adjust. Otherwise abdominal cramping and excess gas can occur. If this happens and does not subside in a couple of days, lower the fiber in your diet.

Other Digestive Problems – “Chewsing” Foods Wisely.

After spinal cord injury, your stomach may empty more slowly. This can cause acute reflux or heartburn. Limit high fat foods and other irritants such as caffeine-containing beverages, mint, carbonated beverages, and citrus or tomato products. You may need to eat small, frequent meals instead of a few large ones. Sitting upright and avoiding crouching forward during eating is recommended. It is usually better to avoid lying flat.
after meals and you may find elevating the head of the bed while sleeping helpful. Avoid
smoking, steer away from late-night snacks and wear comfortable clothing.

**Dysphagia.**

Difficulty swallowing is called dysphagia. It is treated on an individual basis and
involves changing the texture of foods and beverages to assure a safe swallow. See
Chapter on Cognition, Voice and Swallowing.

**Bladder Function - Going with the Flow**

Adequate water intake is required for a good bowel program and for wellness, such
as in regulating the body’s temperature. With less physical activity, urinary tract
infections and kidney stones can become a problem especially if the urinary tract is not
well flushed and the urine not properly diluted. While fluid needs vary from person to
person, two to three quarts of fluid may be needed daily. Spacing fluids throughout the
day instead of drinking large amounts at one time can help avoid over-distending your
bladder and keep intermittent catheterizations about the same size.

Water is one of the best sources of fluid for your system to work properly. For some
individuals, cranberry juice appears to prevent urinary tract infections due to its unique
composition. Note that juices of any type are high in calories (8 oz. of regular cranberry
juice = 150 calories) and can contribute to obesity. Use no-added-sugar juices and
watch portion sizes. Regular sodas and other sugary drinks are similarly high in calories
and can be substituted with diet sodas, sugar-free iced tea and the like, as part of a
weight management program. Caffeine-containing drinks can have diuretic effects and
may complicate a bladder program. Alcohol does not mix well with many medications, is
high in calories, can increase fat in your bloodstream, and should be avoided, or at least
discussed with your physician. Ice cream, sherbet, gelatin and soups also add to your
daily fluid intake.

**Obesity - Don’t Take It Lightly!**

After spinal cord injury, extra weight can cause problems with your breathing,
overall health, self-help skills, mobility and transfers. Overuse syndromes involving the
musculoskeletal systems, especially of the shoulders, are more likely to develop with
added weight. Additionally, heart disease, arthritis, stroke and diabetes are health risks
linked with obesity. Those who assist you when transferring also must carry the extra
pounds you may carry.

Metabolism (how fast the body burns calories) slows down when your activity and
muscle mass are decreased. Simply stated, fewer calories are needed to maintain your
weight. Your needs may decrease only slightly or may be decreased by nearly half.
Weight gain will result unless dietary intake is well managed.

National guidelines on weight management for people with spinal cord impairment
do not exist. This is due to individual health variances such as activity level, metabolism,
level of spinal cord injury, illness, infection, healing needs, and of course gender, age,
weight and height. Yet a simple method to determine your maintenance daily calorie
needs is to multiply your weight in pounds (adjusted if you are obese) by 10-14 calories.
For weight loss efforts, a restricted daily calorie intake of 1500–1800 calories may be appropriate, noting that individual differences should be considered.

3,500 calories make up one pound of fat. Therefore adding even 100 extra calories beyond maintenance needs each day can result in 36,500 extra calories per year, totaling 10 pounds gained over the year!

Because your calorie needs are less than your pre-injury levels, choosing more vitamin-mineral rich foods that are lower in sugar and fat is essential. A good weight reduction plan allows you to include your favorite foods, dine in various types of restaurants and allows for high-calorie food on occasion. Weight management through exercise programs can also benefit endurance, stress levels, functional status and overall health.

As stated above, the daily caloric requirement for a person with paraplegia should be based on ideal body weight that is 5-10% below standard. The ideal body weight for a person with tetraplegia is between 10-15% less than standard. Diets that don’t take this into account lead to obesity.

**Behavioral Changes to Help a Weight Management Program be Successful**

- Work on changing your eating habits in ways that can last a lifetime.
- Eat a variety of foods each day.
- Do not try crash/fad diets that ultimately can lower your metabolism and make dieting even harder over time.
- Eat foods high in fiber since they add bulk and fill you before overeating higher calorie foods.
- Make plans to eat three meals daily. Skipping meals can reduce your body’s ability to burn calories efficiently and also lead to overeating at the next meal.
- Be aware of portion sizes. You may wish to measure food portions for a few days to get an idea of your actual intake.
- Control snacking and be aware of the calorie content of foods. For example, 10 potato chips yield 108 calories; an 8-ounce shake, 285 calories; a can of beer, 150 calories; and one ounce of cheese, 90 calories.

**Cardiac Disease – Take It to Heart.**

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. Weight control is of utmost importance, as your heart should not be burdened with pumping blood the extra distance that comes with extra pounds. An exercise program can improve heart health. Medications may also be beneficial.

**Guidelines for Heart Healthy Eating**

- Limit total fat intake.
- Lower saturated fat (usually from animals) and trans-fats (some processed foods).
- Choose unsaturated fats such as olive oil or canola oil.
• Limit cholesterol-containing foods.
• Increase intake of whole-grain products, fruits and vegetables.
• Limit simple sugars and alcohol intake.
• Curb your intake of excess salt and salty foods if your blood pressure is high.
• Maintain a healthy body weight.

**A Heart Healthy “Sample Supper”**
- Lemon-baked fish
- Baked potato spears
- French-style green beans
- Tomato slices
- Graham crackers
- Skim Milk

**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.
- Avoid frying and use nonstick pans or vegetable sprays in place of fat.
- Remove fat from soups and gravies using a skimmer, or refrigerate the food in advance to permit 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.
- Read package labels to check for unhealthy ingredients such as trans-fats.

**Osteoporosis – Boning Up On Calcium.**

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. This mineral also helps with muscle flexion and nerve reaction, influences heart function and blood clotting. Calcium supplementation with added vitamin D, which helps calcium to be absorbed, is often recommended to treat bone loss, but this should only be done with your doctor’s approval. 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.

If you are directed to bolster your calcium intake, food sources of choice include milk and other dairy products such as cheese and yogurt. Other foods rich in calcium are broccoli, kale, spinach and collard greens, dried figs, blackstrap molasses, legumes, dried beans and peas, tofu (if calcium is added in processing), salmon and sardines with soft bones included, and calcium-fortified juices and cereals. Adding calcium and
vitamin D in pill form to your diet should be done only with the approval of your doctor who will monitor your bone mineral status.

**Healthful Meal Planning – So Many Pastabilities**

A variety of whole grains such as whole wheat, brown rice, assorted fruits and vegetables, will provide essential fiber, vitamins, minerals and other nutrients to help you to function at your best.

Lean meat, seafood, poultry, eggs and low-fat milk products, or suitable vegetarian-style replacements for these will provide needed protein. Ample water intake rounds out your meal plan. Balance is the key.

**A Quick 'N Easy Rule to Help in Planning Your High-Nutrient, Low-Calorie Meal**

- Choose more veggies than fruit
- Choose more fruits than starch
- Choose more starch than meat and dairy products
- Choose more meat and dairy than fat and sugar

**A PRIMER ON NUTRIENTS**

Nutrients are essential for your body to function well. Protein, carbohydrate and fat contribute calories to the diet and therefore must be thoughtfully integrated into a weight-management program. Vitamins, minerals and phytochemicals are substances found within food that permit what we eat to be digested well and help the body run smoothly. Water is essential, as it is needed for complex chemical processes to take place, affecting overall body stability and health.

**Protein.**

Protein affects stamina and vitality, is essential for healthy muscles and skin, and helps the body fight infection and repair tissue. Requirements associated with spinal-cord impairment do not differ from those who are able-bodied. As a rule, the American diet provides ample protein, making deficiency unlikely. Normally, about 20 percent of the total calories in the diet should come from protein; roughly 50-90 grams daily. While it is important to eat enough protein, excess amounts can be harmful to the kidneys and can add to problems associated with osteoporosis, obesity and heart disease, noting that protein rich foods are often high in fat. Chief sources of protein include: egg whites; red meat, seafood and poultry; milk and dairy products such as yogurt, and nuts or legumes such as peanut butter, soybeans and other dried beans.

**Carbohydrate.**

Carbohydrates are the body’s chief source of fuel. It is advised to get at least half of your calories each day from carbohydrates, chiefly from complex carbohydrate rather than simple carbohydrates.

**Simple Carbohydrates.**

Simple carbohydrates such as white flour, table sugar, honey, corn syrup, dextrose, as well as other refined forms, are found in cakes, cookies, candy, and desserts and
snack foods. These foods are referred to as empty calories, or calories without healthful benefit, since most of the vitamins, minerals and fiber content have been stripped away during food processing.

An average American consumes over 10 tablespoons of sugar daily!

- Some sources and their sugar content:
  - One glazed donut – 2 Tbsp.
  - One can of soda – almost 3 Tbsp.
  - Single scoop of ice cream – over 1 Tbsp.
  - One Tbsp Jelly – 1 Tbsp

**Carbohydrates.**

Complex carbohydrates include unprocessed fruits, vegetables, dried beans and peas, and whole-grain breads and cereals. These foods are packed with vitamins, minerals and other chemicals that serve the body in a number of ways. Fiber, or roughage, is a form of complex carbohydrate that aids digestion, specifically the bowel program. The value of fiber is further discussed under Bowel Function in this chapter and in the chapter on Bowel Care.

Milk, while known for its protein content, actually contains more naturally occurring sugar (lactose) than protein! It is neither a simple nor a complex carbohydrate, falling somewhere in between. Watch your milk intake if sugar intake concerns you!

**Fat.**

Fat should make up less than 30% of total calories; under 45 grams for women and under 60 grams for men. Because fat is very dense in calories, no matter the source, only small amounts should be eaten in any one meal especially if you are concerned about your weight. Butter, salad dressing, cream cheese, and cooking oil are examples of foods that add up quickly in terms of fat grams, and therefore, calories. Whole milk, sausage, nuts, pizza, hot dogs, biscuits and cheese are examples of foods with hidden fats. The type of fat should be chosen with care, since saturated fats, can be unhealthy for your heart.

Good oil / fat flows in the bloodstream. This is defined as unsaturated fat that comes mostly from plant sources and is liquid at room temperature. Examples are safflower, canola, olive, corn, peanut, soybean and sesame oils (unless hardened / hydrogenated as found in some processed foods.)

So-called bad fat (saturated fat, hydrogenated fat and trans-fats) can raise blood cholesterol and contribute to hardening of the arteries. They are found mainly in foods of animal origin such as lard, meat, cheese, milk and egg yolk, and are usually solid at room temperature. Dietary cholesterol should also be limited as it can contribute to heart disease. Cholesterol is found in some foods of animal origin; not from plants.

“All fats are created equal.” Whether the source is a “good fat” or a “bad fat,”
the amount of calories is the same
Vitamins, Minerals and Phytochemicals.

There are virtually dozens of required vitamins such as vitamins A, B-complex, C, D, E and K, and minerals including calcium, iron, magnesium, zinc, copper and many others that serve your body. Phytochemicals, a vast group of chemicals found in plants such as lutein, lycopene, isoflavones, and ellagic acid, are now being studied for their roles in preventing and treating diseases. Food sources should be wholesome and not overly processed in order to retain their natural goodness.

- Whole foods are the best sources of vitamins and minerals since other chemicals that help with their absorption are naturally found within the food. A bottled supplement cannot contain all of these healthful substances.
- A one-a-day-type supplement may be of value if your diet doesn't meet daily requirements of
- the basic food groups. Avoid taking high-potency supplements, unless a physician has prescribed them, as these nutrients must be balanced to work properly. A hit-and-miss method may be unhealthy.
- Inform your physician of vitamins, minerals, herbs or any other supplements taken, as they may interfere with your medications.

Water.

Water is vital in that all of the chemical processes that take place in the body do so in a water bath. Adequate fluid intake helps to assure good kidney function, skin integrity and overall health.

Tips For Dining Out

Dining out in a variety of restaurants should be easy to do and be enjoyable. However, foods are often served in abundance and contain high-calorie ingredients. The following are tips to keep in mind to avoid overindulgence.

- Make good substitutions if you are in need of cutting fat and calories. For example, you might trade greasy fries for a baked potato, rich desserts for fresh fruit, regular soft drinks
- for diet drinks and so forth. Sometimes, healthy, smart items are designated on the menu to help you make wise decisions.
- Avoid all-you-can-eat buffets, as there is a tendency to overeat.
- Select grilled, baked or broiled over fried foods. Ask that salad dressing, sour cream or butter be held or served on the side to allow you to control amounts.
- When in doubt about a menu item, ask your server about the ingredients.
- Avoid “mega-sized” meals from fast-food restaurants. A single large sized meal may provide an entire day's worth of calories or fat.
- Some restaurants honor requests for half-portions at reduced prices. If only large portions are served, consider eating only half and taking the rest home.
- Many fast-food restaurants offer nutrition guides, which list food items and their nutrient content, allowing you to make wise choices.
- Strike compromises with regard to food preparation and food portions. For example, if you order regular versus low-fat salad dressing, watch your portion.
you order pizza, choose a vegetable topping over pepperoni or sausage, or fresh fruits as a side with a sandwich instead of potato chips. Select sandwich toppings of lettuce, tomato, pickles and fresh onions for flavor in place of fatty sauces, fried onions and cheese.

Reading the Food Label
Finding healthy foods at the grocery store is easier than ever, due to label regulations by the USDA and FDA. Package labels can be easily read and provide valuable information at a glance. There are two places on the label on which to focus.

- The “Nutrition Facts” panel shows serving sizes and nutrient amounts. It can help you to make wise decisions if you want to increase fiber, cut back on the amount of fat in your diet and lessen the amount of sugar or cholesterol in your diet. Because the amount of each nutrient on the label is based on the serving size listed, be sure to double the nutrient and caloric value if you double your serving size, or adjust downward if you eat only one-half the serving size.
- The “Ingredient List” is a summary of the contents of the product, listed in order from greatest to smallest by weight. For example, if a cereal list ingredients as rice, sugar, nuts, and salt, this means that there is mostly rice in the cereal followed by sugar, and then other ingredients in diminishing amounts. You may find many surprises as you read labels. For example, corn syrup is added to some brands of peanut butter. It can also be surprising to discover what is not contained in the product, such as the lack of a sufficient amount of chicken contained in many canned chicken soups.

Recapping the Role of Nutrition – In A Nutshell
Food is more than just something to eat. It comprises what we are made of and profoundly affects our well-being. By making wise choices when selecting foods, you can optimize your health and at the same time, savor every bite. Enjoy your diet changes and remind yourself of your investment in continued good health. Bon appétit!

REFERENCES AND RESOURCES

GLOSSARY
CALORIE - A measure of the energy value of food; also refers to the heat output of the body. If too few calories are consumed from food as compared to the amount of calories “burned” by the body, weight loss will occur. Conversely, when more calories are consumed than expended, the body stores them and weight increases.

CARBOHYDRATE - One of the six classes of nutrients needed by the body. It serves as the body’s main fuel source and is subdivided into simple and complex carbohydrate groups.

COMPLEX CARBOHYDRATES - Chemically complex foods that take longer to break down and yield more energy for the body as compared to simple carbohydrates. Examples are whole grain cereals, carrots and dried beans. Many of these foods are...
high in fiber, an indigestible form of carbohydrate, and consequently, can help a bowel program.

**CONSTIPATION** - Difficulty having a bowel movement, typically related to inactivity, dehydration and/or narcotic medications. It is important to maintain regular bowel movements to prevent constipation. Routine use of stool softeners and/or suppositories can also help prevent constipation. However, the proper diet can also help to manage/prevent constipation

**DIARRHEA** - A disorder of the intestine marked by abnormal fluid or loose, and/or frequent bowel movements. Sometimes this condition is affected by an infection, medication side effects and/or by diet.

**DIURETIC EFFECTS** - An increase in the secretion of urine. Some ingredients in foods such as caffeine and some medications can cause frequent urination

**DIVERTICULOSIS** - Condition where diverticula, small pouches, push out from the wall of the large intestine. If a pouch becomes blocked or infected, an inflamed state of diverticulitis can occur and become problematic.

**DYSPHAGIA** - An inability to swallow or difficulty in swallowing. Sometimes foods and beverages are modified in texture to help compensate for this condition so foods can be safely swallowed

**FAT** - One of the six nutrients needed by the body. While some fat is important to good health, excess fat can contribute to obesity and other health issues. Fatty foods include butter, margarine, oils and fats hidden in poultry skin, cheese, sausage, olives and nuts among many other sources.

**FIBER** - Portion of a food which is not digestible, remains in the intestine and becomes a component in stool. High fiber foods promote regular bowel movements that are very important to patients with spinal cord injury. Low fiber and/or high sugar diets encourage constipation.

**METABOLISM** - Metabolism refers to how quickly your body uses energy. It is affected by chemical changes that take place with physical growth, body temperature maintenance, energy required for your heart to beat, for breathing to take place, food to digest and many other physiological processes. With less physical activity, metabolism is likely to decrease and the body will need less energy (food) to maintain its self.

**OBESITY** - Obesity or overweight is caused when more calories are taken in than calories burned. Obesity increases risk for developing chronic disease. Nearly half of all people in the US are overweight.

**OSTEOPOROSIS** - Loss of bone density and mineral content occurs when new bone is not created as quickly as old bone is broken down. It can lead to bone brittleness and the risk of increased fractures.

**PROTEIN** - One of the six nutrients needed for the growth and repair of tissue. Some high protein foods are egg whites, milk products, meat, nuts and dried beans/legumes.
SIMPLE CARBOHYDRATE - One of the two subgroups of carbohydrate, which, due to their simple chemical structure, are quick to be absorbed/used by the body. Examples include table sugar, corn syrup, honey and fruit sugar. “Simple carhs” typically offer empty calories or low vitamin/mineral value and should be minimized in a diet plan.

**Ideal Body Weight for Men Following Injury/Disability**

<table>
<thead>
<tr>
<th>Height &amp; Weight</th>
<th>Pre Injury</th>
<th>Paraplegic</th>
<th>Tetraplegic</th>
</tr>
</thead>
<tbody>
<tr>
<td>5'5&quot;</td>
<td>136 lbs.</td>
<td>122-129 lbs.</td>
<td>116-122 lbs.</td>
</tr>
<tr>
<td>5'6&quot;</td>
<td>142 lbs.</td>
<td>128-135 lbs.</td>
<td>121-128 lbs.</td>
</tr>
<tr>
<td>5'7&quot;</td>
<td>148 lbs.</td>
<td>133-141 lbs</td>
<td>126-133 lbs.</td>
</tr>
<tr>
<td>5'8&quot;</td>
<td>154 lbs.</td>
<td>139-146 lbs.</td>
<td>131-139 lbs.</td>
</tr>
<tr>
<td>5'9&quot;</td>
<td>160 lbs.</td>
<td>144-152 lbs.</td>
<td>136-144 lbs</td>
</tr>
<tr>
<td>5'10&quot;</td>
<td>166 lbs.</td>
<td>149-158 lbs</td>
<td>141-149 lbs</td>
</tr>
<tr>
<td>5'11&quot;</td>
<td>172 lbs.</td>
<td>155-163 lbs.</td>
<td>146-155 lbs</td>
</tr>
<tr>
<td>6'0&quot;</td>
<td>178 lbs.</td>
<td>160-169 lbs</td>
<td>151-160 lbs</td>
</tr>
<tr>
<td>6'1&quot;</td>
<td>184 lbs.</td>
<td>166-175 lbs</td>
<td>156-166 lbs.</td>
</tr>
<tr>
<td>6'2&quot;</td>
<td>190 lbs.</td>
<td>171-181 lbs</td>
<td>162-171 lbs.</td>
</tr>
</tbody>
</table>

Further adjustments for frame size, musculature, and degree of impairment may be needed to arrive at the Adjusted Body Weight for the individual.

**Ideal Body Weight for Women Following Injury/Disability**

<table>
<thead>
<tr>
<th>Height Weight</th>
<th>Pre Injury</th>
<th>Paraplegic</th>
<th>Tetraplegic</th>
</tr>
</thead>
<tbody>
<tr>
<td>5'0&quot;</td>
<td>100 lbs.</td>
<td>90-95 lbs.</td>
<td>85-90 lbs.</td>
</tr>
<tr>
<td>5'1&quot;</td>
<td>105 lbs.</td>
<td>95-100 lbs.</td>
<td>89-95 lbs.</td>
</tr>
<tr>
<td>5'2&quot;</td>
<td>110 lbs.</td>
<td>99-106 lbs.</td>
<td>94-99 lbs.</td>
</tr>
<tr>
<td>5'3&quot;</td>
<td>115 lbs.</td>
<td>104-109 lbs</td>
<td>98-104 lbs.</td>
</tr>
<tr>
<td>5'4&quot;</td>
<td>120 lbs.</td>
<td>108-114 lbs</td>
<td>102-108 lbs</td>
</tr>
<tr>
<td>5'5&quot;</td>
<td>125 lbs.</td>
<td>113-119 lbs</td>
<td>106-113 lbs</td>
</tr>
<tr>
<td>5'6&quot;</td>
<td>130 lbs.</td>
<td>117-124 lbs</td>
<td>111-117 lbs</td>
</tr>
<tr>
<td>5'7&quot;</td>
<td>135 lbs.</td>
<td>122-128 lbs</td>
<td>115-122 lbs</td>
</tr>
<tr>
<td>5'8&quot;</td>
<td>140 lbs.</td>
<td>126-133 lbs</td>
<td>119-126 lbs.</td>
</tr>
<tr>
<td>5'9&quot;</td>
<td>145 lbs.</td>
<td>131-138 lbs</td>
<td>123-131 lbs</td>
</tr>
<tr>
<td>5'10&quot;</td>
<td>150 lbs.</td>
<td>135-143 lbs</td>
<td>127-135 lbs</td>
</tr>
</tbody>
</table>

Further adjustments for frame size, musculature, and degree of impairment, may be needed to arrive at the Adjusted Body Weight for the individual.
Chapter 10: SELF CARE & 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 ADL’s are:

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

Your occupational therapist will help you develop skills needed to complete your ADLs as independently as possible. It may be necessary to use adaptive equipment to perform your ADLs. These are devices used to assist with completing activities that you cannot perform as you did prior to the spinal cord injury. The amount of assistance needed to perform ADLs varies from person to person depending on your level of injury, current strength and range of motion, functional abilities, prior health status and any medical complications.

**DRESSING**

**Upper Body Dressing**

Upper body dressing (UBD) includes putting on and taking off any clothing items from the waist up. For the individual with paraplegia, the upper extremities (arms) are usually functioning properly, and UBD is usually completed without difficulty. However, sitting balance and safety precautions should be addressed before attempting UBD from the edge of the bed or while sitting without support on any surface. If balance is impaired, it may be easier to sit in a wheelchair or standard chair for additional back support. If a brace is worn around the torso, loose garments with front closures are suggested. Additionally, comfortable, wrinkle-resistant clothes allow for easier application and a neat appearance.

Upper body dressing techniques for persons with tetraplegic level of injury depend on several factors including:

- Amount of movement in the arms
- Strength of active arm muscles
- Sitting balance and endurance
- Fine motor coordination/hand strength

A person with a tetraplegic level injury may be able to use adapted techniques/adapted clothing, adaptive equipment and/or splints to increase independence when doing UBD. The occupational therapist on your treatment team will instruct you on the most appropriate techniques to use.

**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, persons with a paraplegic level of injury...
might find it helpful to use a combination of alternative techniques and adaptive
equipment. The most common position for performing LBD is circle sitting or long sitting
in bed. This allows the person with SCI to reach his/her feet from a large base of
support, which increases balance. Some of the most commonly used pieces of adaptive
equipment used during dressing include:

- Dressing sticks
- Reachers
- Long-handled shoe horns
- Button hooks
- Velcro®
- Elastic shoe laces
- Sock aids
- Legs straps

LBD is often more difficult for persons with a tetraplegic level of injury and may
require the assistance of others. Several factors influence the level of independence a
person with tetraplegia that may be achieved with LBD. Those factors include:

- Muscle strength in chest and back
- ROM in knees and hips
- Transfer status
- Bed mobility
- Vital capacity or Lung capacity

**BATHING**

In the first few days or weeks following injury, you will most likely sponge bathe from
bed. This process may seem complicated if a brace must be worn or if other medical
complications are present. Once you are medically stable and cleared for showering by
the doctor, your occupational therapist will help you learn to shower safely. If you are a
person with a paraplegic level of injury, you may use some of the following to assist with
safety and completion of your bath:

- Tub chair/tub bench with a back
- Transfer board
- Hand held shower
- Long handled sponge
- Grab bars
- Thermometer

If you have a tetraplegic level injury, you may use some of the following to assist
with safety and completion of your bath:

- Shower chair (with tilt/recline feature)
- Transfer board or mechanical lift
- Hand held shower
- Universal-cuffs or other splints to assist with holding items
TOILETING

Toileting includes the ability to pull down clothing in preparation for elimination, cleaning of the perineal area and pulling clothing up after completion. A person with a paraplegic level of injury is often 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
- Leg straps to assist lifting legs

Toileting for an individual with a tetraplegic level of injury is usually difficult and unique for each person. Your occupational therapist will develop a specialized toileting program for patients/caregivers for the discharge environment.

GROOMING AND HYGIENE

Grooming tasks include brushing teeth, washing face, combing hair, shaving and applying make-up. As with UBD, a person with a paraplegic level of injury usually has full use of their arms and grooming is completed without difficulty from a wheelchair as long as items are in reach. For a person with a tetraplegic level of injury, grooming becomes more difficult and is usually completed in a supported seated position in bed or in a wheelchair. Necessary adaptive equipment and orthotics may include:

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

Once you can tolerate a sitting position, your occupational therapist will help you practice techniques to complete these activities as independently as possible.

FEEDING

Feeding, like upper body dressing and grooming, is usually not difficult for a person with a paraplegic level of injury. This activity, however, can be difficult for a person with a tetraplegic level of injury. Feeding is usually done in a supported seated position in bed with a bedside table or from wheelchair level with a lap tray. There are several splints and pieces of adaptive equipment available to assist with this process. These items include:

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

As soon as you are medically stable and 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 occupational therapist will work with you to discover what works best to be successful.

**REFERENCES AND RESOURCES**

- Activities of Daily Living - [http://www.hmc.psu.edu/rehab/services/spinalcord/therapy/ot.pdf](http://www.hmc.psu.edu/rehab/services/spinalcord/therapy/ot.pdf)
- Adaptive Equipment - [http://www.sammonspreston.com](http://www.sammonspreston.com)
- Adaptive Equipment - [http://www.ncmedical.com](http://www.ncmedical.com)
- Adaptive Equipment - [http://www.gouldsdiscountmedical.com](http://www.gouldsdiscountmedical.com)

**GLOSSARY**

ACTIVITIES OF DAILY LIVING - Basic self-care skills including dressing, bathing, toileting, grooming & hygiene, feeding.

ADAPTED UTENSILS - Forks, spoons, and knives that are modified to assist with feeding.

ADL SPLINT - Allows user to hold utensils without grasp or wrist control.

BED LADDER - Series of connected loops attached to end of bed to assist with bed mobility.

BED MOBILITY - Movement of the body in the bed. Includes rolling and transitioning from sitting edge of bed to lying down.

BEDSIDE COMMODE (BSC): Portable commode with armrests that can be used beside the bed or over the toilet.

BUILT-UP HANDLES - Larger handles used to assist user with weak grasp to perform ADL’s.
BUTTON HOOKS - Assist user who has poor hand control to fasten buttons.

CIRCLE SITTING - Sitting position in which legs are supported on bed, mat, or floor with knees bent and out to the side with bottom of feet touching each other.

DRESSING STICKS - Assist user to reach legs without bending for putting on pants.

DROP-ARM BEDSIDE COMMODE – A portable commode with removable armrests that can be used beside the bed or over the toilet.

ELASTIC SHOE LACES - Shoe laces made out of elastic material, which are laced into shoes and permanently tied to allow shoes to slip on/off.

ENVIRONMENTAL CONTROL UNITS (ECU): Electronic system that allows user to control aspects of his/her environment.

FINE MOTOR COORDINATION - Ability to utilize individual finger movements to complete activities.

GRAB BARS - Mounted onto wall to assist with balance and transfers.

HAND HELD SHOWER (HHS): Showerhead with a hose that allows user to hold shower in his/her hand to direct the spray. A HHS with the controls on the handle is recommended.

LAP TRAY - Wooded or plastic tray attached to wheelchair to provide support for arms.

LEG STRAPS - Attach to users legs at thigh, knee, and ankle to assist with moving legs during activity.

LONG-HANDED BRUSH – Hairbrush placed at the end of flexible, extended handle to allow user to reach hair.

LONG-HANDED SHOE HORNS (LHSH) - Extra-long shoehorn to allow user to keep heel of shoe up without bending over while putting on shoes.

LONG-HANDED SPONGE (LHS): Bath sponge placed at the end of extended handle to allow user to reach legs and feet without bending.

LONG SITTING- Sitting position in which legs are supported on bed, mat, or floor with knees straight.

LONG STRAW - Extended, reusable straw to allow user independently drink from a cup.

MOBILE ARM SUPPORTS (MAS) - Mounted arm supports that assist user with feeding and other ADL’s.

MOUTHSTICK - Allows person with limited arm function to use mouth to access switches.

NON-SKID BOWL - Dish with non-skid material on bottom to provide stability during feeding.
PLATE GUARD - Attaches to rim of plate to allow user to scoop items onto fork/spoon.

RAISED TOILET SEAT (RTS): Attaches to existing toilet to increase the height for easier transfers.

RANGE OF MOTION – The amount of movement possible at a joint when limb is moved.

REACHERS - Allows user to retrieve items out of reach.

SCOOP DISH - Dish with one side sloped upward to allow user to scoop items onto fork/spoon.

SHOWER CHAIR (WITH TILT/RECLINE FEATURE) - Rolling chair with tall back that will recline to assist with balance/safety in a roll-in shower.

SKIN INSPECTION MIRROR - Dual sided mirror attached to extended, flexible handle to assist with inspecting skin for pressure sores.

SOCK AIDS - Allows user to put sock on without bending.

SWIVEL UTENSILS - Utensils attached to moving handle to assist user with getting food into mouth.

TOILET AID - Toilet tissue aid designed to assist user in cleaning perineal area when reaching is difficult.

TRANSFER BOARD (Also known as a sliding board) – Plastic or wooden board used to bridge the gap between two surfaces to make a transfer safer and easier.

TUB CHAIR/TUB BENCH WITH A BACK - Placed into tub or shower to provide a seated surface while bathing.

TUB/SHOWER CHAIR: fits into tub or shower to provide surface for bathing. A shower chair with a back and seatbelt is recommended for increased stability and balance.

TUB TRANSFER BENCH - Base of bench extends outside tub to make transfers easier. A tub transfer bench with back and seatbelt is recommended for increased balance and stability.

UNIVERSAL-CUFF (U-cuff) – Splint that allows user to hold ADL items without grasp.

VITAL CAPACITY - Maximum amount of air a person can breathe in and breathe out.

WASH MITT - Large mitt that can be used by a person with limited hand function to bathe.
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 (ROM) exercises are movements of a joint through the available amount of movement. These exercises are important to do each day to prevent contractures. Contractures occur when muscles become stuck in one position and/or does not allow the joint to move through the full movement that it should normally be able to do. Because you are unable to move like you used to, your joints can become stiff and not bend or straighten as they did before. If this occurs, it can make activities of daily living very difficult to do such as dressing, grooming and eating.

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 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. Your therapist will instruct you in the most appropriate exercises and will teach your family how to help as needed.

Here are some key things to remember when doing range of motion exercises:

- You should be relaxed and comfortable before starting your exercises.
- The room should be quiet, with as few distractions as possible.
- Perform each movement slowly to prevent spasticity (involuntary tightening or twitching of the muscles).
- Avoid jerky or bouncing movements.
- Do not hold your breath during exercises. Holding your breath can cause muscles to tense up.
- Do not go beyond the point of pain or resistance.
- If spasms (involuntary tightening or twitching of the muscles) interfere with the movement, do not fight them. Allow the limb to relax and begin the motion again slowly.

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.
Watch for changes in range of motion of a joint. If it decreases, you may need to spend more time exercising that joint. If it continues to decrease or if you notice more motion than usual, call your physician.

Watch for any area of redness, hardness or hotness over a joint. If this occurs, it could indicate the beginning of a medical condition called heterotopic ossification (HO). You should report these symptoms to your physician immediately. See Chapter on Medical Concerns for more on HO.

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 body to sit up, dress or transferring. Your therapist will teach you which parts of your body need added flexibility. You will also learn which parts of your body not to overstretch.

**Neck and Trunk**

When doing range of motion exercises, it is important to avoid over-stretching the muscles and ligaments on the back of your neck and trunk. Over-stretching can lead to a bent over posture that can make you unbalanced and decrease your ability to breathe. By keeping the muscles of your neck and trunk somewhat shortened, your transfers, bed mobility, and positioning will likely be accomplished more easily. One key thing you can do to prevent over-stretching is to avoid sleeping with multiple pillows under your head. Instead, use one thin pillow or a towel rolled under your head to keep your neck in a neutral position.

**Upper Extremity (Arm)**

Special attention should be given to the shoulder, arm, and hand to maintain a full range of motion for participation in a wide variety of activities. Proper technique should be followed during all exercises to avoid painful movements and to prevent injury. Individuals with tetraplegia will be instructed on specific stretches and exercises to promote optimal hand function. Splints and positioning devices may be issued to assist with stretching. The occupational therapist will give specific instructions regarding upper extremity exercise programs.

**Lower Extremity (Leg)**

More than normal movement is necessary in your hamstring muscles following a spinal cord injury. The hamstring muscles are located on the back of your thigh and are attached to the pelvis and just below the knee. Their purpose is to straighten the hip and to bend the knee. Having at least 110 degrees of hamstring flexibility when doing the straight leg raise stretch will allow you to sit with your legs straight out in front of you (long sit) when dressing, to move in bed without over-stretching your lower back muscles and to
complete transfers from the floor.

Your therapists at Frazier will develop a personalized program of range of motion exercises designed for you to use at home. It is very important to take responsibility to perform self ROM exercises or direct someone else to perform ROM exercises for you in order to maximize your independence. ROM exercises need to be done daily.

**PRESSURE RELIEF**

- Pressure relief is taking weight off a part of your body that has had a pressure on it for a long period of time
- It should be done every 20-30 minutes while seated and every two hours while you are lying down
- It is necessary to prevent pressure ulcers, especially over bony areas
  You may want to get a watch with a timer that will beep every 30 minutes to remind you to perform pressure relief

After experiencing a spinal cord injury, it is very important for you to take good care of your skin. Because you are unable to move like you used to, you may spend more time lying or sitting which puts a lot of pressure on your skin. Pressure pushes blood out of the tiny blood vessels that nourish the skin and underlying tissue. If this pressure is not released, your skin will not get adequate nourishment, and the skin cells may die. This can cause deep tissue injury which can become decubitus ulcers, also known as pressure sores or bed sores.

Any area of skin that you cannot feel normally is at a higher risk for developing decubitus ulcers especially those that are over bony areas such as the shoulder blades, elbows, hips, knees, ankles, heels and buttocks. If you cannot feel a certain part of your body, you will not feel warning signs to help you prevent burns, bruises and skin damage that could lead to skin breakdown. To prevent skin damage and pressure ulcers, it is important to perform pressure relief regularly. Pressure relief should be performed every 20-30 minutes while you are sitting and every two hours while you are lying down. At first, you may not be able to do pressure relief on your own. In this case, you need to learn to instruct a therapist, nurse, or caregiver to help you to relieve pressure.

Below are descriptions of different types of pressure relief. Remember that not everyone will be able to do each type. Your therapists will teach you the most appropriate technique for pressure relief.

**Reclining Pressure Relief.**

This is usually the first method of pressure relief introduced to you when you are able to sit up in a wheelchair. Another person will be needed to help you perform this type of pressure relief.

- Lock the brakes on the wheelchair.
- Recline the wheelchair back as far as it can go or as far back as you can tolerate.
- Lift the right leg so that weight is taken completely off the buttock and hold for 30 seconds. Repeat on the left leg.
• Return the chair to the upright position.
• If you have slipped forward in the chair, ask someone to assist with repositioning.

**Lateral Lean Pressure Relief.**

This is usually done when you have fair to good trunk balance. A person with paraplegia and some with tetraplegia can perform this type of pressure relief independently.

• Lock the brakes on the wheelchair.
• If someone is helping you, he or she should stand in front of you and help you to lean over onto a sturdy table or locked bed surface.
• If you are doing it on your own, lean over the side of the chair and hold either the wheel or lock one arm around the push handle of the chair.
• Make sure weight is completely off one side of your buttock. Crossing your leg will relieve even more pressure from your buttock.
• Hold this position for 30 seconds, then repeat on the other side.

**Wheelchair Push Up Pressure Relief.**

This type is done if you are able to push up with your arms and hold your weight up off the chair surface for at least 30 seconds. Someone with strong triceps can usually do this pressure relief.

• Lock the brakes on the wheelchair.
• Place your hands on either the armrests or wheels of the chair.
• Push down and straighten your arms until your buttock is completely off the seat surface.
• Hold this position at least 30 seconds while maintaining clearance beneath your buttock.
• Return slowly to a seated position.
Forward Lean Pressure Relief.

This technique sometimes requires that loops are added to the push handles on the back of the wheelchair. An individual with either tetraplegia or paraplegia can perform this technique if he or she has adequate balance and arm strength.

- Lock the brakes on the wheelchair.
- Place your hands on your knees and slowly move them down your leg toward your feet.
- Check to make sure weight is off your tailbone. If it is not, you may need to lean further forward.
- Hold this position at least 30 seconds.
- Return to a seated position by either pushing up on your legs or hooking your arms into the loops added to the push handles and pulling yourself up.

Pressure Relief in Bed.

This type of pressure relief will be necessary any time you are lying down. You may have a mattress that provides pressure relief but it is NOT a substitution for changing positions.

- Every two hours you need to change positions in bed and maintain the new position for two hours.
- If you are unable to roll on your own, you will need a therapist, nurse, or caregiver to assist you with the position changes.
- You will need to move from right side lying for two hours, to lying on your back for two hours, to left side lying for two hours and repeat the process for the entire time you spend lying down.

- Once you are medically stable and your skin is strong and healthy, your doctor may instruct you to go longer than two hours before turning in bed. Talk to your doctor before doing so.
When you are lying on your side

Place a pillow between your knees and ankles to reduce the risk of skin breakdown from the pressure of one leg lying on top of the other. You may need to place a pillow behind your back as well to prevent you from rolling onto your back before it is time to change positions. If you are unable to place the pillows yourself, have your caregiver or nurse assist you.

When you are lying on your back,

Place one pillow under your knees and one under your heels to reduce the risk of skin breakdown. You should have only one thin pillow under your head to prevent over stretching of your neck muscles.

If you can lie on your stomach, you do not have to do pressure relief. You need approval from your physician before getting into this position.

The cushion you sit on in the wheelchair is also an important part of pressure relief. Cushions are made to distribute the weight of your body so there is less pressure on bony areas and more pressure on padded areas. Even if you have a great wheelchair cushion, you can still get skin breakdown if you don’t do pressure relief every 20-30 minutes. See Chapter on Skin Care for more information.

**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.

Transfers are how you move from one surface to another. They allow you to get in and out of bed and/or wheelchair, as well as any other surface on which you want to sit or lie. There are a number of different types of transfers. Your therapist will teach you the most appropriate and safest transfers for you to perform.

**Guidelines for Performing Safe Transfers**

- You want the least amount of distance or space as possible between the two surfaces you are moving to/from.
- The height of the two surfaces should be as even or level as possible.
- Lock brakes and stabilize all surfaces including a bed prior to transferring.
- If the wheelchair is on a tile surface, you may want to put a non-skid pad or heavy object under the wheels to prevent sliding.
- Remove arm rests, leg rests, seat belt, chest straps, lateral supports and brake extensions prior to transferring to reduce the risk of injury to your skin. These items also may interfere with the transfer.
- Wear non-slip footwear.
- Make sure catheter lines or any other external lines will not get caught on anything during the transfer.
- To reduce the risk of skin breakdown, try not to scrape your skin or shear your bottom over the wheel, brakes, leg rests or any other surface during the transfer.
- Before doing a car transfer, position the car seat back as far as it will go and slightly recline the seat. Take off all interfering parts of the wheelchair prior to positioning next to the car. During the transfer, try not to hit your head on the door or pull on the door. You may be instructed to sit on your wheelchair cushion when you are sitting in a car seat. Regardless, when you sit in a car, you still need to do pressure relief every 20-30 minutes to prevent skin breakdown. Once you are in the car remember to put on your seatbelt.
- 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. Sliding across the board can cause shearing and skin breakdown. Instead, make sure your buttock is not touching the board when 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 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 transfer but to also have your feet on the floor.
- Before transferring into a tub chair adjust the height to provide a level surface transfer but to also have your feet on the floor.
- Make sure you maintain your balance before, during and after the transfer.
- When possible, transfer to your stronger side.

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.

- Explain to the helper how you want to transfer, giving detailed instructions as to how to assist you.
- Instruct the helper to bend his/her knees and keep his/her back straight throughout the transfer.
- Instruct the helper to lift with his/her legs throughout the transfer.
- If you have a halo, or any other bracing, make sure the caregiver does not pull, tug or hold onto the bracing or halo at any time during the transfer.
- It is recommended that a therapist train you and your caregiver prior to attempting any transfers.
- There are also mechanical lift devices that may be used to assist with transfers. There are portable lifts that involve using slings to support the hips and trunk in...
order to allow a caregiver or therapist to move you from one surface to another. There are also lift systems that having tracks built into the ceiling so that a caregiver or you can operate the lift with a remote that will lift you up inside of a sling and move you to the wheelchair or into the bathroom to the shower or commode. Lift devices replace the need for heavy lifting by a person and can also increase independence with transfers.

REFERENCES AND RESOURCES

GLOSSARY
ACTIVE ASSISTIVE RANGE OF MOTION - Movement of a joint through partial range of movement performed by the patient. The remaining range of movement is performed by a caregiver.

ACTIVE RANGE OF MOTION - Movement of a joint through the full range of movement voluntarily performed by the patient.

BED MOBILITY – Being able to move your body in the bed, which includes rolling and transitioning from sitting edge of bed to lying down.

BEDSIDE COMMODE - Portable commode with armrests that can be used next to the bed or over the toilet.

CHEST STRAP - A strap that goes around the chest to keep the body upright in the wheelchair.

CONTRACTURE - Muscle or joint that “gets stuck” in one position and cannot be moved. Happens when the muscle or joint is not used for a long period of time.

DECUBITUS ULCER - Deep tissue injury caused by pressure over boney surfaces resulting in skin sores also known as pressure sores or bed sores.

HALO - Type of brace used to stabilize the cervical spine (neck) and prevent any movement while healing following surgery. It is embedded into the skull with screws, and a set of rods connects to a body jacket.

HETEROtopic OSSIFICATION - Growth of bone tissue in locations where it should not be found. This condition can cause joints to become stiff and limit movement.

LATERAL SUPPORTS - Supports placed on each side of the wheelchair back support to keep the trunk at midline while sitting in the wheelchair.

LONG SITTING - Sitting with the legs positioned straight out in front.

TRANSFER BOARD - (also known as a sliding board) A plastic or wooden board used to bridge the gap between two surfaces to make a transfer safer and easier.

TUB CHAIR - Placed into tub or shower to provide a seated surface while bathing.

TRANSFER - Technique used to move from one surface to another.
PARAPLEGIA - Loss of motor and/or sensory function in the trunk, abdomen and/or legs caused by injury to the thoracic or lumbar (trunk or low back) segments of the spinal cord.

PASSIVE RANGE OF MOTION - Movement of a joint through the full range of movement performed by a caregiver.

PRESSURE RELIEF - The act of taking weight off a part of the body that has had pressure on it for a long period of time.

PRESSURE SORE - A breakdown in the skin (also called a pressure ulcer) that starts as a red spot on the skin and can grow into a hole in the body that can extend down to the bone if not properly treated. Factors like heat, moisture, poor nutrition and friction or shear can contribute to development of these wounds.

RANGE OF MOTION - Amount of movement possible at a joint when limb is moved.

SELF RANGE OF MOTION - Movement of a joint or body part through the full range of movement performed by the patient. Can be active, active assistive, or passive (See definitions). Often requires the use of fully functioning body parts to move impaired body parts.

SPASM - An involuntary contraction of a muscle.

SPASTICITY - A state of increased muscle tone and excessive response that often occurs when a muscle is stretched. It can cause an arm or leg to feel tight and be difficult to move.

TETRAPLEGIA - (formerly quadriplegia) Loss of motor and/or sensory function in the arms, trunk, and legs caused by injury or disease to the cervical (neck) segments of the spinal cord.

TRANSFER - Technique used to move from one surface to another.

TRICEPS - Group of muscles located on the back of the upper arm that act to straighten out the elbow.
Chapter 12: EQUIPMENT

WHEELCHAIRS & CUSHIONS

- Most patients 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.

Most patients with spinal cord impairments leave rehabilitation needing a wheelchair and cushion. For some, the use of the wheelchair is short term. For others, the wheelchair is needed throughout life. Regardless, it is very important to get a wheelchair that is appropriate for your size, level of function, needs and lifestyle.

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 trained 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?

Most patients will leave rehabilitation with a rental or loaner wheelchair until the customized chair for which you were evaluated is approved by insurance and delivered by a certified rehab technology supplier. Because wheelchairs get old, products improve and because your postural support and pressure management needs will likely change, you should be evaluated for a new chair about every five years. You should come in sooner for a seating check if your skin health, joint health, body size or activity level changes as these may cause your wheelchair to fit poorly or cause injury.

It is recommended that you not order equipment off the Internet or purchase equipment at a retail store unless you have discussed the specific equipment with your therapist and/or doctor. Choosing equipment in this way, though it may appear to save money, may cause serious injury to your body. Frazier seating therapists will be glad to discuss the pros and cons of this equipment purchase with you.
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 a number of different components which will be described along with the advantages and disadvantages of each.

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 energy when pushing the wheelchair because the chair has more movable parts. The moveable parts do allow the chair to flex more when riding over rough surfaces which does provide some shock absorption. 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.

Rear Wheels.

These are the large wheels on the back of the chair used to propel the chair. These wheels are easily removed with a quick release axle. Some chairs allow the angle or camber on the rear wheels to be adjusted. You can get either mag wheels made of a durable plastic or spokes made of metal. Mag wheels are heavier than spoke wheels but are more durable and more difficult to knock out of alignment. Spokes are much lighter but require more maintenance as they can break and become loosened over time.

Tires.

There are a variety of tire selections for a wheelchair. Solid tires are made of hard rubber and are much heavier than the other types of tires. They are the longest lasting and require the least amount of maintenance. They provide a rougher ride and have poor traction outdoors. Pneumatic, similar to bicycle tires, are filled with air. They provide the smoothest ride and best traction of any of the tires. The air pressure can be adjusted depending on the surfaces you will drive over. The main disadvantage to a pneumatic tire is the tire can go flat. It can, however, be easily fixed by placing a new inner tube in the tire as you would a bicycle tire. Stiffer inner tubes, called flat free inserts, are available for tires. A foam insert is placed inside the rubber tire that prevents flat tires. They are lighter weight than a solid rubber tire but provide a less smooth ride than a pneumatic tire.
**Camber.**

Slanting of the top of the tire in toward the user sitting in the chair is called camber. It can be created by placing washers between the frame and the axle plate or by using an angled axle tube. Camber provides improved turning and lateral stability of the chair and improves efficiency of each stroke to the wheels. One disadvantage is that it increases the overall width of the chair which makes maneuvering through smaller spaces more difficult. Camber is most frequently used on adaptive sports chairs.

**Handrims or Pushrims**

Handrims are placed on the outside surface of the wheels and provide a surface on which to push or move the chair. Plastic coated handrims provide better contact (less slip) between the hand and the rim. They are used for a person who has a weaker grip. While they do increase contact, they create more friction and can get hot when trying to slow the chair down especially going down a ramp. Metal handrims are best suited for someone with normal hand function. They do not give as strong of a contact between the hand and rim but do not get hot when slowing the chair down. Projection handrims have knobs or pegs sticking up from the rim. Someone who is unable to grip the rim can brace his or her wrist or palm on the projections to push the chair. Projections may add to the width of the chair which makes it more difficult to maneuver in smaller spaces.

**Brakes.**

These are used to lock the chair into place for transfers, pressure relief and travel in vehicles. Push-to-lock brakes lock by pushing down on the lever and unlock by pulling up on the lever. Pull-to-lock brakes lock by pulling and unlock by pushing forward. One disadvantage of pull-to-lock brakes is they are often in the way for someone performing lateral or sliding board transfers. Both types of locks can get in the way during wheelchair propulsion. Scissor-lock brakes are under the seat of the chair when unlocked making them less obtrusive during propulsion. They lock by pulling them in front of the wheel. Brake extensions are added levers that make the brakes easier to reach and push. These are often used for someone with decreased hand function or decreased balance. They are often removable to get them out of the way for lateral or sliding board transfers.

**Casters.**

Casters are the small wheels in the front of the wheelchair that are usually attached to the frame by a fork. Smaller casters make the chair more maneuverable but make travel over uneven surfaces more difficult. Larger wheels are better for travel over uneven ground outdoors, but increase the turning radius of the chair making the chair more difficult to use in small spaces. Large front casters can also interfere with a person’s feet or heels.

**Back Support.**

This is the back part of the wheelchair that will determine your positioning and posture while sitting in the wheelchair. There are a number of different back options for the chair depending on your needs. The most standard back is upholstered and comes up to the middle of your back. Some can be adjusted by straps in the back of the chair.
to tighten in places needing more support and loosened in places needing less. As your balance improves and you become more comfortable in the wheelchair, you may choose to get a lower back to decrease chair weight and have more room for your arms to propel the chair more efficiently. Backs can be molded for patients who have specific needs.

**Arm Rests.**

These are placed on the chair to provide a place for you to position your arms. Armrests can be either fixed or removable. Fixed armrests should only be used for someone who is able to stand from the chair. Removable armrests are necessary for anyone who performs lateral or sliding board transfers out of the chair. Removable armrests may flip back, swing away or lift off the chair. Height adjustable armrests are also available. These allow you to move the arm rests up or down to better support your arms or to allow you to better fit under tables and desks. Two lengths of armrests are available. Desk length armrests are shorter and allow the user to get closer to tables and desks whereas full-length armrests provide a longer surface for supporting the arms or a lap tray.

**Leg Rests.**

These are placed on the chair to provide positioning for your legs. Good positioning of the legs helps with balance and posture in the wheelchair. You can get fixed or swing away leg rests. Fixed leg rests cannot be removed from the chair. They make the chair smaller and more maneuverable but standing from the chair or positioning your feet on the ground for transfers is more difficult. Swing away leg rests move away from the chair and allow you to place your feet on the ground for transfers or standing. Swing away leg rests can also be ordered as elevating leg rests to help with leg positioning, swelling reduction and spasm control. Elevating leg rests increase the turning radius of the chair and will make maneuvering in tight spaces more difficult.

**Grade Aids.**

Grade aids are mounted along with the brakes on the wheelchair. They allow the wheels to roll forward but prevent them from rolling backward when going uphill. Those who are more adept at wheelchair mobility often get their fingers caught in the grade aids. This feature cannot be used with scissor lock brakes.

**Anti-Tippers.**

Anti-tippers are placed on the back of the wheelchair to prevent the chair from tipping backward during transfers, pressure relief and propulsion over uneven surfaces. They are usually removed once a person becomes more adept at using the wheelchair. They must be removed to perform wheelies or to go up a curb.

**Clothing Guards.**

Clothes guards are placed between you and wheel to protect your clothing and prevent clothes from becoming caught in the wheels during propulsion. They can be cloth or removable plastic to make transfers easier.
**Spoke Guards.**
A spoke guard is a plastic piece placed over spoked wheels to protect the spokes and to prevent fingers from becoming caught during propulsion.

**Push Handles.**
These are placed on the back of the wheelchair so a caregiver can push the wheelchair if needed. Some people hook onto these handles to perform pressure relief or reach down to the floor. The handles can either be fixed or can flip down out of the way when not in use.

**Seatbelt.**
This feature can be used to improve posture and positioning in the wheelchair. It can also be used to prevent falling out of the chair during pressure relief and propulsion over uneven surfaces. Persons who are more comfortable with wheelchair use often do not use a seatbelt.

**Chest Strap.**
A chest strap is a strap attached to the back of the chair that fastens across your chest. It is used to keep someone with poor trunk control upright in the chair.

**Lateral Trunk Supports.**
Lateral supports are pieces generally placed on the outer edges of the wheelchair back. They are used to keep someone with poor trunk control upright in the chair. They can be fixed or removable. Removable lateral supports are generally better for performing lateral or sliding board transfers in and out of the wheelchair.

**Medial and Lateral Thigh Supports.**
These supports are used to maintain the thighs in a neutral position. They can prevent the knees from turning toward one another or too far away from one another.

**POWER WHEELCHAIRS**
A power wheelchair is a battery-powered wheelchair that can increase independence in the home and community for someone who is unable to propel a manual wheelchair. Because power chairs can cost $5,000 to $15,000 or more, insurance companies typically pay for them only when there is a medical necessity. Thus, most insurance companies require a Letter of Medical Necessity or Justification be written by your therapist. Power chairs though can be purchased privately but should not be done unless you have discussed the specific equipment with your therapist and/or doctor. Choosing the wrong equipment, though economical and convenient, may cause serious injury to your body.

Power chairs easily weigh over 300 pounds and cannot be broken down into small pieces to fit into a car so consideration needs to be given to how the power wheelchair can 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.

The most commonly used power chair is a direct drive or power base chair. Here, the motor directly turns the wheels and the seat is mounted on a base instead of the frame of the wheelchair. A power wheelchair has a number of different components. Described below are many components and their advantages and disadvantages.

**Rear Wheel Drive Power Chair.**

This type of drive is an older style power chair that is not commonly used. The wheels on this chair are belt driven and are not direct drive. This type of chair has a very large turning radius.

**Mid Wheel Drive Power Chair.**

This is the most commonly used drive type for power chairs. It has a very small turning radius which makes it easier to use in the home though it can be more difficult to learn to drive. The mid-wheel drive can also feel tippy when stopping. It can also become stuck in ditches or valleys during use over uneven terrain.

**Front Wheel Drive Power Chair.**

This type of drive is an older style that is not commonly used. It is much heavier on the front end of the chair and has a very large turning radius. It is used primarily in power chairs that transition to standing frames.

**Seat Elevator.**

This feature allows the seating portion of the power wheelchair to rise up similar to an elevator. It allows you to be eye level with others and access higher areas such as kitchen cabinets or work surfaces.

**Tilt in Space.**

This is a seating option that allows someone to stay in a seated position while the chair is tilting backward. In the tilted position, weight is transferred from the buttock to the back to provide pressure relief. This is important for persons in power chairs who are unable to perform other types of pressure relief. This option can also be used for persons who are unable to tolerate sitting up straight.

**Head Rest.**

This piece is mounted on the back of the wheelchair to provide support for the head. It is used on tilt in space chairs to support the head when tilted backward. This is an important feature for someone with decreased head control.

**Ventilator Tray.**

This can be added to the chair to transport a ventilator on the wheelchair.
**Joystick Drive.**

This is one method for driving the chair. A joystick, similar to one on a video game, is moved with the hand to change the direction the chair is moving. Someone with good hand control or tenodesis generally uses this drive option. The joystick can be mounted on either side of the chair depending on the person’s needs.

**Goalpost Joystick.**

This is a modified joystick used for someone who has more elbow and shoulder function than wrist and hand function. A splint is often used to keep the wrist supported while the hand is placed on the goalpost and it is moved with shoulder or elbow movements. It can also be mounted on either side of the chair depending on the person’s needs.

**Head Controls.**

This is another method for driving the chair. A switch is located in the headrest of the chair and movements of the head move the chair. This is used for someone with good head control but limited arm function.

**Sip and Puff Control.**

This is a sophisticated method for driving the chair. Someone who is unable to use other drive methods uses this method. A straw located near the person’s mouth is connected to an electronic module. The person gives a series of hard or soft sips or puffs on the straw to start, stop, turn or recline the wheelchair.

**Chin Control.**

This is a method of driving the chair in which a smaller joystick is located next to the chin so that moving the chin directs the chair. This is used by someone with limited arm function but good head control.

**Integrated Controls**

Advanced technology now allows most wheelchair electronic systems to interface with environmental control systems or control a computer or smart phone via Bluetooth communication protocols. Individuals with minimal motor control can then use the same technology they use to drive and control their position in space to turn on lights, change channels, dial a phone, or access the Internet from a wheelchair.

**Tilt**

This is a power seating option that is used when someone cannot effectively or independently change their body position to relieve the pressure of the pelvic bones on their buttock soft tissue, a technique used to prevent pressure ulcers. Tilting the seat surface to 35 degrees (while leaving the seat to back angle unchanged) effectively transitions the force of gravity from the sitting bones to the upper and middle back and allows the blood flow to normalize in the buttock soft tissue. Another advantage of tilting is that it allows a wheelchair user to more easily reposition their buttocks and return to a posture in which they have good support for an upright pelvis. This posture is key for preventing postural collapse and keeping excessive pressure off the coccyx.
Recline.

This is a power seating option that allows someone to open the seat to back angle and recline their head and trunk back in space with the help of a power wheelchair function. This is helpful if needing breaks from sitting upright or if clothing needs to be adjusted or changed. The disadvantage is that you can slide down in the wheelchair and will need assistance to reposition in the chair properly.

POWER ASSIST WHEELCHAIRS

A power assist wheelchair is a fairly new type of wheelchair that is a hybrid of a manual and a power chair. This chair is generally used by someone who is not strong enough to propel a manual chair but wants to be more active than a power chair allows him or her to be. This chair is constructed using a manual wheelchair frame with the most appropriate back and seating options. The wheels have a battery-powered motor in them. As the wheels are manually pushed, the motor is activated and provides an extra push. The driver is able to go further with one push and fatigues less quickly. The motors make the wheels heavy and more difficult to transport. They require regular charging, and like any battery, can lose power if not cared for properly. It is very important for the user to have a set of standard wheels to use in case the battery-powered motor wheels break or need repair.

WHEELCHAIR CUSHIONS

There are many types of wheelchair cushions available. Cushions are used to:

- Provide a comfortable surface on which to sit
- Increase the distance between the floor and your buttocks (this gives your legs more room, which is even more important if you are very tall)
- Improve your 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

There are a number of things to think about before deciding which cushion is right for you. Your therapist will discuss different cushion options with you to determine the most appropriate choice. Your therapist will also discuss how you can best care for your cushion. General care tips are as follows:

- If you are using an air cushion, you should check the air each day. Be careful not to air it up too much or you will be sitting on a hard surface and will not get pressure relief as you should. If the cushion is not aired up enough, your buttocks will sink down and rest on the hard seat of the wheelchair.
- If you are using a gel cushion, be sure to knead it each day to move the gel back under your buttocks. If you allow the gel to stay out to the side, you will not get the pressure relief as you should. Also, do not leave your gel cushion out in the cold as it may freeze.
- Never dry your cushion cover in the dryer. Always let it air dry. You may want to purchase a second cushion cover to have while you are cleaning your other cover.
Seating and Positioning Clinic

At Frazier’s Seating and Positioning Clinic, you can try out new chairs, seating and positioning options. A physical therapist specially trained in seating and positioning will perform an evaluation and discuss various seating and positioning options with you and your caregivers. The therapist works very closely with your therapy team and a number of equipment vendors to provide each patient with the most appropriate equipment and service. If you are in need of a wheelchair and/or seating and positioning equipment or a check on your seating, you can be evaluated at Frazier’s Seating and Positioning Clinic. 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.

SPLINTING

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 prevented with range of motion exercises, positioning, casting and splinting or bracing. Various types of splints and braces for the upper and lower limbs are used. Splints and braces 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 increase function.
- Provide comfort and reduce pain.
- Correct or reduce any misalignment or deformity of joints and muscle weakness.

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

Upper Extremity Splints

Resting Hand Splint

The resting hand splint (RHS) is a splint 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.

Dorsal Wrist Splint (ADL Splint)

The dorsal wrist splint allows the wrist to be supported for better hand function. It has a cuff part that can be used to hold a spoon or fork to increase the use of the hand in self-care activities.
**Tenodesis Splint.**

The tenodesis splint allows proper positioning of the fingers and thumb when the wrist is bent back to allow one to grasp and release objects.

![Tenodesis Splint](image1)

**Wrist Cock up Splint.**

The wrist cock up splint supports the wrist in a bent back position for better hand use.

![Wrist Cock up Splint](image2)

**Long Opponens Splint.**

The long opponens splint has a thumb component to position the thumb in order to improve grasp and release during self-care activities.

![Long Opponens Splint](image3)

**Short Opponens Splint.**

The short opponens splint allows tenodesis use of the hand in individuals with the ability to use their wrists.

![Short Opponens Splint](image4)
Universal Cuff.

The universal cuff (U-cuff) is a hand-based splint 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.

MP Block Splint.

The MP block splint supports the joints of the fingers to prevent clawing of the hand and promote normal grasp and release movement during functional tasks.

Elbow Extension Splint.

The elbow extension splint or cast can be used to reduce tightness to allow normal elbow range of motion.

Overhead Suspension Slings.

Overhead suspension slings can be used to support weak muscles against the force of gravity while allowing the individual to use the hand for functional tasks such as feeding and computer tasks. Moveable rods can allow the individual to adjust the height for different tasks.

Shoulder Support Slings.

Various shoulder slings such as the shoulder saddle or GivMohr sling can be used to support a weak or painful shoulder and arm, especially for individuals who are working in a standing position in which the arm would dangle without a sling’s support.

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. This brace is made of plastic and can either be prefabricated or custom molded to an individual’s foot. Solid AFO’s allow very little movement at the ankle. Articulated AFO’s have hinges at the ankle joint and allow some movement at the ankle joint. This type of AFO can be adjusted and changed frequently depending on the person’s needs. Articulated AFO’s are often made of a combination of plastic and metal pieces.

There are a number of other bracing options for individuals who are learning to walk. Unfortunately these braces are often heavy, difficult to use and require a lot of energy. They 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. When you begin wearing a new
brace, you should wear it for 10-15 minutes at a time for the first few days and increase wearing time from there. You should check for red marks on the skin after you take off the brace. Any areas of redness should go away after 30 minutes of having the brace off. If the redness does not go away after 30 minutes, stop wearing the brace and contact your physician. Skin inspection is extremely important as you may not be able to feel the areas as you did before.

ASSISTIVE TECHNOLOGY

Patients with spinal cord injury or impairment may have limited movement in their arm(s), hand(s) and/or leg(s). Those with limited mobility in the upper body may be concerned that independently operating a TV/VCR/CD player, answering a phone and being functional on a computer or wireless will no longer be possible. These issues and many more can be addressed in the Assistive Technology (AT) 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 use various pieces of assistive technology that may help you be more independent in your home, work or school environments. Vocational Rehabilitation is often a key payor for assistive technologies which are related to the world of work or education. Thanks to the amazing changes brought by digital technologies many types of work are now easily accomplished through adaptations to computing.

Assistive technologies, as defined by the Assistive Technology Act of 1998, are “products, devices or equipment, whether acquired commercially, modified or customized, that are used to maintain, increase or improve the functional capabilities of individuals with disabilities.” Environmental control, computer access and home accessibility are three assistive technology areas of focus in the AT Clinic at Frazier.

Controlling Your Environment.

In the AT Clinic, 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 touch pads may be used to turn on/off equipment. Smart phones and tablets have made this technology much less expensive and easier to accomplish. Individuals with a modest budget can now create an accessible environment at home or at work for communication, sharing and learning.

On the ‘higher end’ of technology, some computer based environmental control units (ECU) may allow voice recognition software to operate home equipment. ECUs typically control TVs, lights, etc., but can also control equipment in many areas of the house, e.g., entrance door locks, remote cameras, curtains, thermostats and hospital bed positions. ECUs can also be integrated into a power wheelchair controller. Some ECUs and specialized phones offer hands-free phone capabilities.

Computer Access.

Since computers are widely used for leisure, work and/or school related activities, computer access is often needed for those with upper extremity limitations. The Adapted Computer Access program can, introduce you to adapted keyboards, touch screens, sip and puff devices, adaptations available for a computer mouse, mouth stick
use and voice recognition to name but a few. Specific computer software is also available to increase one’s productivity and independence. Recommendations are also made regarding the proper set up of computer tables/workspace to increase computer usability and minimize user fatigue.

**Home Accessibility.**

Being able to move around in your home environment is important for one’s independence. Your independence may be increased with installation of an outdoor ramp to your entrance door, power door openers, a stair lift or specific bathroom equipment. Other items many consider include grab bars in a bathroom, a hand-held shower head, replacing round door knobs with lever style handles, lowering light switches and raising electrical outlets.

Home remodeling might include widening narrow door/hallways needed for wheelchair or walker access; installing a roll-in shower; lowering the height of cabinets in the kitchen, bathroom and/or home office for efficient use at a wheelchair level; and installing a ceiling mounted patient lift system which can move a person from bed to wheelchair, toilet and/or bath tub to name but a few. Some users of a ‘patient lift system’ are able to operate the lift without the assistance of another person.

As stated, therapists in the AT Clinic will give you and your family information regarding available technologies designed to improve your independence and quality of life. Additionally, they will help determine the most affordable equipment that might meet your needs and explore funding options/resources with you.

**REFERENCES AND RESOURCES**

Equipment data base - [http://www.abledata.com](http://www.abledata.com)
Wheelchairs and Accessories - [http://www.sportaid.com](http://www.sportaid.com)
Wheelchairs Accessories - [http://www.pimpmychair.com](http://www.pimpmychair.com)
Wheelchair reviews - [http://www.wheelchairjunkie.com](http://www.wheelchairjunkie.com)

**GLOSSARY**

ABDUCTION WEDGE - An attachment for the seat of the wheelchair to keep the legs in a neutral position.

ADDUCTION WEDGE - An attachment for the seat of the wheelchair to keep the legs in a neutral position.

ANKLE FOOT ORTHOSIS - A brace placed into the shoe that comes up on 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.
ANTI-TIPPERS - Projections placed on the back of the wheelchair to prevent the chair from tipping backward during transfers, pressure relief, and propulsion over uneven surfaces.

ASSISTIVE TECHNOLOGY - Advanced technology created to make tasks possible or easier for individuals with physical disabilities.

CAMBER - Slanting of the top of the rear tire in toward the wheelchair

CASTERS - The small wheels on the front of the wheelchair.

CHEST STRAP - A strap that goes around the chest to keep the body upright in the wheelchair.

CHIN CONTROL - A control used to drive a power chair that is activated by chin movements.

CLOTHES GUARD - A plastic or cloth attachment to the wheelchair to prevent clothes damage during movement of the wheels.

DORSAL WRIST SPLINT (ADL SPLINT) - Allows the wrist to be supported for better hand function. It has a cuff part that can be used to hold and ADL item such as a spoon or fork to increase the use of the hand in self-care activities.

ELBOW EXTENSION SPLINT OR CAST - Splint used to reduce tightness to allow normal elbow ROM.

ENVIRONMENTAL CONTROL SYSTEM - Advanced technology systems for home or office used to control lights, phone, doors, television, bed and other items using remote control devices.

FRAME - Main part of a wheelchair to which all other parts are attached.

GOALPOST - A control used to drive a power chair that looks similar to a football goalpost.

GRADE AIDS - An attachment mounted along with the brakes on the wheelchair that allow the wheels to roll forward, but prevent them from rolling backward when going uphill.

HANDRIM - Rim on the outside of the wheels that provide a surface on which to push to move the chair.

HEAD CONTROLS - A control used to drive a power chair that is activated by head movements.

LATERAL SUPPORTS - Supports placed on the side of the chair to keep the trunk upright while sitting in the wheelchair.

LOANER WHEELCHAIR - A wheelchair that is loaned to a patient from the equipment vendor until the custom wheelchair can be ordered and delivered.

LONG OPPONENS SPLINT - Splint with a component to position the thumb in order to improve grasp and release during self-care activities.

MANUAL WHEELCHAIR - A wheelchair that requires the user to push the wheels for movement.
MP BLOCK SPLINT - Splint that supports the joints of the fingers to prevent clawing of the hand and promote normal grasp and release movement during functional tasks.

OVERHEAD SUSPENSION SLING - Sling that can be used to support weak muscles against the force of gravity, while allowing the individual to use the hand for functional tasks such as feeding and computer tasks. Moveable rods can allow the individual to adjust the height for different tasks.

POWER ASSIST WHEELS - A hybrid system that allows power pushrims to be added to the frame of a manual chair. The battery powered wheels assist with propulsion especially with weaker shoulders or more challenging terrain.

POWER WHEELCHAIR - A battery powered wheelchair that moves by a controller.

PRESSURE RELIEF - The act of taking weight off a part of the body that has had pressure on it for a long period of time.

PUSH HANDLES - Handles on the back of the wheelchair used by a caregiver to push the chair.

RENTAL WHEELCHAIR - A wheelchair that is rented by a patient or insurance company to use for a short period of time.

RESTING HAND SPLINT (RHS) - Splint that keeps the hand in a position that supports the wrist and hand to reduce the risk of joints getting stuck in one position.

SHORT OPPONENS SPLINT - Splint that allows tenodesis use of the hand in individuals with the ability to use their wrists.

SHOULDER SUPPORT SLINGS - Sling used to support a weak or painful shoulder and arm, especially in individuals who are working in a standing position in which the arm would dangle without a sling’s support.

SIP AND PUFF CONTROL - A control used to drive a power chair that is activated by a series of sips or puffs on a straw.

SKIN INSPECTION - Looking at the skin for areas of redness or skin breakdown, especially over bony areas of the body.

STANDING FRAME - A device that supports a person in a standing posture.

SPOKE GUARDS - Plastic covering placed over a wheel to protect the spokes from damage.

TENODESIS - The ability to pinch or grasp objects with the thumb and index finger through the use of a specific wrist movement.

TENODESIS SPLINT - Allows proper positioning of the fingers and thumb when the wrist is bent back to allow one to grasp and release objects.

TILT IN SPACE WHEELCHAIR - A wheelchair that tilts backward while keeping the user in a seated position.

TRANSFER - Technique used to move from one surface to another.

UNIVERSAL-CUFFS (U-Cuff) - Splint that allows user to hold ADL items without grasp
VENTILATOR TRAY - An attachment used to transport a ventilator on the wheelchair.

WRIST COCK UP SPLINT - Splint that supports the wrist in a bent back position for better hand use.
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. Most people do make some modifications to their home however others relocate to a residence better suited to their mobility and independence needs.

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 for a standard wheelchair and minimum space requirements for each room of your home based on Americans with Disabilities Act (ADA) Standards for Accessible Design using a standard adult wheelchair. The measurements on your wheelchair will depend on its size and style and may vary from those of a standard adult wheelchair.

**DIMENSIONS FOR STANDARD ADULT WHEELCHAIR.**

- Armrest height: 29-30 inches
- Seat height: 19-20 inches
- Seat depth: 16-18 inches
- Wheelchair width: 25-30 inches
- Wheelchair length: 45-50 inches (allowing for feet)

**MAXIMUM HEIGHT AT WHICH OBJECTS SHOULD BE PLACED FOR REACH FROM AN AVERAGE ADULT WHEELCHAIR USER:**

- Overhead reach: 50-60 inches from floor level
- Forward reach: 48 inches from floor level
- Side reach: 54 inches from floor height
- Downward reach: 5-10 inches above floor height

**INTERIOR AND EXTERIOR DOORS**

- Entry doors should be at least 36 inches wide with at least 32 inches of clear opening for a standard wheelchair to enter.
- Interior doors should have at least 32 inches of clear space when open. When necessary, the bedroom and bathroom doors may be removed and replaced with curtains to create enough space for a wheelchair to pass.
- If the person with spinal cord injury has impaired hand function, horizontal door handles 34-36 inches from floor can be installed to make a door easier to open.
- Avoid thresholds that rise above the level of the floor if possible.
- There should be at least 4 feet of unobstructed space surrounding each closed door to ensure an easy path to maneuver the wheelchair.

**WIDTH OF HALLWAYS**

- You will need at least 32 inches of clear opening for a standard wheelchair to pass down a hallway.
• A hallway at least 36 inches wide will allow a wheelchair user in a standard chair to make a 90-degree independent turn into an adjoining room.

**KITCHEN COMPONENTS**

• Counter tops should be 28-36 inches from the floor.
• Continuous countertops with built in stovetops are ideal. Electric stoves are recommended instead of gas to avoid clothing catching fire. All appliance controls should be located in the front or on the side.
• Allow for as much knee space under the sinks and countertops as possible. Ideally, there should be 27 inches of height, 30 inches of width and 19 inches of depth under the sink for knee clearance. You may consider removing existing cabinets to create this space.
• Sinks should be a maximum of six inches deep to allow the wheelchair user to place palms on the bottom of the sink. Sinks should be installed 32-34 inches from the floor. 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.
• Wall cabinets should have adjustable shelves and be 30-34 inches high by 20 inches wide by 14 inches deep.
• Cabinets should be placed 10-14 inches above countertops.
• Base cabinets should be 32 inches high by 22 inches wide by 24 inches deep. Be sure to leave toe space under the cabinets for footrests which are typically nine to ten inches high by six to eight inches deep.
• Other modifications include: lazy Susan’s, heat resistant countertops, pull-out trays and mounted mirrors above the stove to monitor items on the back burner.

**ACCESSIBLE BATHROOM**

• A sliding pocket door can make for easier entry into the bathroom. If using a standard door, it often more convenient if the door can swing out.
• Commodes should be 20 inches high and as wide as possible. A raised toilet seat or other toilet accessories may be needed to raise toilet height to a safe level for transfers.
• Commodes should have at least 32 inches of clearance on one side to allow for transfers from the wheelchair.
• If space is limited, a bedside commode may be used to complete toileting.
• Sinks should be a maximum of 6-inches-deep and allow the wheelchair user to place palms on the bottom. Sinks should be installed 32-34 inches from the floor. The piping should be located as far back as possible and insulated to avoid leg burns when the pipes are hot.
• Bathtubs should be 18 inches deep with a single lever faucet. A hand held shower is recommended with a hose length of five to six feet and controls on the handle.
• 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. Your occupational therapist will work with you to determine measurements specific to your situation. DO NOT USE TOWEL BARS/RACKS AS GRAB BARS, AS THEY ARE NOT DESIGNED TO SUPPORT BODY WEIGHT.
• A tub/shower chair is recommended. There are several unique designs available. Your occupational therapist will practice using different models to assist with selecting the model that is right for you.
• Mirrors should be mounted with the bottom of the mirror no lower than three feet.

DESIGN FOR SAFE 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. Below is a list of general guidelines for proper ramp construction:

• The maximum incline or slope for a ramp is 1:12 meaning for every 1 foot of total height in step(s), 12 feet of ramp length is required. For example, a two step entry with each step seven inches high would require 14 feet of ramp.
• Ramps should be a minimum of 36 inches wide and a maximum of 30 feet long. If the ramp must be longer than 30 feet, a landing should be considered.
• 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.
• Ramps should have non-skid surfaces for safety.

If there is not enough room to build a ramp long enough to meet the above specifications, alternate means of accessing the home such as a porch lift will be needed. Your therapist and care coordinator will discuss the various options specific to your situation. Your care coordinator can also provide you information community programs that offer assistance with ramp construction. These programs often have waiting lists so it is very important to make application and begin to plan home modifications early in your rehabilitation.

HOME ACCESSIBILITY – GENERAL TOPICS
• To create more space in which to use a wheelchair, remove all unnecessary furniture and rugs.
• 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.
• 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. Tracking systems can even be installed into the ceiling to allow the lift to move someone from the bed/wheelchair into the bathroom or any other room in the house that is preferred. These lift devices can be controlled by the user of the lift device to increase his/her independence or by the caregiver.

REFERENCES AND RESOURCES


● Home modification - http://www.infinitec.ort/manual/index.html -

● Home modification - http://www.mhfa.state.mn.us/homes/access -

GLOSSARY

BEDSIDE COMMODE - Portable commode with armrests that can be used beside the bed or over the toilet.

HAND HELD SHOWER - Showerhead with a hose that allows user to hold shower in his/her hand to direct the spray.

RAISED TOILET SEAT - Attaches to existing toilet to increase the height for easier transfers.

TUB/SHOWER CHAIR - Fits into tub or shower to provide surface for bathing.
Chapter 14: PSYCHOLOGICAL CARE

GRIEF AND LOSS

“This body that I’ve been living in since I was born, doesn’t work as it used to. In fact, some parts don’t work at all. I can’t feel them. I can’t move them. And what I’ve learned is that they can be heavy like a lump of clay getting from bed to the wheelchair. They feel useless. Me worried? Scared to death. What’s next? Don’t know? (Jason, age 24, two weeks after spinal cord injury.)”

After injury and hospitalization, perhaps, you, like many, sense deep within that life is going to be different from what it used to be. Yet, it is difficult to know exactly what to think, or how to feel, because there are so many uncertainties. Various thoughts, feelings, questions are common, such as:

- Do the doctors really know what’s wrong?
- It doesn’t really matter what they say because I’ve always come back from injury—I work hard. Think positive, I’ve got to think positive.
- What will my friends and family think of me?
- I don’t want my girlfriend to see me like this. Maybe I should have died?
- My toes and ankles must be asleep. I must be asleep. This is a dream, it’s unreal.

After injury, you may also find it difficult to think clearly. You may experience considerable anxiety or worry and find it difficult to handle emotions. This may be a reaction to the injury and may be due to pain, drugs, poor sleep and/or being in the hospital. You may also have received a brain injury at the time of your spinal injury, which can contribute to mental and psychological changes even though they may be mild or short lived. It is not uncommon to sustain a brain injury and a spinal cord injury in the same accident.

You may have difficulty perceiving your body accurately because of nerve damage. For example, you may feel your legs bent at the knees when in reality they are straight. When sitting, you may feel you are leaning to the left when in fact you are sitting up straight. Some people sense that their body below the neck is like a balloon floating in air or feel a limb move when it is lying flat on the bed. These experiences can add to your anxiety, confusion and concern.

In addition, you may come to discover:

- You have little control over what happens to you or your body early in your hospitalization
- How dependent on others you have become for even the most minor tasks like getting a drink of water
- Small amounts of physical activity can cause extreme exhaustion
- The rehab process feels slow and will require long, hard work
- When friends and family come to visit, the responsibility to put others at ease often falls to you.

Given the above, it is common to think about giving up, and to want to be left alone to stay in bed all day. Feelings emerge of wanting to forget about rehab and focus on
the perfect healing. You might even ask yourself if people with injury or impairment and their families usually go through a period of grief and loss, and that answer is commonly, yes.

Everyone’s experiences after injury/impairment are different. For example, you may not experience much grief or sense of loss. Instead, you may feel energized, intensely focused and determined to rise above the injury or impairment, determined to move forward. If this is true, you probably will work extremely hard in your rehab and accomplish much. Nonetheless, it is not uncommon to have episodes, sometimes months after injury, when the pain associated with this life style change or the pain of the losses do appear and are intense. Should it happen to you, it is important to be prepared.

The Process of Grief, Grieving the Loss

Moving through a period of grief is a normal, healthy reaction when something or someone important to you is lost. Experiencing grief is common regardless of whether the loss is thought to be short-lived or long-term. The grieving process helps one come to terms with the emotions associated with the loss, to accept the reality of life as it is today and to begin to make adjustments so life can be lived with a reason to get out of bed everyday. Those who have no purpose for daily life often become depressed as their relationships with family and friends deteriorate. By contrast, those who live with purpose can find health, happiness and self worth, while maintaining and/or strengthening their relationships with others.

The symptoms of grief are many and can include sleep disturbance, low energy, loss of appetite, increased appetite, lack of motivation, tearfulness, feelings of sadness, social withdrawal, wishes for death, thoughts of suicide, anger, impatience, moodiness, longing, confusion, feelings of guilt, anxiety, loneliness, disbelief and agitation.

These symptoms are not necessarily bad or unhealthy as they represent the normal process of moving through grief and may continue for weeks, months and possibly years, though the frequency of the symptoms and their intensity may vary. However, you and those around you should become concerned if the symptoms continue, get worse and/or you feel stuck. If this happens, you should consider talking with your doctor, a counselor or psychologist, or trusted individual who has the skills to help. Specifically, thoughts of suicide should not be ignored and professional help should be found.

The symptoms of grief mentioned above need to be addressed by you and your family so they can be resolved. Remaining involved with your rehab doctor and team of professionals at the rehab center is strongly recommended to assist and advise you with life style changes and adjustments as you work to re-enter your community after hospitalization.

Seeing the Reality of the Loss, Accepting Change.

Most would agree a leg amputated due to injury or disease is gone and will not grow back. By comparison, it is more difficult to accept losses due to spinal cord injury or disease because they are often not seen so clearly. For example, you may not be able to move your arm or leg today but they are still attached to the body, seemingly ready to
be used. As you sit quietly in a chair or lie in bed, you may look and feel very much as you always did. Recovery is about getting the nerves connected and working again.

Like others, you may have great hope and determination for recovery but struggle that medical science can seldom, if ever, guarantee recovery. Perhaps you don’t want to hear what the physicians think about your injury. If you don’t improve after a few weeks, months or years, should you give up hope?

Some do give up hope, yet others do not choosing instead to believe in themselves, believe in the power of prayer and that advances in spinal cord research and treatment hold great promise. And it is true there have been significant advances in both the research lab and the clinic settings. Nonetheless, believing in a cure returning you to perfect health is a future possibility. Nevertheless, losing the ability to control your bowel and bladder, to walk as you once did, or to bath independently is about today. How you deal with today is very important to you and those around whom you love and who love you.

One of the first steps needed to deal with loss or change is to see today truthfully. For example, a transfer board and assistance may be required for you to get out of bed; a rolling shower chair and hand held controls might be needed to bath. Admitting to yourself that this is the way it is today hopefully means that you will make great effort to learn to help with transfers and bathing as best you can. Being active with your body may in fact be very helpful to recovery, as researchers have learned that activity causes the spinal cord to be stimulated and that, in turn, can produce movement.

Experiencing the Emotional Pain Associated with the Loss.

Having control and sensation of one’s body for toileting, mobility, sexual activity, and, in general, to be independent, allows one to maintain a certain life style, which is an important element in how we perceive ourselves. Emotional pain is a reflection that something, valued or treasured, has been lost temporarily or forever.

Those who see the reality of their loss of sensation and control of body typically allow themselves to experience the loss emotionally. The emotions are often very strong and can be difficult to manage. Anger, sadness, hopelessness, guilt, fear and a sense of injustice are very common. Talking, screaming, yelling, cursing, crying, sleeping, praying, biofeedback and deep breathing exercises, looking for the positive, being active, learning the truth about spinal cord injury and disease, and meeting former patients who have been successful dealing with spinal cord injury or disease are often helpful. Eating, watching TV, listening to music, sleeping, medications and daydreaming may be helpful for a break from the emotional pain but can become unhealthy if used too often. Thus, the emotional pain can remain unresolved or stored up waiting for release, resolution and healing. Those individuals who do not successfully handle this task in the grief process frequently lose motivation and interest in many activities. They withdraw from friends and family, become bitter and resentful, stay depressed, develop poor personal hygiene or eating habits, and many seriously abuse drugs and alcohol. However, those who have some success dealing with the emotions related to loss, move forward.
Making Adjustments after Spinal Cord Injury.

Adjustment means effectively learning to deal with the changes caused by the spinal cord injury, disease or impairment. Learning new ways to cope may become necessary. For example, if you ran 2 miles a day for stress relief, you may need to find alternative ways to relieve stress after injury. If you were accustomed to a varied daily schedule with irregular hours for food and sleep, you may find regularity is important for proper control of bowel and bladder and your overall health. If you were used to making plans spontaneously, you will learn that it takes time to prepare for an outing as you consider transportation options, accessibility of buildings and the amount of time needed to prepare yourself for an outing. Additionally, you may need to learn new vocational skills because you may not be able to do your old job as you once did. An important component of a patient’s rehabilitation program is to:

- Venture out in the community and learn how it is possible to function
- Discover that the fears or discomfort of being in the community often go away with time
- Learn how to appropriately ask others for a little help

Bouncing Back.

Bouncing back requires a willingness to take a risk, which is something you have already done many times since injury though you may not have noticed or given yourself credit for taking a risk. For example, you may have been scared and unsure the first time transferred out of bed, the first days of rehab and the first few times going out in public. With practice and experience, these activities and many others become easier and more manageable. If you hadn’t taken a risk, you would likely still be in bed.

Those who do well after injury, take risks often, even though they may be scary or difficult. For example, a woman with paraplegia, always shy and passive, decides it is important to push herself to be more talkative around others in order to feel better about herself and less lonely. Another example of taking a risk is the young man with tetraplegia who enrolls in a community college to learn job skills though he believed himself to be low average student in high school.

Bouncing back also means having goals and having a reason to get out of bed each morning. As said above, those who don’t are often depressed; those who do create the opportunity to move forward. Success here usually involves setting both short and long-term goals that are realistic and obtainable with effort on your part. Soon after injury, short-term goals are particularly important because of the loss of independence. Thus, setting a goal to lift a weight more today than yesterday, to do better taking your pants off tonight, to bath or brush your teeth with greater independence is good. If you can see daily progress, chances are good you will feel less depressed and more encouraged knowing, “Hey, I can do that. I might be able to do more.” You are encouraged to organize your thoughts and identify goals that are reasonable to accomplish with effort on your part.

Lastly, bouncing back means allowing laughter and humor to be a part of your daily life. If only for a brief moment, one who laughs, lets go of pain, loneliness and fear. A good laugh is living in the present, not connected to the past or fearful of the future and
allows you to relax and experience pleasure. Many patients believe that incorporating humor helped their recovery. Examples include watching a comedy, purposely remembering a funny event, planning an enjoyable event or get-together, teasing someone or telling a joke.

About Your Family and Loved Ones
As you may struggle after injury/impairment, those who love you also struggle. Most believe that spinal cord injury and impairment doesn’t just happen to you but to the entire family. Though your experiences may be different, there are many similarities. For example:

- They too miss seeing you up and walking around or seeing you do things that you have enjoyed
- They too struggle as you try to dress, bath or brush you teeth, activities which were simple things in the past
- They too have concerns and questions about your future
- They too want your old life back. They too want their old life back

Simply said, rather short term or long term, their life is also different. As such, they too will likely experience many emotions related to spinal cord injury and impairment as described below. If you pay attention to your family’s concerns, you can be helpful to them as they are helpful to you. Saying things like, “Thank you for coming to the hospital, for taking care of my apartment/house, for helping with my personal care, for not abandoning me” helps keep you family going, helps them feel appreciated and useful.

Summary
Dealing with grief and loss following injury is often difficult and continues for months and often years. It is important to:

- Be patient with yourself
- Accept that ups and downs are normal realizing there will be good days and bad days
- Take risks to do things challenging or outside your comfort zone
- Work to accomplish something important to you everyday
- Give yourself the freedom to laugh and have fun
- Give yourself permission to ask others for help and assistance
- Practice making decisions about your life…take charge

After injury, many do take charge. David was 16-years-old when he dove into a swimming pool and sustained a C5 complete spinal cord injury. While in the hospital bed, he could see no future other than lying in bed. Twenty years later, he had completed two college degrees, married a wonderful and supportive woman, had a full-time career, drove his vehicle independently, frequently flew for business and pleasure, and enjoyed many leisure activities. “Back when I was in my hospital bed, I thought it would be impossible for someone like me to accomplish the things I’ve accomplished.”
HOW FAMILIES CAN HELP

When one of your loved ones 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 (LO). Stories from intensive care units describe family members staying at the hospital for days or weeks, and eating and sleeping in the waiting rooms. They shower using the sinks in the hospital rest rooms. Family members sit together, worry, often cry and wait to hear the next words from the doctors and nurses. The crisis from injury or illness often unites families, and proves over, and over again they can be incredibly strong.

What Can Families Do To Help?

Perhaps most difficult for families is their inability to fix the spinal cord and return their LO to life as it was before injury or impairment. If families cannot fix the spinal cord, what can they do to be helpful?

Actually, families can do a great deal that is helpful, which makes a difference even though it may not seem so at the time. Those that have lived with spinal cord injury or impairment have said:

- My family got me through the first few days. Just knowing they were there helped.
- My wife and kids… that is why I wanted to live. Without them, I would have given up.
- I wouldn’t be where I am today if it were not for my family.
- My wife said, “You are still you,” even though I couldn’t see it at the time.
- I could see their love for me as they cried when I couldn’t move my arms or legs.
- I knew they still wanted me.

Relate to Your Loved One as You Did in the Past.

If you laughed in the past with your loved one (LO), expect to laugh together again. If you disagreed about things in the past, expect to disagree again. If you shared special thoughts and feelings and helped each other in important ways, expect that to happen also. If you told your LO when you were angry, when he/she was insensitive, lazy, or stubborn, plan to do it again.

Your Loved One is More than Body. Even though the body may not work as it once did, your LO remains a person of value. Express that to your LO in as many ways as you can. For example, bring in a special food, give your LO a hug, do something you know your LO will know is special, call just to say hello or learn how to do some of the care your LO needs.

Practice Being a Good Listener.

A good listener tries not to interrupt or offer too much advice unless asked to do so. Listening to your LO as he/she begins to talk is helpful. You may not like what you hear, but to know your LO’s thinking is valuable. If you become disturbed by what you hear, you may talk with the psychologist or other staff member for support and guidance. It is not your job to solve all problems or have the perfect answer to every question your LO
may have. However, just being with someone at a difficult time, being a good listener is a great way to be supportive.

**Encourage the Expression of Feeling.**

Express interest in your LO by asking questions about what is happening in therapies. Ask what has been good or discouraging difficult about rehab. Ask about things such as current events, sports, family news, etc. As you ask questions of interest, you will encourage your LO to express himself/herself.

**Reinforce Independence.**

Encourage and expect your LO to make decisions about important like discharge plans, as well as other decisions about what to eat for supper, what clothes to wear and what to watch on television. Your LO made decisions about his/her life in the past and will need to again. Be careful as you try to be helpful that you don’t make decisions that your LO should be making. Sometimes, you are most helpful when you do not rush in and do things your LO needs to try to do even when difficult.

**Learn about Spinal Cord Injury and Impairment.**

The more you learn, the better you will come to understand what your LO is going through and know better how to be helpful. With more knowledge, you can become more confident and comfortable as you spend time with your LO. If your LO sees you making effort to learn, your LO knows you care and are being supportive.

**Attend Family Teaching Days at Frazier.**

The staff at Frazier wants you and others in your family to attend therapy with your LO. As you participate in what we call Family Teaching, you will see how the therapists work with you LO, you will learn why things are done as they are, and your can practice specific ways to can help your LO. For example, you might learn how you can help with meals but not help too much, how you can help your LO be more comfortable in the wheelchair or in bed, and how to stretch a sore arm or leg. Being comfortable providing hands on assistance to you LO is a wonderful way of expressing your love and support.

**Join a Spinal Cord Advocacy/Support Group.**

Struggling with the realities of spinal cord injury or impairment for many is difficult. Many find it helpful to be around those who have dealt with similar issues and found ways to be successful. You and your LO might consider attending meetings sponsored by organizations like the National Spinal Cord Injury Association (NSCIA). In Louisville, the Derby City Chapter of NSCIA meets at Frazier monthly and welcomes those with injury, family members and friends. For information, contact the Frazier’s Psychology Department at (502) 582-7484 or the Therapeutic Recreation Department at 502-582-7618.

**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. Understandably, most want to care for their loved one
(LO) first and their self 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 LO over the long term.

You may find value in reading the section above on Grief and Loss. Specific questions and concerns can be directed to your rehab doctor, psychologist or others on your rehab team.

**CAREGIVERS**

During inpatient rehabilitation, family members will often be asked to learn how to do hands-on care for their LO. This may involve activities of daily living (bathing, dressing, eating), transfers from bed to wheelchair, specific medical care (wound dressing, tube feedings), procedures for skin protection and bowel/bladder management. The level of your LO’s spinal 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 LO. If not done, then the LO might not reside in a home situation but rather a long-term care facility in the community. Most caregiving is done as an expression of love. 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 LO. Caregivers are advised to learn to give yourself permission to care for yourself, learn how to do it well and do it regularly. Examples would include:

- Learn as much about your LO’s injury so you know how to provide the care well but efficiently
- Work to create a daily routine so you have an idea of what should happen when. Accordingly, you will be able to identify time each day of off duty and free yourself to do things you like
- Exercise regularly if only a regular walk around the yard, block or through the shopping mall
- Schedule others to help with your LO’s care so you can be away from the situation on a regular basis
- Reach out and ask for help and be involved with others

**DEPRESSION**

Depression is a mood disorder that affects about five percent of the general population. The frequency is higher (six -10 percent) among those with illness and disability. While most living with spinal cord injury do not experience a Major Depressive Disorder (MDD) after injury, the rate of occurrence after injury is 23-30 percent. MDD unfortunately can result in longer hospitalizations; fewer gains in rehabilitation; increased number of pressure sores, urinary tract infections and other medical complications; increased family and caregiver stress; and attempts at suicide. (Bombardier, Univ. of Washington Newsletter, Summer 2001, 10-2)

The signs and symptoms of depression include the following:

- Feeling down, blue, sad, helpless, guilty or hopeless
- Having trouble falling asleep, awakening multiple times during the night, sleeping only brief periods and then have trouble falling back asleep, and/or sleeping very long periods of time, though still feeling tired when awake
- Loss of interest in people, activities hobbies that were once meaningful or pleasurable
- Feeling irritable or angry more often than normal
- Difficulty with memory and concentration
- Little interest in getting up in the morning, less attentive to bathing, grooming and dressing
- Loss of appetite or weight gain
- Little interest in sexual activity
- Increased use or heavy use of drugs and/or alcohol
- Trying to make things better, but regardless feeling tired and unsuccessful.
- You can do an on-line screen for depression at http://www.agingwithdisability.org/factsheets/depfactsht.htm

Fortunately, treatments are available for depression. The most common include counseling and medication. Sitting down with a trained counselor, psychologist, clinical social worker, or marriage and family therapist has proven to be helpful to many. Antidepressant medication, prescribed by your physician, can also very helpful. Such medications, when prescribed properly, impact the chemistry of the brain to decrease many of the depressive symptoms described above. Studies indicate that treatment that employs both counseling and medication is often most helpful.

Your rehab team is sensitive and responsive to the emotional stressors related to spinal cord injury. If you or members of your family are struggling with depression, let it be known so help can be provided in a confidential professional manner.

SUBSTANCE ABUSE

It is clear that alcohol use is a significant factor in traumatic spinal cord injuries although the statistics are not totally clear. Somewhere between 17-49 percent of all traumatic spinal cord injuries are the result of the individual being intoxicated (eMedicine.com, 2005). Some studies indicate over 50% of all traumatic injuries are related to drug or alcohol use.

Abusing alcohol and other drugs can cause additional problems after spinal cord injury. When intoxicated or high, pressure relief and other self-care procedures can be ignored. The likelihood of injury from falls or hitting objects when up in a wheelchair, is increased. One’s nutritional status falls. Bowel and bladder function is often negatively affected. Respiratory function is threatened and overall memory and judgment becomes impaired. You can do an on-line screen for alcohol abuse at http://www.alcoholscreening.org You can do an on-line screen for drug abuse at http://www.schickshadel.com/drugtesting.asp

If you or family members have in the past, or are currently struggling with substance abuse, let it be known to someone on your rehab team or a community based professional so help can be provided in a confidential, professional manner.
BRAIN INJURY AND SPINAL CORD INJURY

At the time of spinal cord injury, it is not uncommon to also have had a brain injury. Brain injury can affect memory, your ability to concentrate and learn new material, judgment, personality, vision, swallowing, balance and coordination, and the ability to read and write, to name but a few. The severity of brain injury can be mild to severe. Your rehab team may want you to meet with a neuropsychologist to access your brain function and to make recommendations for treatment if needed.

REFERENCES AND RESOURCES

- About caregivers - http://www.caringinfo.org/
- About caregivers - http://www.thefamilycaregiver.org
- About Depression, Substance Abuse, Psychology - http://www.mageerehab.org

GLOSSARY

CAREGIVER – One who provides care and assistance to another. Caregivers may be family members, volunteers and/or hired employees.

DEPRESSION - Situational depression is a type of depression that is a fairly common response to a loss of a loved one, failure, problem, loss of a job, or some other event like injury/illness. Adjusting one’s attitude or activities is very instrumental in constructively dealing with this type of depression. A second type of depression, often referred to as a Major Mood Disorder has symptoms that include, but are not limited to, the following: too little sleep or too much sleep; change in appetite; loss of interest in happenings that were once stimulating or enjoyable; lowered sex drive; low energy; short temper; and/or no drive to do anything. Counseling or psychotherapy may be helpful with both types of depression. For the later though, antidepressant medication is often needed.

GRIEF PROCESS - Individuals following a loss typically go through a period of grief. Some elements common to successfully moving through the process are seeing the reality of the loss, experiencing the associated emotional pain, learning to deal with the world given the physiological changes and investing in life in the present.

SUBSTANCE ABUSE – Over use of alcohol or other drugs that can result in physiological and psychological addiction, are sometimes used to deal with boredom, frustration, anger, depression and other stressors.
Chapter 15: HUMAN SEXUALITY

It is just as normal after injury, as before, to have sexual thoughts, feelings and interests. A person with paraplegia or tetraplegia can and often does develop or maintain an enjoyable sexual relationship that is likewise enjoyable for the partner. What is most important to underscore is you do have permission or the right to be active sexually in accordance with age and emotional maturity. You may not be thinking about sexual activity soon after your injury, but most people do report that sexual interests do return at some point. Because of impaired sensation and/or motor control, sexual activity may happen differently but can still be enjoyable, meaningful and satisfying.

FOR FEMALES

Generally, a spinal cord injury does not prohibit a female from being sexually active, becoming pregnant or delivering a baby via natural child birthing methods. However, it is important that the attending physician understand it is possible for a woman (with an injury above T_{6}) to have autonomic dysreflexia during delivery and that the delivery itself may come very suddenly. (Autonomic dysreflexia is discussed in Chapter on Medical Concerns.) Accordingly, the physician may follow the mother-to-be more closely particularly toward the end of the pregnancy. It is advised that your physician consult with your rehab physician to fully understand spinal cord issues that could affect your pregnancy.

If you are female, you may discover that immediately following your injury your menstrual cycles appear to have stopped or become irregular. It is important to understand they will typically return within the first six months following injury. Be aware that during this six-month period and beyond, it is possible to become pregnant. Thus, if you are going to be sexually active, you might want to consider some form of birth control. Prior to starting/resuming any birth control pill, your attending physician should be consulted. Some physicians prefer that those with spinal cord injury not use birth control pills because one of the possible side effects is blood clotting in the lower extremities. Because of lack of sensation, intrauterine devices (IUD’s) are usually not recommended because warning signs of IUD complications can go unnoticed. You may be advised to use other methods of birth control.

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. Water-soluble lubricants such as KY Jelly can be purchased at a local drug store. Vaseline, or any other oil based product, are not recommended because they tend to remain in the vaginal area for a long time and can become a possible breeding ground for bacteria, thereby causing infection.

Women may not have a clitoral or vaginal orgasm as they previously did because of the spinal cord injury. However, women do report having orgasm like experiences
following stimulation of the body where sensation remains. It is through exploration that you may find such sensitive areas of your body.

**FOR MALES**

Erections occur when blood fills the penis and causes it to become hard and erect. Normally, two types of stimulation produce an erection. A psychogenic erection is an erection that originates in the brain as the male thinks sexual thoughts, hears a particular song, remembers an event, sees a film or picture or fantasizes. These thoughts/feelings then send signals from the brain down the spinal cord and stimulate the genitals causing many changes including the pooling of blood in the spongy tissue of the penis, which produces the 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.

The second type of erection is called reflexogenic. Here touching the penis or other erogenous zones (ears, nipples, and neck) can cause an erection. Many males do have reflexogenic erection unless nerves in the sacral areas (S₂—S₄) are damaged.

Males with complete spinal cord injuries typically do not have an orgasm during intercourse nor do they ejaculate and release sperm through the penis that can fertilize the egg inside the female. Some men after injury have what are called retrograde ejaculations, which means that 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. Some males with complete injuries do report orgasm-like experiences when areas of the body that still have feeling are stimulated.

For males with incomplete injuries, it is very difficult to predict specifics about sexual function. Time and sexual experiences will give the male information about whether he is able to have a psychogenic or reflexogenic erection, if he will be able to maintain an erection needed for sexual intercourse, and whether he will reach a climax and ejaculate. Sexual function may also improve over time for those with incomplete injuries.

**Erection Aids.**

If a male does not have psychogenic/reflexogenic erections or erections are weak/short-lived, there are several treatment options available. Medications such as Viagra (Sildenafil) improve the quality of erections for many. Viagra is a pill taken by mouth. Caverject (Alprostadil) is a medication injected through a syringe and needle directly into the shaft of the penis and often generates an erection suitable for intercourse. Another medication option uses a drug pellet (containing Alprostadil) which is placed directly into the opening at the end of the penis. Once inside, the pellet dissolves causing blood vessels to relax and fill with blood causing an erection.

Another aid for erections is the vacuum pump. It is a narrow tube that is open on one end and has a small pump on the other. Once the tube is placed over the penis, the pump then evacuates the air in the tube creating a vacuum. The vacuum creates pressure inside the tube, which pulls blood into the penis generating an erection. The tube is then removed and a rubber “O” ring is put around the base of the penis to prevent the blood from leaving the penis, thus the erection is preserved during sexual
activity. The most important caution about this devise is to remove the “O” ring after sexual activity. Otherwise, the “O” ring can begin to work as a tourniquet restricting blood entering or leaving the penis. If not removed the cells in the penis can die and the penis can be injured.

Some men choose to have an erection aid or prosthesis surgically implanted in the penis. These implants or rods are semi-rigid or bendable. An inflatable device is also available that is surgically implanted in the penis. This device, when filled with fluid, creates an erection; after sexual activity, the fluid is removed.

If you are a male, your rehab doctor, urologist or specialty-trained physician can help you understand erection options most appropriate for you. Some options may be covered by your medical insurance.

Male 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 spinal cord injury, disease or impairment, 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 during intercourse. Masturbation may be done by hand or using a hand held vibrator. Another method, called electroejaculation, 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.

Bowel, Bladder And Catheterization

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 but it may hurt one’s pride or be embarrassing. Most couples find that bowel and bladder issues are a challenge that needs to be discussed openly so that if an accident occurs they have a plan established. Many couples, after clean-up, 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.

Sexually Transmitted Diseases

Those with spinal cord injures can acquire sexually transmitted diseases just as anyone else. Everyone is at risk for contracting gonorrhea, syphilis, herpes and the HIV virus. Individuals are encouraged to learn about sexually transmitted diseases and how to protect one’s self. Using a condom is often recommended.
Summary

Human sexuality is a normal part of life prior to and after injury or impairment. After injury questions and uncertainties about sexual function, performance and fertility are expected. It is important for you to speak with your physician to clarify when the spine is stable and it is safe to resume sexual activity. Your doctor and others on the rehab team are able to provide you with information about sexual issues and answer your questions. How soon a person begins sexual activity following clearance from the doctor varies considerably.

Perhaps it is most appropriate to end this section with a few statements about an enjoyable sexual relationship. What is it? Many describe it as a relationship where two people communicate well their needs and preferences verbally and/or nonverbally. Sexual contact feels good, as the partners are close both physically and emotionally. For the younger aged person, sexual contact has a very strong body experience. For those older, the psychological dimensions of sexual contact tend to become increasingly more significant, i.e., “good sex” is more powerfully tied to a feeling of being accepted, valued and respected by one’s partner.

Another characteristic of a good sexual relationship is that it typically develops over time as each partner learns about his/her own sexual likes and dislikes and also learns about the partner’s likes and dislikes. This learning is healthy and helpful and comes from observation, talking and/or experience. Oftentimes, spinal cord individuals and their partners will need to go through a new period of learning about what is comfortable and enjoyable.

The acceptance of self and the reality of the bodily changes following spinal cord injury are very important components in a good sexual relationship. Acceptance may prove to be a tough challenge taking months or years. However, many have proven it possible and worthwhile doing. With this acceptance comes the freedom and courage to participate lovingly in sexual activity.

You are encouraged to discuss your questions and concerns with your physician, rehab psychologist, and/or other rehab team members and your partner.

RESOURCES
University of Alabama at Birmingham, Pregnancy - http://www.spinalcord.uab.edu/show.asp?durki=22442 -
University of Alabama at Birmingham - http://www.spinalcord.uab.edu/
“Sexuality Reborn” a video from Kessler Institute of Rehabilitation, 1-800-248-6977.- http://ww.kessler-rehab.com/
GLOSSARY

AUTONOMIC DYSREFLEXIA - An emergent, potentially dangerous condition associated with a spinal cord injury patient whose level of injury is T6 or above. This condition is usually related to a noxious stimulus that is not sensed or felt by the individual due to the neural impulses blocked in the spinal cord due to the injury. During an episode of autonomic dysreflexia, the blood pressure can become very and can cause stroke if not treated appropriately.

CLITORAL ORGASM – Sexual climax from stimulation of the clitoris.

EJACULATION – The process whereby semen and sperm are released through the urethra, the tube in the penis.

ELECTROEJACULATION – Placement of a probe in the rectum with electrical stimulation used to produce an ejaculation.

INTRAUTERINE DEVICE (IUD) – A T-shaped device with string attached that is placed in the uterus by a doctor to prevent pregnancy.

PSYCHOGENIC ERECTION - An erection that originates in brain activity as the male experiences sexual thoughts and feelings.

REFLEXOGENIC ERECTION – An erection caused by touching the penis or other erogenous zones (ears, nipples, and neck).

VAGINAL ORGASM – Sexual climax from stimulation of the vagina.

VACUUM PUMP - A pump on one end of a plastic cylinder that is placed over a penis. Pressure in the cylinder created by the pump pulls blood into the penis creating an erection.
Chapter 16: RECREATION AND WELLNESS

Frazier Rehab Institute supports the belief that recreation, leisure, sports and play activities, offer many health benefits to participants of all ages and abilities as well as their friends and families. These may include: maintaining or enhancing muscle strength and endurance; weight management; cardio-vascular health (healthy heart); improved bowel and bladder function; emotional health rather than a tendency toward depression and anxiety; helpful sleep; positive relations with friends and family; and life with purpose. Specifically, if you have a purpose for getting out of bed each day, studies indicate, you will most likely take better care of yourself. If you participate in an activity that is fun, a challenge, or, at times, competitive then it is likely that you will feel better about yourself and your self-esteem will be positive.

Learning about the variety of recreation, leisure and play activities available to persons with spinal cord injury or impairment is a major focus of the Therapeutic Recreation and Adapted Sport Programs. Accordingly, your recreation therapist will provide you the opportunity to learn techniques that will allow you to participate in some of your previous activities and sports, as well as providing you the opportunity to develop new skills and/or try new activities and sports for leisure or competition. For example, if you previously enjoyed bicycling, your recreation therapist might introduce you to hand-cycling if you have weakness in your legs or hands; if you enjoyed video or computer games, your recreation therapist might introduce you to adapted computer technologies if you have weakness in your hand(s); if you enjoyed playing basketball, your recreation therapist may introduce you to a version of the sport played using a wheelchair; if you have weakness in your legs or problems with your standing/running balance your recreation therapist will encourage you and your family to create a recreation plan according to your needs and interests. In accordance with your recreation plan, your recreation therapist may:

- Introduce you to a variety of community resources and programs in your area
- Provide information about private and public transportation options
- Help you gain experience being in public places after injury
- Teach you how to locate adaptive equipment appropriate for an activity of interest and may provide you an opportunity to try-out various pieces of adaptive equipment

THERAPEUTIC RECREATION PROGRAMS

Leisure Education and Awareness.

Frazier Rehab Institute offers individual and group discussions that provide you and your family the opportunity to learn about issues related to disability. Leisure education topics may include information about the Americans with Disabilities Act (ADA), which will help you understand the rights of citizens with disabilities. Leisure education also addresses time management skills as well as ways to manage and resolve stressful situations. You will also be provided with options for both public and private transportation and travel and the overall benefits that recreation can provide to you and
your family. Every effort will be made to help you develop a resource packet specific to your needs and interests that you can use after returning home to your community.

**Community Re-Entry.**

With the support of your Spinal Cord Medicine Team, family and/or caregivers, and while you are still an inpatient, the Community ReEntry Program can provide you the opportunity to travel to community settings such as your workplace or school, a shopping mall or store, or a ballgame or restaurant. These outings become opportunities to: test and/or improve your community mobility skills; problem-solve in familiar and unfamiliar situations; manage difficult situations you may encounter in public; and be appropriately assertive in positive ways. More specifically, if a person uses a wheelchair, it is important to know how to maneuver in crowded areas, safely get up and down curbs, open doors and use elevators. Outings can also be a good opportunity to learn how to ask for help when it is needed and how to respond to others who offer help when it is not wanted. Finally, outings can also provide you a way to learn or re-learn skills in recreation and sports such as basketball, tennis, fishing, camping, or swimming to name a few. The ultimate goal for the Community Re-entry Program is for you and your family to gain valuable experience in a variety of community situations and gain the confidence needed to return to being active in your home community.

**Recreation, Sports and Wellness.**

The Therapeutic Recreation Program at Frazier offers a wide variety of adapted sport programs on both a recreational and competitive/elite level. You may be introduced to these programs while you are an inpatient and you will certainly be encouraged to become involved in these programs after your discharge and once you are medically stable.

Many individuals with spinal cord injuries report the positive impact that participating in recreation and sport activities has had on their lives. These participants and former patients indicate they feel healthier while at the same time they feel less depressed and less socially isolated because they are choosing to actively engage in activities they enjoy. Many studies have been conducted to show that participating in recreation activities can also help to reduce “secondary medical conditions” such as heart and lung disease, urinary tract infections and skin care problems.

The Adapted Sports Program at Frazier is open to individuals with Spinal Cord Injuries and other related conditions.

Programs currently being offered include:

- Wheelchair basketball
- Wheelchair tennis
- Wheelchair rugby
- Sitting volleyball
- Adapted rowing
- Road racing
- Track and Field
Chapter 18 Resource Guide

- Handcycling
- Golf
- Wheelchair fencing

Frazier Rehab Institute, in partnership with BlazeSports America, US Paralympics and/or other community agencies and organizations provide active, year round sports training for individuals with physical disabilities throughout the State of Kentucky. Programs offered are both recreational and competitive in nature and can provide first time opportunities for many individuals who thought they could no longer participate in these activities due to their physical disability.

The direct involvement of nationally and internationally ranked Paralympic athletes with physical disabilities as coaches and mentors in the recreation and sport programs offered by Frazier Rehab Institute provides you with strong role models of individuals participating in these programs. These role models lead full, active, productive lives and also perform at the highest level of sport.

The Community Fitness and Wellness Facility.

The Community Fitness and Wellness Facility began operation in October of 2007. This new and innovative program was specifically designed and implemented to focus on the health and wellness of individuals with physical disabilities within the community. The Community Fitness and Wellness Facility is an activity-based exercise program which assists an individual in the improvement of cardiovascular/aerobic fitness, muscular strength and flexibility. Individuals can exercise on a regular basis in an accessible gym with state of the art equipment designed specifically for individuals with disabilities. Highly skilled staff provide strong leadership in creating an exercise program specific to the needs of each client. There are specialized exercise program and membership packages available to individuals and their family members.

Adaptive Equipment.

Adapted equipment is used in a variety of activities such as dressing, bathing and eating. Your recreation therapist will introduce you to adaptive equipment that is designed to help you maintain and/or learn leisure, recreation and sport related activities. Adaptive equipment is used in sports, arts and crafts, horticulture, and outdoor activities to name just a few. When appropriate, you and your family will be given the opportunity to learn about and how to use this equipment as a part of your rehabilitation program. You will also be given resource information on how to identify and locate equipment that you may want to purchase after your return home. (See Page 10.)

Community Resources and Programs.

The Therapeutic Recreation Department at Frazier has developed partnerships with many local, regional, national and international agencies and organizations that support activities for those with spinal cord injury and impairment. This section provides you and your family with a list of many such organizations as well as some suggested resources for sports, recreation and wellness information, activities and contacts. Please be aware
that this is by no means a ‘complete list’ of the resource information available to you as an individual with a spinal cord injury.

**RESOURCES**

**Ability Magazine.**

ABILITY Awareness is a non-profit organization dedicated to enhancing the quality of life for people with disabilities through housing, education, employment, media and volunteer opportunities and by publishing a monthly magazine. For more information, please contact:

1001 West 17th Street Costs Mesa, CA. 92627
949-854-8700

[www.abilitymagazine.com/](http://www.abilitymagazine.com/)

**Disabilities Resources Monthly.**

Disability Resources Inc., a non-profit organization that promotes awareness, availability and accessibility of information for independent living. It monitors and reviews publications, audio video materials, online services and other information resources. It publishes a newsletter and maintains an active website that features the DRM Guide to Disability Resources. For more information, please contact:

DRI Dept. IN
4 Glatter Lane Center Reach NY, 11720-1032
516-585-0290

[www.disabilityresources.org/](http://www.disabilityresources.org/)

**Fire Safety and Disaster Preparedness.**

Fire safety and disaster preparedness information is addressed monthly in Frazier Rehab’s Spinal Cord Medicine Education Group. Handouts on the topics provided by the American Red Cross, NSCIA, and the Christopher & Dana Reeve Foundation are discussed. For more information please contact:


**Mainstream.**

This magazine describes itself as the ‘Magazine of the Able-Disabled which is, produced by, for and about people with disabilities.’ Mainstream magazine covers news & current affairs, new products & technology, profiles of ‘movers & shakers’ in the disability world, education, employment, sexuality & relationships, housing, transportation, travel & recreation. For more information, please contact:

National Spinal Cord Injury Association (NSCIA).  
National Spinal Cord Injury Association, the membership division of United Spinal, was founded in 1948 to improve the lives of all paralyzed Americans. Our mission is to improve the quality of life of all people living with a spinal cord injury or disease. We provide active-lifestyle information, peer support and advocacy that empower individuals to achieve their highest potential in all facets of life. For more information, please contact:

75-20 Astoria Blvd. Jackson Hts, NY 11370
(718) 803-3782
www.spinalcord.org

New Mobility.  
This monthly wheelchair lifestyle magazine, subtitled “Life on Wheels,” runs the gamut of topics from accessible travel to medical research, legislative issues, relationships and sexuality. The Magazine publishes many articles on health and innovations in medical care. It also publishes an annual Consumer Guide on new equipment and has a web site that features an active message board, archives, great links and interactive forums with disability experts. For more information, please contact:

No Limits Communication Inc.
P.O. Box 220 Horsham, PA 19044
(215) 675-9133
www.newmobility.com/

Paraplegia News.
First published in 1946, PN is the magazine of the Paralyzed Veterans of America (PVA) and is intended primarily for veterans with spinal cord injuries and other related physical disabilities. Topics addressed are spinal cord research, employment, housing, health care, accessible travel and specific news for veterans. For more information, please contact:

Paraplegic News
2111 East Highland Ave. Suite 180, Phoenix AZ. 85016-4702
888-888-2201 or 602-224-0500
www.pn-magazine.com/

Peer & Family Support Program.
The Peer & Family Support Program (PFSP) is the Christopher & Dana Reeve Foundation’s national peer to peer mentoring program. The goal of PFSP is to provide critical emotional support, as well as, local and national information and resources to people living with paralysis, and their families and caregivers. PFSP matches people with certified peer mentors who are of similar age, location, gender, and level of injury or type of paralyzing condition. The program helps people discover what their possibilities
are, and how to reach for them. Frazier Rehab has certified Peer Mentors available as well. For more information please contact:

(800) 539-7309
Peer @christopherreeve.org
Or, at Frazier: Jill Farmer (502) 582-7618 or Emily Coons (502) 407-3296

Sports N’ Spokes.

SPORTS ‘N SPOKES is an international wheelchair sports and recreation activities publication. The magazine covers many diverse topics, e.g., bass fishing, tennis, golf, rugby, basketball and snow skiing. Each issue provides information on training, nutrition, people in sports, national and international competition, new products and a calendar of events. For more information, contact:

Paralyzed Veterans of America
2111 East. Highland Ave. Suite 180 Phoenix, AZ 85016-4702
(888) 888-2201 or 602-224-0500
www.sportsnspeokes.com/

Vocational Rehabilitation.

The Kentucky Office of Vocational Rehabilitation assists Kentuckians with disabilities to achieve suitable employment and independence. The office employs approximately 140 rehabilitation counselors in over 50 offices covering all 120 counties in Kentucky. For more information please contact:

(800) 372-7172 (V/TTY)
www.ovr.ky.gov

Wheelin’ Sportsman.

Outdoor magazine for hunters and anglers with disabilities with features on equipment and resources of interest to the outdoor enthusiast as well as a calendar of events, a monthly magazine and a website. For more information, please contact:

800-THE-NWTF
www.wheelinsportsmen.org/

LOCAL, STATE & REGIONAL ORGANIZATIONS

Kentucky Wheelchair Athletics Association (KWAA).

The Kentucky Wheelchair Athletics Association (KWAA) is an independent, not-for-profit organization supporting sports and recreation opportunities for individuals with physical disabilities. They offer an array of competitive and non-competitive athletic and recreational activities to meet the diverse interests and activities of its members. KWAA offers opportunities to individuals with disabilities to enhance quality of life, promote physical fitness, introduce recreational and wheelchair sports, and challenge
participants to perform at a competitive level. These activities include, but are not limited to, wheelchair basketball, fencing, rowing, tennis, rugby, track & field and wheelchair racing. The KWAA is supported by fundraising activities and community involvement. It has the support and endorsement of the leading rehabilitation and health care organizations in the state.

Friends for Michael Foundation

Michael Brent of was in a car accident on July 21, 1997 as he returned home from PGA Valhalla Golf Course in Louisville, KY. He had been caddying on an extremely hot day, unknowingly became dehydrated and blacked out while driving home. Michael had earned an academic/golf scholarship to attend college in the fall of 1997 and was working all summer to improve his game in order to compete at the collegiate level. The organization, which was originally founded to help Michael with immediate financial burdens, has turned into much more. It is now a non-profit 501(c)(3), volunteer based, organization that raises funds primarily for spinal cord injury research, grants for victims and their families, spinal cord injury prevention/ awareness education and scholarships for locally active high school graduates. It is also one of three founders of the Spinal Cord Injury Association of Kentucky. Contact: Cindy Norton in Campbellsville, Kentucky Cnort4@insightbb.net

Derby City Chapter of the National Spinal Cord Injury Association (NSCIA).

The Derby City Area Chapter of the National Spinal Cord Injury Association is a membership organization for individuals with spinal cord injuries, their families and health professionals. Founded in 1984 as a Charter Member of the National Spinal Cord Injury Association, it was incorporated as a not- for-profit organization. The Board of Directors consists of the Officers, Past President and the Board Members At Large. The group meets on the third Monday of each month at Frazier Rehab Institute, 220 Abraham Flexner Way, Louisville, Kentucky 40202. The meetings begin at 6:30PM and run until 8:00PM. All interested individuals are welcome to attend. Frazier Rehab Institute Therapeutic Recreation Department 220 Abraham Flexner Way, 11th Floor Louisville, Kentucky 40202Contact: David Allgood, President (502) 589-6620 dallgood@cal.ky

Opportunities Without Limits (OWL).

Winners On Wheels is a nationally recognized program designed specifically for youth with mobility impairments (i.e. wheelchairs, walkers, crutches, canes or leg braces). Similar to a Boy or Girl Scout program the participants receive Merit badges or “Wheels” for participation in planned activities. This program meets twice a month for themed activities and field trips within the community. Frazier Rehab Institute Therapeutic Recreation Department 220 Abraham Flexner Way, 11th Floor Louisville, Kentucky 40202Circle Leader: Michelle Bazeley (502) 451-5601 bazeleycei@bellsouth.net

Amputee Golf Charities

Contact: Sienna Newman, President (502) 829-0121 www.AmpGC.com/
COACHES/PROGRAM LEADERS - LOUISVILLE, STATE OF KENTUCKY AND THE REGION

Wheelchair Basketball
Men’s/Women’s Head Coach Jill Farmer (502) 582-7418
Juniors Head Coach- Bob Davis (502) 724-6813

Adapted Rowing
Contact: Randy Mills and Bobby Hurley (502) 419-0033

Wheelchair Fencing
US Paralympic/Head Coach- Les Stawicki (502) 540-5004

Wheelchair Tennis
David Hartsek and Meg Peavy (859) 327-4318

Handcycling and Wheelchair Racing
Jill Farmer and Paul Erway (502) 582-7618

Track and Field
Jill Farmer and Paul Erway (502) 582-7618

Golf
Amputee Golf Charities Sienna Newman and Jill Farmer (502) 321-0501

Wheelchair Rugby
Jill Farmer (502) 582-7618
**Adaptive Equipment Used for Recreational Activities**

<table>
<thead>
<tr>
<th>Equipment</th>
<th>Description</th>
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<tbody>
<tr>
<td>Action Life Glove</td>
<td>Enables the user to grip objects and form a closed fist which is helpful in various recreational activities. Action Life Glove used to grip a tennis racket.</td>
</tr>
<tr>
<td>Action Life Glove</td>
<td>Used to grip a fishing pole.</td>
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<tr>
<td>Card Holder</td>
<td></td>
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<tr>
<td>Embroidery Hoop</td>
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<tr>
<td>Image</td>
<td>Description</td>
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<tr>
<td><img src="image1.png" alt="Image" /></td>
<td><strong>Book Butler</strong> will turn pages in a book, magazine or newspaper</td>
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<tr>
<td><img src="image2.png" alt="Image" /></td>
<td><strong>Pool Cue Cuff</strong> is adjustable for secure grasp and hand placement</td>
</tr>
<tr>
<td><img src="image3.png" alt="Image" /></td>
<td><strong>Strong Arm</strong> is one of many devices used to hold a fishing pole</td>
</tr>
<tr>
<td><img src="image4.png" alt="Image" /></td>
<td><strong>Fishing Pole Holder</strong> is clamped onto a wheelchair, lawn chair or beach chair to allow for one hand operation.</td>
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<tr>
<td>Image 67x542 to 202x720</td>
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<tr>
<th>Image 67x152 to 261x541</th>
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<tr>
<th>Velcro Golf Strap is an assist when gripping and swinging the golf club</th>
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<tr>
<th>Wrist and Ankle Cuff can be hooked onto pulley weights and lateral bars for strength training exercises.</th>
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<tr>
<th>Gun Trigger Activator is a simple crank/lever which can be easily attached to the trigger of rice.</th>
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<table>
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<tr>
<th>Bowling Ball With Handle retracts once the ball has been released from the hand</th>
</tr>
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</table>

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Frazier Rehab Institute - Louisville, Kentucky
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Bowling Ball Ramp requires only a light push to roll the ball down the lane.

RESOURCES
Chapter 17: GLOSSARY

ABDOMINAL MUSCLE - Another name for the stomach muscle; essential for a productive cough.

ABDUCTION WEDGE - An attachment for the seat of the wheelchair to keep the legs in a neutral position.

ACTIVE ASSISTIVE RANGE OF MOTION - Movement of a joint through partial range of movement performed by the patient. The remaining range of movement is performed by a caregiver.

ACTIVE RANGE OF MOTION - movement of a joint through the full range of movement voluntarily performed by the patient.

ACTIVE RANGE OF MOTION EXERCISES - Exercises that a person can perform under voluntary control. See Passive Range of Motion Exercises.

ACTIVITIES OF DAILY LIVING (ADL) - Basic self-care skills including dressing, bathing, toileting, grooming & hygiene, feeding.

ADAPTED UTENSILS - Forks, spoons, and knives that are modified to assist with feeding.

ADAPTIVE EQUIPMENT - Any device that enables an individual to interact more effectively with the environment following injury.

ADDUCTION WEDGE - An attachment for the seat of the wheelchair to keep the legs in a neutral position.

ADL (ACTIVITIES OF DAILY LIVING) - Basic self-care skills including dressing, bathing, toileting, grooming & hygiene, feeding.

ADL SPLINT - Allows user to hold utensils without grasp or wrist control.

ALCOHOL ABUSE - Loosely defined as drinking to excess and/or using drink as a way to deal with boredom, frustration, anger, and depression. Some individuals feel less inhibited or less shy/more sociable after a few drinks. Alcohol can be abused and include physical dependence.

ALCOHOLIC - Alcoholic Anonymous often defines an alcoholic as a person who uses alcohol to the degree that it creates a problem in at least one area of a person’s life. Examples would include a problem with a relationship, job, finances, education, sleep, appetite, or sex, to name but a few. Alcoholics are well known for their denial of alcohol related problems. Unfortunately, those who are close to the alcoholic sometimes try to take responsibility for the alcoholic drinking less or may in subtle ways strengthen the alcoholic’s determination to drink. Professional help is often appropriate for both the alcoholic and family.

ALVEOLI - Air sacks in the lung where oxygen enters the blood and waste products leave the blood.

AMBULATE - To walk.
AMYOTROPHIC LATERAL SCLEROSIS (ALS) - A progressive neurological disease affecting motor neurons that is considered fatal.

AMERICANS WITH DISABILITIES ACT of 1990 (ADA) - Gives civil rights protection to individuals with disabilities. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services and telecommunications.

ANKLE FOOT ORTHOSIS - A brace placed into the shoe that comes up on 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.

ANTI-COAGULANTS - Medications that lower the clotting ability of the blood.

ANTI-TIPPERS - Projections placed on the back of the wheelchair to prevent the chair from tipping backward during transfers, pressure relief, and propulsion over uneven surfaces.

ARCHITECTURAL BARRIERS - Typical architectural barriers may include steps, curbs, narrow doors, inaccessible toilet and sink facilities, carpet, and many more. Overcoming these barriers and learning about accessibility is typically a major concern to a spinal cord injured individual.

ARTERIAL BLOOD GAS - Measurement of oxygen levels, carbon dioxide levels, and acid/base status of the blood.

ASSERTIVENESS - People standing up for their rights. Being assertive means expressing one’s needs, beliefs and expectations clearly and openly in a tactful, tasteful manner. It is not an excuse to be rude, angry or aggressive. Spinal cord injured persons are encouraged to learn appropriate assertive skills in order to facilitate effective and successful interactions with family, personal care attendants, employers and numerous professionals that may be in position to help provide services related to the spinal cord injury.

ASSISTIVE TECHNOLOGY - Advanced technology created to make tasks possible or easier for individuals with physical disabilities.

ATROPHY - Decrease of muscle size that happens when a muscle is not used.

AUGMENTED COUGH - A cough that is assisted by pressing down and up on upper abdominal muscles to increase the productiveness of the cough. Often helpful with persons with quadriplegia who cannot cough on their own.

AUTONOMIC DYSREFLEXIA - An emergent, potentially dangerous condition associated with a spinal cord injury patient whose level of injury is T6 or above. This condition is usually related to a noxious stimulus that is not sensed or felt by the individual due to the neural impulses blocked in the spinal cord due to the injury. During an episode of autonomic dysreflexia, the blood pressure can become very high and can cause stroke if not treated appropriately.

BED LADDER - Series of connected loops attached to end of bed to assist with bed mobility.
BED MOBILITY - Ability to roll from side to side, sit, and lie down in bed.
BEDSIDE COMMODE (BSC) - Portable commode with armrests that can be used beside the bed or over the toilet.
BLADDER - The sac that stores urine from the kidneys prior to urination.
BLADDER DISTENTION - When the bladder holds more than the usual amount of urine resulting in stretching of the bladder.
BLADDER PROGRAM - Individualized program to manage the urinary eliminator process in a predictable and controlled manner. Most people with spinal cord injury are placed on a bladder program while in rehabilitation.
BOWEL PROGRAM - Individualized program to manage stool elimination process in a predictable and controlled manner. Most people with spinal cord injury are placed on a bowel program while in rehabilitation.
BREATHING EXERCISES - Exercises designed to strengthen the muscles involved in respiration (moving air in and out of the lungs).
BRONCHI - Air passages in the lungs that lead to the small alveoli.
BRONCHIAL TREE - Passageway of respiratory system through which air moves to get to air sacs (alveoli) in lungs.
BRONCHOSCOPY - A procedure that allows a visual examination inside of the lungs.
BUTTON HOOK - Assist user fasten button with impaired finger coordination.
BUILT-UP HANDLES - Handles with larger handles to assist user with weak grasp to perform ADLs.
BUTTON HOOKS - Assist user who has poor hand control to fasten buttons.
CALORIE - A measure of the energy value of food; also refers to the heat output of the body. If too few calories are consumed from food as compared to the amount of calories "burned" by the body, weight loss will occur. Conversely, when more calories are consumed that expended, the body stores them and weight increases.
CAMBER - Slanting of the top of the rear tire in toward the wheelchair.
Carbohydrate - One of the six classes of nutrients needed by the body. It serves as the body's
CAR OR VEHICLE MODIFICATIONS - Changes made to a vehicle, usually in the form of hand controls that will allow the spinal cord injured person to drive independently. Modifications may also be made in the form of wheelchair lifts, so that a person can stay in their wheelchair and be lifted into a van.
CASTERS - The small wheels on the front of the wheelchair.
CAT SCAN - Computerized Assisted Tomography is a radiographic test that takes a series of x-rays from numerous different perspectives. A computer analysis of the information provides multiple pictorial slices of the x-rayed body part.
CATHETER - A small, flexible tube used for urinary elimination (catheterization).

CATHETERIZATION - A procedure where a tube (catheter) is placed into the urethra to remove urine from the bladder.

CAUDA EQUINA - Literally “horse’s tail”. The collection of peripheral nerves that have exited from the spinal cord, but have not exited from the bony canal. Located at the lumbar level and below, they have the appearance of a horse’s tail.

C.C. - Abbreviation for cubic centimeters - metric term for measurement of volume, usually liquid (30 cc = 1 fluid ounce; 360 cc = one 12 ounce can of soft drink).

CERVICAL - Term referring to the neck region.

CERVICAL VERTEBRAE - Bones making up the spinal column in the neck region. The upper most 7 vertebrae of the spinal cord.

CHEST STRAP - A strap that goes around the chest to keep the body upright in the wheelchair.

CHIN CONTROL - A control used to drive a power chair that is activated by chin movements.

CHRONIC PAIN - The term typically reserved for those cases where pain is interfering with daily functioning and has been present for greater than a 6-month period, and is generally unresponsive to a variety of interventions such as surgery, medications and local treatment such as heat or ice.

CILIA - Hair like structures in the bronchi that move in a wave like fashion to remove pollutants from the lungs.

CIRCLE SITTING - Sitting position in which legs are supported on bed, mat, or floor with knees bent and out to the side with bottom of feet touching each other.

CLEAN Technique - A procedure used in urinary catheterization that helps minimize contamination without using sterile supplies.

CLOTHES GUARD - A plastic or cloth attachment to the wheelchair to prevent clothes damage during movement of the wheels.

COMPLETE INJURY - An injury to the spinal cord where no neural signals are communicated past the level of injury, either from the brain to body parts below the injury or sensory signals from the lower body to the brain.

COMPLEX CARBOHYDRATES - These found components are more chemically complex and take longer to break down to yield energy for the body as compared to simple carbohydrates. Examples are whole grain cereals, carrots and dried beans. Many of these foods are high in fiber, an indigestible form of carbohydrate, and consequently, can help a bowel program.

COMPRESSION - Pressure on the spinal cord that can disrupt or stop the flow of information up and down the spinal cord.

CONDOM - Also known as prophylactic. A sleeve that can be rolled onto the penis in much the same way as a glove on the finger. Condoms are used to prevent
sexually transmitted diseases such as gonorrhea, syphilis and AIDS, and also used to prevent pregnancy, as they prevent sperm from entering the vagina. Condoms are typically made of latex rubber and, therefore, petroleum-based lubricants should never be used, as these will weaken the latex rubber and can lead to breakage or leakage. Other condoms are made from animal tissue and are effective in preventing pregnancy, but are not effective in preventing transmission of AIDS.

CONDOM CATHETER - Type of condom that is fitted over the penis. This condom serves as a collection device for urine as it has an opening at its tip where a small tube attaches allowing urine to flow into a collection bag.

CONSTIPATION - Difficulty having a bowel movement, typically related to inactivity, dehydration and/or narcotic medications. It is important to maintain regular bowel movements to prevent constipation. Routine use of stool softeners and/or suppositories can also help prevent constipation. However, the proper diet can also help to manage/prevent constipation.

CONTRACTURE - Muscle or joint that “gets stuck” in one position and cannot be moved. Happens when the muscle or joint is not used for a long period of time.

CONTUSION - A bruise on the spinal cord that can disrupt or stop the flow of information up and down the spinal cord.

CREDE' - This term is typically seen in conjunction with the word “technique” or “maneuver,” such as Crede’ technique/Crede’ maneuver, and refers to the technique of pressing on the lower abdomen just above the pubic bone to either initiate a bladder contraction, thereby emptying the bladder of urine, or to help the bladder completely empty once a bladder contraction has started.

DECUBITUS ULCER – Breakdown of the skin due to unrelieved pressure.

DEEP VEIN THROMBOSIS (DVT) - A blood clot within a vein, typically caused by pooling of blood in the vein. This can prevent blood from returning to the heart, thereby causing the extremity to swell. If a piece of this blood clot breaks loose it may return to the heart and be pumped out to the lungs, where it will block blood vessels going to the lung. If the blood clot is large enough, it can cause death.

DEHYDRATION - Excessive loss of water.

DEPRESSION - Situational depression is a type of depression that is a fairly common response to a loss of a loved one, failure, problem, loss of a job, or some other event. Usually this “downness” will pass in due order. Adjusting one’s attitude or activities is very instrumental in constructively dealing with this type of depression. A second type of depression, called bio-chemical depression, is the result of chemical changes that take place in the brain that adversely affect normal brain activity. Counseling or psychotherapy may be helpful with both types of depression. For the later though, antidepressant medication is often needed. Typical symptoms of bio-chemical depression include, but are not limited to, the following: too little sleep or too much sleep, change in appetite,
loss of interest in happenings that were once stimulating or enjoyable, lowered sex drive, low energy, short temper, and/or no drive to do anything.

**DIAPHRAGM** - Major muscle of breathing (inspiration) that is attached to the bottom of the lungs and lower ribs. Those with spinal cord injuries below C-3 typically remain in control of the diaphragm.

**DIARRHEA** - A disorder of the intestine marked by abnormal fluid or loose, and/or frequent bowel movements. Sometimes this condition is affected by an infection, medication side effects and/or by diet.

**DIETITIAN** - Is a nutritionist who has completed 1) an approved college degree in nutrition, 2) specific clinical experiences and 3) a registration examination given by the American Dietetic Association. A dietitian analyzes a person’s diet for adequacy of energy, protein and other nutrients and also makes practical suggestions for diet improvements.

**DIGITAL STIMULATION** - Rotating a finger in the rectal vault to assist with bowel elimination.

**DISC** - The cushion between each vertebrae of the spine that acts as a shock absorber.

**DISCHARGE PLANNING** - Team plan for transitioning the patient from inpatient to home. Coordinated by the Case Manager it addresses the concerns of the patient, family and treatment team to ensure a smooth and efficient program focused on patient/family needs.

**DIURETIC EFFECTS** – An increase in the secretion of urine. Some ingredients in foods such as caffeine and some medications can cause frequent urination.

**DIVERTICULOSIS** – This is the condition where diverticula, small pouches, push out from the wall of the large intestine. If a pouch becomes blocked or infected, an inflamed state of diverticulitis can occur and become problematic.

**DORSAL WRIST SPLINT (ADL SPLINT)** - Allows the wrist to be supported for better hand function. It has a cuff part that can be used to hold and ADL item such as a spoon or fork to increase the use of the hand in self-care activities.

**DRESSING STICKS** - Assist user to reach legs without bending for putting on pants.

**DROP-ARM BEDSIDE COMMODE** - Portable commode with removable armrests that can be used beside the bed or over the toilet.

**DYSPHAGIA** – A condition in which there is an inability to swallow or difficulty in swallowing. Sometimes foods and beverages modified in texture can compensate for this condition in assuring that foods are safely swallowed.

**EDEMA** - Collection of fluid in soft tissues. Typically seen in the feet, it is also referred to as swelling.

**ELASTIC SHOE LACES** - Shoelaces made out of elastic material that are laced into shoes and permanently tied to allow shoes to slip on/off.

**ELBOW EXTENSION SPLINT OR CAST** - Splint used to reduce tightness to allow normal elbow ROM.
ELECTRICAL STIMULATION (E-Stim) - The use of electrical current to cause a muscle contraction. Electrodes are placed on the skin over the muscle to be worked. It can be used to strengthen a weak muscle, maintain muscle tone of non-functioning muscle, or re-educate muscle to work. It cannot strengthen a muscle that does not have active movement.

ELECTROMYOGRAPHIC (EMG) - An electrical tool used for evaluation and treatment of muscles.

ENABLER - A person who encourages ("enables") directly or indirectly the dysfunctional behavior of another person. In spinal injury, an enabler might meet his or her own needs by indirectly encouraging dependency or helplessness from the injured person. Such dysfunctional relationships often are not recognized by either party.

ENDURANCE LEVEL - Tolerance level for activities can be measured in weight, repetitions or length of time it takes to complete an activity.

ENVIRONMENT CONTROLS - Devices which enable an individual with spinal cord impairment to control certain aspects of their environment, i.e., television, stereo, telephone, lights, doorways, etc.

ENVIRONMENTAL CONTROL SYSTEM - Advanced technology systems for home or office used to control lights, phone, doors, television, bed and other items using remote control devices.

ENVIRONMENTAL CONTROL UNITS (ECU) - Electronic system that allows user to control aspects of his/her environment.

FAMILY TEACHING DAY - Family members spend the day at Frazier with the patient learning about the specific care needs of the patient that may be required of them when the patient returns home.

FAT - One of the six nutrients needed by the body. While some fat is important to good health, excess fat can contribute to obesity and other health issues. Fatty foods include butter, margarine, oils and fats hidden in poultry skin, cheese, sausage, olives and nuts among many other sources.

FIBER - Is the portion of a food which is not digestible, which remains in the intestine and becomes a component in stool. High fiber foods promote regular bowel movements that are very important to patients with spinal cord injury. Low fiber and/or high sugar diets encourage constipation.

FINE MOTOR COORDINATION - Ability to utilize individual finger movements to complete activities.

FLACCID - Absence of tone in muscles and/or soft tissues. Synonymous with the term "limp." Can be used to describe an extremity such as the leg, a body part such as the penis or a muscle such as the bladder.

FLACCID BOWEL - The result of reflexes not working properly and the anal muscles remain relaxed.

FRAME - Main part of a wheelchair to which all other parts are attached.
FRIEDREICH’S ATAXIA - A progressive disease affecting the nervous system impacting muscles used for movement, bowel and bladder control, speech and heart function.

GAIT - The walking pattern a person uses.

GASTRIC TUBE - Feeding tube surgically implanted through the abdominal wall into the stomach.

GRAB BARS - Mounted onto wall to assist with balance and transfers

GRIEF PROCESS – Individuals following a loss typically go through a period of grief. Some elements common in the process are seeing the reality of the loss, experiencing the associated emotional pain, learning to deal with the world given the physiological changes and investing in life in the present.

GOALPOST - A control used to drive a power chair that looks similar to a football goalpost.

GRADE AIDS - An attachment mounted along with the brakes on the wheelchair that allow the wheels to roll forward, but prevent them from rolling backward when going uphill.

HALO - Type of brace used to stabilize the cervical spine (neck) and prevent any movement while healing following surgery. It is embedded into the skull with screws, and a set of rods connects to a body jacket.

HAND HELD SHOWER (HHS) - Showerhead with a hose that allows user to hold shower in his/her hand to direct the spray. A HHS with the controls on the handle is recommended.

HANDRIM - Rim on the outside of the wheels that provide a surface on which to push to move the chair.

HAND SPLINT/ORTHOTICS - Individually fabricated braces that are frequently utilized to prevent the development of contracture and deformity as well as to promote optimal hand functions.

HEAD CONTROLS - A control used to drive a power chair that is activated by head movements.

HETERO TOPIC OSSIFICATION - Growth of bone tissue in locations where it should not be found. This condition can cause joints to become stiff and limit movement.

IDEAL BODY WEIGHT - Is the healthy weight for an individual based on sex, height, frame size and activity factors. Following a spinal cord injury, a person’s ideal body weight typically is lowered due to muscle loss and decreased activity levels.

IMPAC TION - Hard, firm stool that is unable to be removed with a normal bowel movement.

INCENTIVE SPIROMETER - Device used to encourage deep breathing.
INCOMPLETE SPINAL INJURY - An injury to the spinal cord where some neural signals are communicated past the level of injury, either from the brain to body parts below the injury or sensory signals from the lower body to the brain.

INCONTINENCE - Inability to voluntarily control the bladder or bowels.

INFORMATION AND REFERRAL CENTER - Many community agencies provide information that may be beneficial to the spinal cord injured person, or, if unable to help, they may refer you to another agency or someone who can help. In the Louisville area, the Crisis & Information Center is a 24-hour telephone service that provides counseling as well as information and referral.

INTERMITTENT CATHETERIZATION (IC) - A procedure used to empty the bladder of urine using a catheter at scheduled times.

LAMINECTOMY - A surgery to one or more of the vertebra of the spine. The surgery actually removes a portion of the bone that makes up the spinal canal through which the spinal cord passes. The purpose of this surgery is to prevent pressure on the spinal cord in case the spinal cord is swollen and might press against this bone.

LAP TRAY - Wooded or plastic tray attached to wheelchair to provide support for arms.

LARYNX - Voice Box.

LATERAL SUPPORTS - Supports placed on the side of the chair to keep the trunk upright while sitting in the wheelchair.

LEG STRAPS - Attach to users legs at thigh, knee, and ankle to assist with moving legs during activity.

LESION - A general term meaning damage or an abnormality to some part of the body. A person can have a spinal cord lesion, skin lesion, bone lesion, etc.

LEVEL OF INJURY - Refers to the lowest level where the spinal cord is functioning normally.

LOANER WHEELCHAIR - A wheelchair that is loaned to a patient from the equipment vendor until the custom wheelchair can be ordered and delivered.

LONG-HANDLED COMB/BRUSH – Comb or brush placed at the end of flexible, extended handle to allow user to reach hair.

LONG-HANDLED SHOE HORNS - Extra-long shoehorn to allow user to keep heel of shoe up without bending over while putting on shoes.

LONG-HANDLED SPONGE (LHS) - Bath sponge placed at the end of an extended handle to allow user to reach legs and feet without bending.

LONG OPPONENS SPLINT - Splint with a component to position the thumb in order to improve grasp and release during self-care activities.

LONG SITTING - Sitting with the legs positioned straight out in front.

LONG STRAW - Extended, reusable straw to allow user independently drink from a cup.
LOWER EXTREMITIES - The hips, legs and feet.
LOWER MOTOR NEURON INJURY - A lower motor neuron injury occurs below the L1-2.
LUMBAR - Refers to the low back region that includes five vertebrae between the thoracic and sacral regions.
MAGNETIC RESONANCE IMAGING (MRI) - A radiology imaging study using a very large magnet in the shape of a doughnut that allows improved precision of images compared with traditional x-rays.
MANUAL DISIMPACITION - Using a finger to manually remove stool from the rectum.
MANUAL RESUSCITATOR - Device which allows increased amount of air or oxygen to be given to lungs.
MANUAL WHEELCHAIR - A wheelchair that requires the user to push the wheels for movement.
MEDICAID - Is a federal and state funded medical assistance program that pays for approved and needed medical care for persons who meet specific requirements. If a person could be included in one or more of ten different categories they may be able to receive Medicaid benefits. The spinal cord injured person would be included in the disabled category. To receive Medicaid benefits a person must also meet other requirements including residency, citizenship, income and resource criteria.
MEDICARE - Is a federal program that pays for approved and needed medical care for persons who are eligible. It is divided into two parts. Part A is Hospital insurance that protects you against the costs of hospitalization, certain related inpatient, skilled nursing facility care, and home health services. Part B deals primarily with doctors’ fees, most outpatient hospital services, and certain other related services. Medicare may be available to the spinal cord injured patient if they are age 65 or older or after they have been receiving Social Security disability benefits for 2 years.
METABOLISM - Refers to energy and material changes that occur in the body. It reflects chemical changes that take place with physical growth, body temperature maintenance, energy required for your heart to beat and for breathing to take place, food to digest and many other processes to carry on. Simply stated, your metabolic rate reveals how quickly your body uses energy. With decreased physical activity, your metabolic rate is likely to decrease. A “low metabolism” infers that the diet should be managed to prevent overloading of calorie/food intake.
MOBILE ARM SUPPORTS - Mounted arm supports that assist user with feeding and other ADL’s.
MOTOR NERVES - Nerves that carry information from the brain to muscles for muscles to contract, create movement.
MOUTHSTICK - Allows person with limited arm function to use mouth to access switches.

MP BLOCK SPLINT - Splint that supports the joints of the fingers to prevent clawing of the hand and promote normal grasp and release movement during functional tasks.

MUCUS - Viscous fluid secreted by the mucous membranes and glands.

NASOGASTRIC TUBE - Feeding tube from nose to the stomach.

NON-SKID BOWL - Dish with non-skid material on bottom to provide stability during feeding.

OBESITY - Refers to an overweight condition that is in an unhealthy range and which increases your risk for developing chronic disease. It is the result of an imbalance in the amount of calories taken in and the amount of energy expended. Nearly half of all people in the US are overweight.

OCCUPATIONAL THERAPIST - Therapist who specializes in daily living skills; develops pre-vocational and leisure skills. Designs, fabricates, or applies selected orthotic and prosthetic devices or selected adaptive equipment; Uses specifically designed exercise and activities to enhance upper extremity functional performance.

ORTHOSIS - A bracing or splinting device that is placed on a body part for positioning, protection, alignment, support or comfort. Examples include wrist splints, tenodesis splints, oyster shell braces, leg braces, etc.

ORTHOSTATIC HYPOTENSION - A condition where the blood pressure suddenly drops when going from a lying to an upright position.

OSTEOPOROSIS - The condition of porous bones; the loss of bone density and mineral content which occurs when new bone is not created as quickly as old bone is broken down - It can lead to bone brittleness and the risk of increased fractures.

OVERHEAD SUSPENSION SLING - Sling that can be used to support weak muscles against the force of gravity, while allowing the individual to use the hand for functional tasks such as feeding and computer tasks. Moveable rods can allow the individual to adjust the height for different tasks.

PARAPARESIS - Weakness or partial paralysis of both legs.

PARALYSIS - Inability to control movement in one or more parts of the body.

PARAPLEGIA - Loss of motor and/or sensory function in the trunk, abdomen and legs caused by injury to the thoracic or lumbar (trunk or low back).

PARAPLEGIC - Paralysis that includes weakness or paralysis both legs.

PASSIVE RANGE OF MOTION - Movement of a joint through the full range of movement performed by a caregiver.
PASSIVE RANGE OF MOTION EXERCISES - Exercises employed by an individual to move limbs and joints that may be paralyzed. The individual may need someone to provide assistance with these exercises.

PASSY MUIR SPEAKING VALVE - Placed on the end of a tracheostomy tube that allows a person to speak and be heard.

PERISTALSIS - Wave like muscle contractions that helps move food through the digestive tract.

PHLEGAM - Thick mucus.

PHYSIATRIST - A physician who specializes in physical and rehabilitative medicine.

PHYSICAL THERAPIST - Therapist who works to increase overall strength, endurance, and mobility most frequently in the lower extremities. Physical therapists focus on learning techniques to increase bed mobility, transfers, fit patients with an appropriate wheelchair, wheelchair mobility and provide assistance with walking if appropriate.

PLATE GUARD - Attaches to rim of plate to allow user to scoop items onto fork/spoon.

PNEUMONIA - Infection in the lungs.

POSTURAL DRAINING - To help drain the lungs, the patient is placed in a posture (head below feet while lying in bed).

POWER ASSIST WHEELCHAIR - A mixture between a manual and power wheelchair. It has the frame of a manual chair, but has power driven wheels to assist with propulsion.

PRESSURE RELIEF - The act of taking weight off a part of the body that has had pressure on it for a long period of time.

PRESSURE SORE - A breakdown in the skin that starts as a red spot on the skin and can grow into a hole in the body that can extend down to the bone if not properly cared for.

PRESSURE ULCER - (see pressure sore)

PRONE - Position lying on the stomach.

PROTEIN - One of the six classes of nutrients needed by the body, specifically for the growth and repair of tissue. Some high protein foods include egg white, milk products, meat, nuts and dried beans/legumes.

PUSH HANDLES - Handles on the back of the wheelchair used by a caregiver to push the chair.

QUAD COUGHING - A cough that is assisted by pressing down and up on upper abdominal muscles to increase the productiveness of the cough. Often helpful with persons with quadriplegia or tetraplegia who cannot cough on their own.

QUADRIPARISIS - Weakness or partial paralysis of both arms and legs.

QUADRIPLEGIC - Paralysis (i.e. inability to move) that affects both arms and legs.
RAISED TOILET SEAT (RTS) - Attaches to existing toilet to increase the height for easier transfers.

RANGE OF MOTION - Amount of movement possible at joint when limb is moved.

RANGE OF MOTION EXERCISES - Movements of a joint or body part through the available amount of motion.

REACHERS - Allows user to retrieve items out of reach.

RECREATIONAL THERAPIST - A professional who focuses on helping patients develop continued satisfaction in activities of recreation and leisure.

RECTUM - Area between the end of the colon and the anus.

REFLEXIC BOWEL - When the bowel becomes full, it triggers a reflex that automatically empties the bowel.

RENTAL WHEELCHAIR - A wheelchair that is rented by a patient or insurance company to use for a short period of time.

RESPIRATOR - Breathing machine.

RESTING HAND SPLINT (RHS) - Splint that keeps the hand in a position that supports the wrist and hand to reduce the risk of joints getting stuck in one position.

SCOOP DISH - Dish with one side sloped upward to allow user to scoop items onto fork/spoon.

SACRUM - Refers to the area involving the lowest 5 vertebrae below the lumbar area in the buttock/tailbone region.

SCAR TISSUE - Results from the human body’s attempt to heal itself, most commonly seen as scar tissue on the skin which, for the most part, can serve its purpose of protecting the body, but scar tissue is never as good as the previously normal tissue. After a spinal cord injury, the body attempts to heal itself; typically, this results in the formation of scar tissue in the spinal cord at the level of injury. Scar tissue in the nerve tissue in the spinal cord slows or stops signals to and from the brain.

SELF RANGE OF MOTION - Movement of a joint or body part through the full range of movement performed by the patient. Can be active, active assistive, or passive (See definitions). Often requires the use of fully functioning body parts to move impaired body parts.

SENSATION - The body’s ability to perceive external stimuli such as odors, taste and vision. In spinal cord injury, is most commonly used to describe the skin’s ability to perceive stimulus such as pain, heat, touch, vibration and position in space.

SHORT OPPONENS SPLINT - Splint that allows tenodesis use of the hand in individuals with the ability to use their wrists.

SHOULDER SUPPORT SLINGS - Sling used to support a weak or painful shoulder and arm, especially in individuals who are working in a standing position in which the arm would dangle without a sling’s support.
SHOWER CHAIR (WITH TILT/RECLINE FEATURE) - Rolling chair with tall back that will recline to assist with balance/safety in a roll-in shower

SIMPLE CARBOHYDRATE - One of the two subgroups of carbohydrate, which, due to their simple chemical structure are quick to be absorbed/used by the body. Examples include table sugar, corn syrup, honey, and fruit sugar. Often times “simple carbs” offer empty calories, meaning low vitamin/mineral value and should be minimized in a diet plan.

SIP AND PUFF CONTROL - A control used to drive a power chair that is activated by a series of sips or puffs on a straw.

SKIN INSPECTION - Looking at the skin for areas of redness or skin breakdown, especially over bony areas of the body.

SKIN INSPECTION MIRROR - Dual sided mirror attached to extended, flexible handle to assist with inspecting skin for pressure sores.

SOCIAL SECURITY – This typically applies to the money paid to a person after they retire. The amount a person receives each month is primarily based on the persons’ work history. A person with a spinal cord injury may also be able to receive social security after being declared disabled, and does not have to be 65 years of age or older. In this case, the money received each month is referred to as Social Security Disability Insurance. If the spinal cord injured person has minor children they may also be eligible for social security benefits.

SOCIAL WORKER – A medical social worker assesses, refers, and links patients and their families with necessary resources in regard to their discharge plan. Discharge planning includes, but is not limited to durable medical equipment orders, acute care placements, home health and/or outpatient service set-up, resource referral, and communication with insurance companies.

SOCK AIDS - Allows user to put sock on without bending.

SPASM - An involuntary contraction of a muscle.

SPASTICITY - A state of increased muscle tone and excessive response that often occurs when a muscle is stretched. It can cause an arm or leg to feel tight and be difficult to move.

SPHINCTER - Round, donut shaped muscle that constricts an opening. For example, the sphincter when closed, keeps stool in the rectum; when the sphincter is relaxed, stool can be passed.

SPINAL CORD IMPAIRMENT - Any damage to the spinal cord that results in loss of sensation or muscle control.

SPOKE GUARDS - Plastic covering placed over a wheel to protect the spokes from damage.

STANDING FRAME – A device that holds a person in a standing position.

STOOL SOFTENERS - Medications that are used to keep the stool soft as it moves through the digestive tract making elimination easier.
SUCTION - Use of external vacuum to remove secretions from trachea and lungs.

SUPPLEMENTAL SECURITY INCOME - Pays monthly checks to people who are aged, disabled or blind and who have limited income. People who qualify for SSI usually are eligible for food stamps and a Medical Assistance card which helps pay doctor and hospital bills.

SWIVEL UTENSILS - Utensils attached to moving handle to assist user with getting food into mouth

TED HOSE - Tight fitted stocking that is used to prevent pooling of blood and other body fluids in the lower extremities. TED hose assist in venous blood return to the heart.

TENODESIS - The ability to pinch or grasp objects with the thumb and index finger through the use of a specific wrist movement.

TENODESIS SPLINT - Allows proper positioning of the fingers and thumb when the wrist is bent back to allow one to grasp and release objects.

TETRAPLEGIA - (formally quadriplegia) Loss of motor and/or sensory function in the arms, trunk, and legs caused by injury or disease to the cervical (neck) segments of the spinal cord.

THORACIC - The region involving 12 vertebrae in the spine that runs from the shoulder to the lower ribs. It is below the cervical region and above the lumbar region.

THRESHOLD INSPIRATORY MUSCLE TRAINER

TILT IN SPACE WHEELCHAIR - A wheelchair that tilts backward while keeping the user in a seated position.

TOILET AID - Toilet tissue aid designed to assist user in cleaning perineal area when reaching is difficult.

TRACHEA - Wind pipe carrying air to and from the lungs.

TRACHEOSTOMY - Opening in the throat, through trachea which allows a tube to be inserted.

TRANSFER - Technique used to move from one surface to another.

TRANSFER BOARD - Plastic or wooden board used to bridge the gap between two surfaces.

TRICEPS - Group of muscles located on the back of the upper arm that act to straighten out the elbow.

TUB CHAIR/TUB BENCH WITH A BACK - Placed into tub or shower to provide surface for bathing.

TUB/SHELTER CHAIR - Fits into tub or shower to provide surface for bathing. A shower chair with a back and seatbelt is recommended for increased stability and balance.
TUB TRANSFER BENCH - Base of bench extends outside tub to make transfers easier. A tub transfer bench with back and seatbelt is recommended for increased balance and stability.

UNIVERSAL-CUFFS (U-Cuff) – Splint that allows user to hold ADL items without grasp

UPPER MOTOR NEURON INJURY - An upper motor neuron injury occurs above the L1-2 level.

URINARY TRACT INFECTION (UTI) - A bacterial or fungal infection occurring in the kidneys, ureters or urinary bladder.

VENTILATION - Movement of air in and out of lungs.

VENTILATOR - Machine used to move air in and out of the lungs for individuals unable to adequately control respiratory muscles.

VENTILATOR TRAY - An attachment used to transport a ventilator on the wheelchair.

VERTEBRA - A single bone in the spinal column.

VERTEBRAE - Plural form of vertebra.

VITAL CAPACITY - Maximum amount of air a person can breathe in and breath out

VOCATIONAL REHABILITATION - A state funded agency that assists individuals with disabilities return to employment through the provision of continued education, job training, additional therapy and assistive technologies.

WASH MITT - Large mitt that can be used by a person with limited hand function to bathe.

WORKER’S COMPENSATION - Programs funded by employers, insurance companies and government to pay employees for some part of the cost incurred if they were injured on the job. Depending on the policy, the compensation may involve a monthly benefit as well as coverage for medical care, equipment and other support services.

WRIST COCK UP SPLINT - Splint that supports the wrist in a bent back position for better hand use.
Chapter 18: Resource Guide
SPINAL CORD MEDICINE HANDBOOK FOR PATIENT & FAMILY

Community Resource Guide

Frazier Rehab Institute
KentuckyOne Health™

Frazier Rehab and Neuroscience Center
220 Abraham Flexner Way
Louisville, Kentucky
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(866) 540-7719 (Toll Free)
(502) 582-7415
www.spinalcordmedicine.com
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### LISTING OF RESOURCES

#### Assistive Technology

Assistive technology (AT) is about using technology to find new ways to do things. It includes equipment and adaptations that enable a person with a spinal cord injury or other disability to compensate for physical limitations, learning disabilities or visual problems. AT might include: a wheelchair with specialty controls or a customized drive method, ramps, driving adaptations, computer adaptations like an alternative keyboard or speech recognition software for hands free computer operation. Today, so many common activities like banking, shopping, video chats and healthcare research can be performed with a computer and the Internet. The ability to use a computer opens the door to education, employment and important sources of volunteerism and community interaction. Thus, learning to use the computer may be an important new life skill for a person with a spinal cord injury.

Frazier has an Assistive Technology Resource Center (ATRC) on the 11th floor next to the outpatient Spinal Cord Medicine rehab gym. It provides evaluation and training in the use of: Wheelchair Seating and Mobility, Adapted Computer Access, Electronic Aids to Daily Living, Alternative and Augmentative Communication, and home
and workplace modifications. A referral from a physician is needed for evaluation funded by health insurance. A referral can also be made by a vocational rehabilitation counselor and/or a worker’s compensation case manager. Dr. Mary Ellen Buning is the director of Frazier’s ATRC. To schedule an evaluation appointment call 502 582-7660.

The Kentucky Assistive Technology Network (KATS) is a statewide AT resource. The services it provides include:

- Loan of assistive devices
- Assessments and evaluations
- Consultations on appropriate technologies
- Low interest loans for purchasing AT
- Funding information and referrals

KATS – Center in Louisville  
www.katsnet.org  502 429-4484  502 429-7114  800 327-5287

enTECH or Enabling Technologies, is also part of the KATS network and is located within Spalding University’s Occupational Therapy Department. The center provides consultations, demonstrations, training and information about how microcomputer technology can assist people with disabilities.

Joy Vessels at jvessels@spalding.edu  502 585-9911 or  800 896-8941

All states have federally funded assistive technology programs. Regional programs include:

- The Indiana Assistive Technology Project  www.patinsproject.com/
- Assistive Technology of Ohio  http://www.atohio.org/

Some additional AT resources for Spinal Cord Injury include:

- Microsoft  www.microsoft.com/enable
- Ctr for AT & Environmental Access  www.catea.gatech.edu
- Jim Lubin  www.makoa.org/jlubin/closeup.htm
- WheelchairNet  www.wheelchairnet.org
- Wheelchair Junkie  www.wheelchairjunkie.com

**Assistive Technology Products**

Each site has a database for assistive technology products and their manufacturers.

- AbleData  www.abledata.com  800 227-0216
- EnableMart  www.enablemart.com  888 640-1999
- Broadend Horizons
- AbleNet
Caregivers

Persons with spinal cord injuries may require 24 hour supervision or assistance from a caregiver initially at discharge or indefinitely. Most medical insurance policies do not provide such coverage though some do. There are agencies that can be hired to provide caregiver services for specified rates. Some families will hire caregivers privately. If you are interested in caregiver assistance, please discuss this with your Frazier case manager.

The Personal Care Attendant Program coordinated by the Center for Accessible Living may provide some assistance in paying for caregivers though the waiting list is usually long.

The Center for Accessible Living and other organizations continue to advocate for additional federal funding for the personal care attendant program. You can help by contacting your state and federal representatives to voice your concern for the need for adequate funding.

Children - Services for

Early Intervention Services

Early Intervention Services provide: evaluation and development of individual family service plans; nursing and nutrition assessments; physical and occupational therapy; communication development; assistive technology; skill development services; vision and audiology services; respite; and transportation to children age birth to 3 years.

Kentuckiana District, First Steps
3717 Taylorsville Rd.
Louisville, KY 40220
502 459-0225

Southern Indiana, First Steps
2520 Shrader Avenue
New Albany, IN 47150
812 945-2353

Education and School Re-Entry

Legislation, such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, provides all children the right to a free and appropriate education. The law says that children with disabilities must be provided the same opportunity to learn as children without disabilities. State Departments of Education provide many services including: home/hospital tutoring and the development of an individualized education plan for school entry and re-entry for children with special needs.

Kentucky Department of Education
502 564-2000

Capital Plaza Tower
500 Mero Street
Frankfort, KY 40601

www.kde.state.ky.us
Division of Preschool Programs in Jefferson Co, KY 502 564-7056
Jump Start (Ages 3-4) - Jefferson County only
Head Start (Ages 4-5)

Indiana Department of Education www.doe.state.in.us 317 232-6610
Room 229 State House
Indianapolis, IN 46204

Health Care Assistance for Children
The following agencies may assist in funding for services, testing or equipment not covered by health insurance. Families will need to meet specified income criteria. Also see Medical Assistance in section below.

Kentucky Commission for Children with Special Health Care Needs 502 595-4459
1405 E. Burnett
Louisville, KY 40217

Indiana Children's Special Health Care Services 812 794-3227
(Floyd Co.)
824 University Woods, Suite 9
New Albany, IN 47150

Education
Adult Education
Lifelong Learning www.adulted4u.com 502 922-9436
546 S 1st Street

Aherns Learning Center www.jcpsky.net/ 502 485-8636
546 S 1st St

Canaan Community Dev. Ctr. www.ccdcky.org/ 502 776-6369
2840 Hikes Lane

KCAC www.kentuckianacollegeaccess.org/ 502 584-0475

120 Robbins Hall

Jefferson Co Technical College
http://www.jefferson.kctcs.edu/Current_Students/ARC.aspx 502 213-2449

Other Helpful Websites
The international Center for Disability Resources on the Internet
www.icdri.org/financial%20aid/finaid.htm

College grants and scholarships for students with disabilities
www.collegescholarships.org/grants/disabilities.htm

www.disabiility.gov/education

Employment

Vocational Rehabilitation

State and Regional Offices of Vocational Rehabilitation provide: assessment and testing for determining eligibility and vocational interests; counseling and guidance; physical and mental restorative services; vocational training, placement, and job coaching; transportation (driver’s evaluation/vehicle modification); and telecommunications tools and other rehabilitation technological aids and devices.

You can call your local or state office of Vocational Rehabilitation to get information and/or to apply for services. If you are determined eligible, the counselor will work with you to determine which programs/services are appropriate to help you meet your vocational goals. Vocational Rehabilitation counselors will sometimes meet with patients, arranged through your case manager, while at Frazier.

Kentucky Office for Vocational Rehabilitation
502 564-4440
209 St. Clair St.
Frankfort, KY 40601
www.ovr.ky.gov/index.htm

Louisville Area Vocational Rehabilitation Office
502 595-4173
Jefferson County (KY)
600 West Cedar St
Louisville, KY 40202

Indiana Family & Social Services Administration
800 545-7763, ext. 1319
Department of Vocational Rehabilitation
402 West Washington
PO Box 7083
Indianapolis, IN 46207
www.in.gov/fssa/ddrs/4938.htm

Dept. of Vocational Rehab
812 288-8261
Clark, Harrison, Floyd Counties & Scott Counties (IN)
1452 Vaxter Avenue
P.O. Box 2517
Clarksville, IN 47131-2517
Return to work for Agricultural Occupations

Kentucky AgrAbility provides education and technical assistance to agricultural operators and farm family members who face the challenges of a disability.

Kentucky AgrAbility 606 257-1846
304 Garrigus Building 800 333-2814

University of Kentucky
Lexington, KY 40546-0215
www.ces.ca.uky.edu/agrability/

Indiana AgrAbility, Breaking New Ground Voice/TT: (800) 825-4264
ABE Building Voice/TT: (765) 494-5088
225 S. University St.
West Lafayette, IN 47907
www.cobweb.ecn.purdue.edu/~agenhtml/ABE/Exension/BNG/Resource%20Center/resourcecenter.html

AgrAbility in other states: www.agrabilityproject.org/stateprojects.cfm

Helpful Websites

Career Opportunities www.cosdonline.org
Search engine specific for job searches specific for people with a disability.

CREW Center www.crew.cc.careerlinks.aspx
Connecting Resources Education and Workforce – individual career counseling, assessment, resume writing, job correspondence, co-op and internship opportunities and tutorials on Word, Excel and other software.

Search Engine www.disaboomjobs.com
Specific for people with a disability.

Suits www.dressforsuccess.org/affiliate.aspx?sisid=39&pageid=1
Provides professional attire, career development tools, and network of support for women with and without a disability.

Center for Accessible Living www.calky.org
Provides professional interview attire for men with and without a disability.

Career connections www.gettinghired.com
Online community for people with a disability to gather, network, and find success in the workplace with employers.

Job Accommodation Network (JAN) http://askjan.org/
Information, consulting, referral, and assistance with self-employment and small business development options for people with a disability.

OWL: Opportunity for Work and Learning [www.owlinc.net/]
A community rehabilitation program providing vocational services.

Medicaid Works [http://chfs.ky.gov/dms/medicaid+works.htm]
Insurance for people with a disability who work.

Work Incentives [www.nls.org/wkboklet.htm]
Removes barriers for people with a disability who want to return to work, but are concerned about losing their health coverage.

NBDC [www.nbdc.com/index.aspx]
National Business and Disability Council – Resume database, job postings, accessibility services for people with a disability.

Career Decider [www.typefocus.com]
Helps pinpoint your personality type and choose a career that fits with you as a person.

Ticket to Work [www.yourtickettowork.com/program_info]
Removes barriers for people with a disability who want to return to work, but are concerned about losing their health coverage.

PASS [www.passplan.org/learn/default.htm]
A Plan for Achieving Self-Support - Allows individuals to exclude income and resources that would otherwise affect SSI eligibility or payment amounts, when the money is used to meet a vocational goal.

Kentuckiana Works One Stop Career Center
600 West Cedar Street 6th & Cedar
Louisville KY 40202
Education, training, job searching, resume writing, etc for people with or without a disability.

Emergency Assistance & Preparedness
Conference Affairs Office, Society of St. Vincent 502 587-1977
1015C S Preston St [www.svdplou.org]
Provides referrals for financial assistance, some emergency assistance (change of clothes, bus tickets, diapers, etc.)

Salvation Army 502 625-1170
[www.salvationarmylouisville.org/]

Childcare
Community Co-coordinated Child Care (4C’s) 502 595-4323
Clothing
Clothe-A-Child Consortium 502 772-1225
2124 W Muhammad Ali Blvd.

Infant Resource Center 502 584-2343
417 E Broadway
Call for an appointment. Need ID and proof of guardianship.

Walnut Street Baptist Church 502 589-3454
1111 S. 3rd St

Groceries
Dare to Care Food Bank 502 966-3821

Meals
Wayside Christian Mission 502 584-3711
822 E Market Street
(6:45a-8:30a, 11a-12:30p, 4p-5:45p)

Louisville Commodity Supplemental Food 502 595-3031
1616 Rowan St
Provides monthly supplemental food packages for pregnant women, infants, children up to age 6, and anyone over 60 who meets income guidelines and are not participating in WIC.

Emergency Assistance and Preparedness
The following websites provide information on how to prepare for an emergency if you are disabled.

- www.disability.gov/emergency_preparedness
- www.dhs.gov/disabilitypreparedness
- www.inclusivepreparedness.org
- www.osha.gov/SLTC/emergencypreparedness/index.html
- www.dol.gov/odep/programs/emergency.htm
- www.dotcr.ost.dot.gov/asp/emergencyprep.asp
- www.cdihp.org/products.html
- www.jik.com/disaster.html
- www.disability911.com
- www.nod.org
- www.amputee-coalition.org/inmotion/jan_feb_08/pocket_survival_guide.html
- www.diversitypreparedness.org

Utilities
Home Energy Assistance 502 574-1157
1200 S 3rd ST
www.loukymetro.org/dePARTMENT/cap
Provides financial assistance, heating, blankets, and fuel.

LIHEAP 800 456-3452
http://chfs.ky.gov/dcbs/dfs/liheap.htm
Low Income Home Energy Assistance Program

Summer Heat Relief Program 502 574-1157
810 Barret Ave Rm. 127
Tues/Thurs 1-4p

**Equal Opportunity Agencies**
The Rehabilitation Act of 1973 and the Americans with Disability Acts (ADA) of 1990 and 1995 prohibit discrimination on the basis of disability. The ADA addresses equal opportunity for:

- Title I Employment
- Title II Public Services
- Title III Public Accommodations
- Title IV Telecommunications
- Title V Miscellaneous

*To learn more about the ADA contact:*
Southeast Disability and Business Voice/TDD 800 949-4232
Technical Assistance Center
490 10th St.
Atlanta, GA 30318
www.sedbtac.org

West Virginia University Voice/TDD 800 526-7234
P.O. Box 6080 800 232-8675
Morgantown, WV 26506-6080
Helps provide ideas for problems with accessibility

The President's Committee on Employment of People with Disabilities Voice 202 376-6200
1331 F. Street, NW, Suite 300
Washington DC 20004-1107
Promotes employment of persons with disabilities

National Easter Seal Society 312 726-6200
230 W. Monroe, 18th Floor
Chicago, IL 60606
Promotes independence for persons with disabilities

Architectural and Transportation Barriers Compliance Board Voice/TDD 800 872-2253
1331 F. Street, NW, Suite 1000
Financial Assistance

The Social Security Administration (SSA) manages the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. Both programs provide benefits to individuals/families based on disability or blindness.

Comparison of the SSDI and SSI Disability Programs

The SSDI and SSI programs share many concepts and terms, however, there are also many, very important differences in the rules affecting eligibility and benefit payments. If you are judged disabled, SSDI payment is based on your tax contributions during the years you worked. SSI does not require any tax contributions. To be eligible for SSI, you must be judged disabled and meet the household income requirement. Individuals may apply or be eligible for benefits under both programs. The following table summarizes other differences between the SSDI and SSI programs.

<table>
<thead>
<tr>
<th>SSDI</th>
<th>SSI</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Source of Payments</strong></td>
<td>Disability Trust Fund</td>
</tr>
<tr>
<td><strong>Minimum Initial Qualification Requirements</strong></td>
<td>Must meet SSA’s disability criteria, Must be “insured” due to contributions made to FICA based on your own payroll earnings, or those of your spouse or your parents</td>
</tr>
<tr>
<td><strong>Health Insurance coverage provided</strong></td>
<td>Medicare after 2 year waiting period</td>
</tr>
<tr>
<td><strong>How do they figure your monthly payment amount?</strong></td>
<td>Your SSDI monthly payment amount is based on the worker's lifetime average earnings covered by Social Security. They may reduce the amount of payments if you receive Workers’ Compensation (including Black Lung payments) and/or public disability benefits, e.g., certain State and civil service disability benefits. Other income or resources do not affect the payment amount. The monthly payment amount is adjusted each year to account for cost-of-living changes.</td>
</tr>
</tbody>
</table>
The SSA will consider all applicants for disability. You will be granted disability payments when SSA has determined that you will be disabled (unable to work) for greater than one year. The application process can take several months for the initial decision. Some applicants are deferred and progress is reviewed after a period of time before a decision is made. Many applicants are denied, though there is an appeal process, which is explained in the denial letter. The appeal process can take 1-2 years. Many people have found that legal assistance can speed up this process. If you are declared disabled, you will be awarded disability based on the amount of money you contributed to the Social Security tax system from your work history.

You can use the toll free numbers below to schedule a phone interview to start your application process or visit your local Social Security office to request an application. Please be sure that all of the requested information is submitted with the applications and that you follow the deadlines.

Social Security Administration
www.ssa.gov 800 772-1213
TTY 800 325-0778

Local Social Security Administration Main Office 502 582-6690
601 West Broadway
Louisville, KY 40202

IN Social Security Administration Federal Building 812 948-5288
121 West Spring Street
New Albany, IN 47150

Numbers which may be helpful to complete disability application:

Medical Records
Baptist Hospital East 502 897-8167
Clark Memorial Hospital 812 283-2275
Frazier (Jewish Hospital) 502 587-4416
Kindred Hospital 502 627-1165
Kosair Children’s Hospital 502 629-8700
Norton’s Hospital Audubon 502 636-7333
Norton’s Hospital Downtown 502-629-8700
Norton’s Hospital Suburban 502 893-1018
St. Mary’s and Elizabeth 502 361-6623
Southern Indiana Rehab Hospital 812 941-6131
University of Louisville Hospital 502 562-3372

Legal Documents (Birth, Death, Marriage & Divorce)
KY Bureau of Vital Statistics 502 564-4212
IN Bureau of Vital Statistics 317 233-2700
National Record Network 800 255-2414
Legal Assistance
Lawyer Referral Service 502 583-1801
Legal Aid Society 502 584-1254

State Assistance Programs

The Cabinet for Health and Family Services (CHFS) is home to most of the state’s human services and health care programs, including Medicaid, the Department for Public Health, and the Department for Community Based Services (DCBS). DCBS has programs for seniors, adults, children, and families. Services are administered through a network of nine service regions and offices in each of Kentucky’s 120 counties. The department provides family support, child care, child/adult protection, eligibility determinations for Medicaid and food stamps, energy assistance to low-income households, and administration of an energy cost assistance program. To find an office in your county, visit the website or call the number below.

Division of Family and Children 812 948-5480
Floyd County
842 University Woods, Suite 9
New Albany, IN 47150

Department of Social Insurance 502 595-4238
Jefferson County
908 West Broadway
Louisville, KY 40203

Cabinet for Health and Family Services www.chfs.ky.gov 502 595-4238
Jefferson County, KY
908 West Broadway
Louisville, KY 40203

Family and Social Service Administration (FSSA) 800 403-0864
www.in.gov/fssa
Floyd County Division of Family Resources
800 East 8th Street
New Albany, IN 47150

Agencies provide most of the following services: Aid to Families with Dependent Children (AFDC), food stamps, Temporary Assistance to Needy Families (TANF), cash assistance, and Medicaid.

Community resources that MAY assist with medications, rent, bills, etc.:
Community Action Agency 502 574-1157
Crisis & Info Center Line 502 589-4313
Louisville Metro Human Services 502 574-8000
Metro Call 311
Home Accessibility

In preparing for discharge, make sure you complete and turn in the Frazier’s Patient Home Accessibility Form to your therapy team. The information you provide on this form will allow your physical and occupational therapists to make recommendations for equipment or modifications needed in the home to maximize safety and independence after discharge. Your physical or occupational therapist will make the Accessibility Form available to you.

If you have steps to enter your home, you may need to make your home accessibility a priority for discharge planning. Insurance companies do not typically provide coverage for ramps. The resources below may provide some financial assistance but funds are typically limited and often there are waiting lists. You may need to have a ramp built by a private contractor. If you call the Center for Accessible Living, they can give you some names of contractors who may be available and have reasonable costs. (See Housing below.) The KATS Network may be able to assist you with locating used portable ramps or other sources of funding. (See Assistive Technology above.) The Michael Brent Resource Center at Frazier has ramp-building guides for professionals and/or family or friends skilled in construction. These resources offer basic specifications for design and construction of a ramp. The Center for Accessible Living also has lists of area apartments that are wheelchair accessible should you need to consider alternative housing. Ramps take time to build and you should discuss with the treatment team member if one is needed. Please be aware that there are extensive waiting lists at all of these agencies. It is sometimes helpful to ask church congregations or other volunteer organizations to help with construction and/or fundraising.

Ramps
Center for Accessible Living www.calky.org 502 589-6620
New Directions Housing Corporation www.ndhc.org 502 589-2272
1000 E. Liberty Street, Louisville, KY 40204 888 757-8790
New Directions Housing Corporation www.ndhc.org 888 757-8790
701 E. Spring Street, Suite 208, New Albany, IN 47150
KATS Network www.katsnet.org 800 327-5287
Jefferson County Ramp Program 502 574-5134
Lifespan Resources 812 948-8330
Multi-purpose Community Action Agency (MPCAA) 502-633-7162
Provides services to elderly or low income individuals in need, Covers Bullitt, Shelby, and Spencer Counties, http://www.mpcaa.org/mpcaa/Home/tabid/36/Default.aspx
Centenary United Methodist Church, Shelbyville, KY 502-633-4526
Federal Tax Benefits
When building ramps or modifying your home, you will need to save your receipts. Home modifications for the disabled and some medical expenses are tax deductible, but are not covered by Medicare or Medicaid. Check with your tax advisor or contact the IRS to determine your eligibility for excluded income, itemized deductions and/or tax credits.

Internal Revenue Service (IRS)  
www.irs.gov  
800 829-1040

Housing
The Centers for Accessible Living in Louisville and Murray provide individuals with disabilities and their families the following services: advocacy, employment programs, housing, independent living skills, peer counseling, personal care attendant program and ramp building.

Center for Accessible Living  
www.calky.org  
502 589-6620
305 W. Broadway, Suite 200  
888 813-8497
Louisville, KY 40202  
TTY: 502 589-6690

Murray, KY  
270 753-7676
1051 N. 16th Street, Suite C  
888 261-6194
Murray, KY 42071  
TTY: 270 767-0549

River Falls Access Ability Center  
812 949-4717
845 Park Place  
New Albany, IN 47150

CALKY and River Falls will assist with the following:
- Advocacy
- Employment programs
- Housing
- Independent Living Skills
- Peer Counseling
- Personal Care Attendant Program (CALKY only)
- Ramps

Kentucky Housing Corporation
The Kentucky Housing Corporation provides lower-than-market-rate home mortgages; home ownership education and counseling; rental assistance; and housing rehabilitation and repair programs.

www.kyhousing.org  
800 633-8896
1231 Louisville Road, Frankfort, KY 40601
Chapter 18 Resource Guide

www.barrierfreehome.com
www.hud.gov/offices/fheo/disabilities/pwd.cfm
www.axesshomes.com

Emergency Shelters
Center for Women and Families 502 581-7222
226 W. Breckenridge Street
(Domestic Violence – Females only and children)

Haven House
1727 Green Street 812 285-1197
Jeffersonville, IN
Homeless Shelter for men, women, and children

The Healing Place
1020 W Market Street (Men) 502 584-6606
1607 W Broadway (Women) 502 568-6680
Addiction detox or the overnight stay program for the homeless

Interlink Counseling Services Inc.
8311 Preston Highway 502 964-7147
Serves veterans suffering from mental illness or substance abuse

Hoosier Hills PACT
Salem, IN 812 883-1959
Women’s Domestic Violence Shelter includes children

Wayside Christian Mission
812 E Market Street (Men) 502 584-3711
Women and Family 502 589-1581
Serves all homeless and also mentally ill or disabled

Information Centers – Drug and alcohol
Alcoholics Anonymous 502 582-1849

Alcohol Abuse Hotline 800 234-0246

Crisis and Information Center
800 221-0446
Narcotics Anonymous 812 948-5772

Narcotics Abuse Hotline 800 234-0420
**Information Centers – Spinal cord Injury - National**

American Spinal Association
404 345-9772
[www.asia-spinalinjury.org](http://www.asia-spinalinjury.org)

BME: Biomedical Engineering Resources
[www.bmenet.org](http://www.bmenet.org)

Christopher and Dana Reeve Foundation
800 225-0292
[www.christopherreeve.org](http://www.christopherreeve.org)

National Institute on Disability and Rehab Research
[www.ed.gov/about/offices/list/osers/nidrr](http://www.ed.gov/about/offices/list/osers/nidrr)

National Information Center for Children and Youth with Disabilities
[www.nichcy.org](http://www.nichcy.org)
800 695-0285

National Institute of Health

National Rehabilitation Information Center
[www.naric.com](http://www.naric.com)
301 562-2400
800 346-2742

National Spinal Cord Injury Association
[www.spinalcord.org](http://www.spinalcord.org)
301 214-4006
800 962-962

Paralysis Resource Center
[www.paralysis.org](http://www.paralysis.org)
800 539-7309

Paralyzed Veterans of America
[www.pva.org](http://www.pva.org)
800 795-4327

Spinal Cord Injury Information Network: University of Alabama
[www.spinalcord.uab.edu](http://www.spinalcord.uab.edu)
205 934-3283

**Information Centers – Spinal cord Injury – State and regional**

Center for Accessible Living: Disability Resource Center
Louisville, KY
502 589-6620
[www.calky.org](http://www.calky.org)
888 813-8497
TTY 502 589-6690

Murray, KY
270 753-7676
TTYD 270 767-0549
888 261-6194

Derby City Chapter, NSCIA
David Allgood, President
Louisville, KY
david.allgood@amerihealthmercy.org
502 588-8574

Kentucky Assistive Technology Network
[www.katsnet.org](http://www.katsnet.org)
502 429-4484
800 327-5287

KY Office. of Vocational Rehabilitation
Internet Access

If you do not have access to a computer with internet access, visit your local public library. The internet has massive amounts of informational materials available regarding spinal cord injury from all over the world.

Louisville Free Public Library 502 574-1611
Main Branch
301 York St.
Louisville, KY 40203

Jeffersonville Branch 812 282-7765
211 East Court Ave

Clarksville Branch 812 285-5640
1312 Eastern Blvd.

New Albany Branch 812 285-8464
180 West Spring

While at Frazier, visit The Michael Brent Resource Center located on the 11th Floor at Frazier Downtown. The Center offers free internet access.

Legal Considerations

- Advance Directives are documents that allow you to make decisions regarding your future medical treatment.
- A Living Will tells health care professionals and your family whether or not you want life-prolonging treatment if you are in a terminal condition or a permanently unconscious state. Hospitals and doctors’ offices are required by law to ask you if you have this document. Hospitals often have Living Will forms for you to complete if you have done so in the past.
- A Health Care Surrogate is a person you select to make health care decisions if you are unable. You can designate a health care surrogate within your Living Will document.
**Financial Planning.**

The following are documents you can draft to prepare for the management of your personal affairs, financial holdings or debts and/or medical treatment decisions. You must be competent to draft these documents. To complete such documents, most consult an attorney.

- A Will directs how you would like your personal belongings and financial holdings managed after your death.
- A Power of Attorney designates a person to handle your financial affairs in your absence.
- A Durable Power of Attorney designates a person to act on your behalf at the time you become incapacitated. It allows your designated person to make personal, financial and medical treatment decisions on your behalf. If you have this document, there is no need to pursue guardianship should you become incapacitated. If you do not have a Durable Power of Attorney in place at the time you become incapacitated, a person who wishes to assist you with your affairs must pursue guardianship.

**Guardianship.**

Disability Court for Jefferson County 502 595-4933
514 W. Liberty St. (Old Jail Building)
Louisville, KY 40202
Filing fee/petition $47.00 ($87.00 for Emergency Guardianship)
Process (Evaluated by court appointed interdisciplinary team)
Evaluations reviewed by judge—makes decision

Time periods for hearings:
Emergency Guardianship 48 hours to 7 days
Guardianship 30 to 60 days
Legal Aid Protections/Advocacy 800 372-2988

**MEDICAL ASSISTANCE**

The Mission of Family Health Centers, Inc. is to provide residents of Louisville and Jefferson County access to high quality primary and preventive health care services without regard to the ability to pay. Services provided at 7 locations for Louisville and Jefferson County residents include adult and pediatric medical care, Urgent Care, preventive health services/patient education and more. The Centers also accept most health and dental insurance.

Family Health Center, Inc www.fhclouisville.org 502 774-8631
Medscape www.medscape.com
Healthfinder www.healthfinder.org

**Nutritional Information – General**

American Dietetic Association www.eatright.org 800 877-1600
Ask the Dietician www.dietician.com
Cooking  
www.cookinglight.com

Other Resources

Indiana Neighborhood - www.ec-online.net/community/neighborhood/in.htm
Government links, listing of county offices on aging, local services, agencies, and associations

Indiana Family and Social Services Administration - www.state.in.us/issa/
Listing for services for older adults and persons with disability and healthcare information

Al-Anon Family Group - Indiana 812 283-4491
Alcoholics Anonymous - Louisville 502 582-1849
American Red Cross 502 589-4450 812 283-8416

Derby City Chapter www.derbycityspinalcord.org/
Social group for people living with SCI. Meets monthly at Frazier

Facing Disability www.facingdisability.com/
More than 1,000 videos drawn from interviews of people with SCI, their families, caregivers and experts.

Friends of Frazier www.friendsoffrazier.org
Online community for those connected to Frazier Rehab Institute (family, patients, employees) to gather information, network, ask questions, and tell their stories.

Seven Counties 502 589-8600
Crisis & Information Center 502 589-4259 800 221-0446

Kentucky Relay Service 800 648-6056
(Deaf and Hearing Impaired) Voice users: 800 648-6057

Kentuckiana Regional Planning & Development Agency (KIPDA) 502 266-5571 866 737-3363
Provides a multitude of services including case management, transportation, advocacy, support for independent living, meals on wheels, respite care and some legal services.

Lifespan Resources 812-948-8330
Meals on Wheels  (Louisville)  502 589-8600
(Southern Indiana)  812 948-8330

Michael Brent Resource Center  www.spinalcordmedicineresources.com
Lending library providing resources on SCI and other disabilities. Located at Frazier Rehab Institute on the 11th floor.

Best Deal Clothing (special needs clothing)  502 961-9588
5007 Poplar Level Road

Laundry Services
Baptist Towers  502 587-6632
1014 S 2nd St

Hillebrand House  502 634-4878
1235 S 3rd St.

Support Groups
Support groups bring together people who have common needs or problems for the purpose of sharing information and experiences.

Alzheimer
National Alzheimer Association  www.alz.org  800 272-3900
Kentucky Alzheimer Association  www.alzinky.org  502 451-4266

Arthritis
Indiana Arthritis Foundation  800 783-2342
Kentucky Arthritis Foundation  502 893-9771
National Arthritis Foundation  www.arthritis.org

Cancer
American Cancer Society  www.cancer.org  800 227-2345
Indiana Chapter  812 282-4266
Kentucky Chapter  502 584-6782

Cardio-Pulmonary
American Heart Association  www.americanheart.org
Indiana Chapter  317 352-9226
Kentucky Chapter  502 587-8641
National Lung Association  800 586-4872
Kentucky Chapter  www.kylung.org  502 363-2652
Better Breathers Club  812 941-8300

Caregiver Support
Chapter 18 Resource Guide

National Family Caregivers Association  800 896-3650
www.nfcacares.org

Death and Grief
Hospice Foundation of America  www.hospicefoundation.org  800 854-3402
Hospice of Southern Indiana  812 945-4596
Vistacare Hospice  812 944-3690

Diabetes
American Diabetes Association  www.diabetes.org  800 342-2383
Indiana Chapter  317 352-9226
Kentucky Chapter  502 452-1201

Multiple Sclerosis
National Multiple Sclerosis Society  www.msindiana.org  800 344-4867
Indiana Chapter  317 870-2500
Kentucky Chapter  www.kynmss.org  502 451-0014

Stroke
National Stroke Association  www.stroke.org  800 787-6537
Kentucky Chapter  502 896-7221
Stroke Education Group @ Frazier  M, W, F 1p 7th Floor Dining Room

Stroke Support Group @ Southern IN Rehab  812 941-8300
2nd Tuesday of each month 1-2:30p
Stroke Support Group @ Frazier  502 582-3947
3rd Wednesday of each month 12-1:30p at the Douglass Community Center (off Bardstown Rd)

Southeast Christian Church  502 499-0190
Offers more than 20 different support groups

Pain Management
American Pain Society  www.ampainsoc.org/
Partners Against Pain  www.partnersagainstpain.com/
National Foundation for the treatment of Pain  www.paincare.org/

Prescription Assistance
If you do not have Medicare Part D or have no prescription drug coverage, you may qualify for one of the prescription discount cards listed in the chart below. Call the toll free number, or visit the website with the company to learn more and/or apply.
<table>
<thead>
<tr>
<th>Pharmaceutical &amp; Card Name</th>
<th>Phone</th>
<th>Qualification</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior Discount Prescription Plan Card</td>
<td>800-977-3862</td>
<td>Free to anyone over 18, no limit on income or health coverage, Not limited to one pharmaceutical company.</td>
<td>Savings of an average of 22% on name brands and an average of 50% on generics,</td>
</tr>
<tr>
<td>GlaxoSmithKline Orange Card</td>
<td>888-672-6436</td>
<td>1 person-income less than $26,000 per year. Couple-income less than $35,000 per year.</td>
<td>You receive an average 30% discount on GlaxoSmithKline products</td>
</tr>
<tr>
<td>Eli Lilly and Company Lilly Answers Card</td>
<td>877-RX-LILLY 877-795-4559 <a href="http://www.lilly.com">www.lilly.com</a></td>
<td>1 person income less than $18,000 per year. Couple-income less than $24,000 per year.</td>
<td>You pay a flat $12 fee on any Lilly retail drug for up to 30 day supply</td>
</tr>
<tr>
<td>Pfizer, Inc. Pfizer Share Card</td>
<td>800-459-4156</td>
<td>1 person income less than $18,000 per year. Couple-income less than $24,000 per year.</td>
<td>You pay a flat $15 fee on Pfizer prescription drugs for up to a 30 day supply</td>
</tr>
<tr>
<td>Together RX</td>
<td>800-865-7211</td>
<td>Receive Medicare, 1 person income less than $28,000 per year. Couple income less than #38,000 per year. Have no type of prescription coverage.</td>
<td>Varies depending in the company – ranging from 20% - 40%.</td>
</tr>
<tr>
<td>Lovenox</td>
<td>888-632-8607</td>
<td>Patient cannot have or qualify for any prescription coverage for Lovenox, including all federal, state, and local programs. Patient must be a legal resident of the United States. Lovenox must be administered for outpatient use only. 1 person income less than $17,720 per year. Couple income less than $23,880 per year.</td>
<td>Varies depending on demonstration of need.</td>
</tr>
</tbody>
</table>

Other suggestions to try to get a prescription filled:
- Ask your private doctor (not the ER doctor) if she/he can provide samples of the medications.
- Ask your private doctor if she/he can refer you to an indigent drug program. These programs require a letter from the doctor.
• Borrow money from a family member or friend.
• Ask your pharmacy to partially fill your medication according to how much you can afford. Then when you get paid, have the rest filled.
• Discuss with your doctor the possibility of transferring to a Family Health Center where they may provide assistance with medications. For more information and locations of Family Health Centers, call 502-574-6520 or 502-574-6660.
• Ask your pharmacy if they have any discounts or coupons to distribute.

Items available at Pharmacy Plus, located on the first floor of the Frazier building:
Self care items or grooming, dressing, hygiene, and feeding:

| Button Hook | Suction Denture Brush | Weighted Utensils |
| Zipper Pull | Long Handled Comb & Brush | Rocker Knife |
| Dressing Stick | Stainless Plate Guard | Suction Cup |
| Walker Basket | Beverage Cup Holder | Wanchik Writers |
| Long handled reachers | Expiratory Muscle Trainers | A dysphagia product: Thickening agent for liquids for patients with swallowing difficulties |

Wish’s Drugs 502.425.1146
Local resource providing low prices on medications that are paid for out-of-pocket.

Needy Meds
Provides information on pharmaceutical manufacturers that have special programs to assist people who can’t afford their medications. [www.needymeds.com/](http://www.needymeds.com/)

**Protective Services**

Most commonly, victims of abuse are children under the age of 18 years, spouses or significant others, disabled adults and the elderly. There are 5 types of abuse: physical, sexual, emotional/psychological, neglect (including self-neglect), and exploitation. State law requires that all abuse, even suspected abuse, be reported. You can make an anonymous report. The Cabinet for Human Resources will not reveal the source of the referral. When reporting, provide as much information as possible regarding the situation, abuser, victim, any others present/witnesses, and demographics (including the time and place where the incident occurred). To make a report, please call:

Kentucky
Adult Protective Services 502 595-4803
Child Protective Services 502 595-4550

Indiana 800 752 6200
Adult Protective Services 812 285-6264
Child Protective Services 812 288 5400
Floyd County, Indiana 812 949-4055
Harrison County, Indiana 812 738-8168
PUBLICATIONS – SPINAL CORD INJURY/DISABILITY

Ability Magazine  www.abilitymagazine.com  949 854-8700
Mainstream Magazine  www.mainstream-mag.com
New Mobility Magazine  www.newmobility.com/  215 675-9133
Paraplegic News  www.pn-magazine.com/  888 888-2201
Sports N’ Spokes  www.sportsnspokes.com/  888 888-2201
Wheelin’ Sportsman  www.wheelinsportsmen.com/  800 THE-NWTF

Recreation & Wellness

The Community Fitness and Wellness Facility at Frazier Rehab Institute is an activity-based exercise program designed specifically for individuals with physical disabilities who are living in the local community. This fully accessible facility is designed to assist clients with cardiovascular/aerobic fitness, muscular strengthening and flexibility. Learn more at ______

Other Recreation Programs

Community Fitness & Wellness  www.jhsmh.org  502 582-7411
Louisville Metroparks  www.louisvilleky.gov  502 456-8148
Louisville Metro Senior Services  502 485-8165
  Provides lunch, educational and recreation activities in a multigenerational atmosphere. Call 24 hrs. in advance for reservations.

Jewish Community Center  www.jccoflouisville.org  502 459-0660
  Provides exercise, health promotion, disease prevention, nutrition counseling, recreation, weight management, self defense, hobbies, etc.

Neighborhood House  www.nhky.org  502 774-2322
  Provides recreational and physical activities, like bing, line dancing, card games, tai chi, outings, scheduled activities. Daily lunches require a reservation one day in advance.

New Zion Community Development  502 778-7711
  Provides free exercise and line dancing classes to residents of Park Duvalle and surrounding neighborhoods

Transportation, Parking, & Driver Evaluations

Applications for handicapped parking permits are available at the County Clerk’s Office or the License Bureau. Permits require a physician signature and must be notarized. Permits are available that:
  ● Attach to the rear view mirror and can be moved from car to car
• Are license plates
• Are street signs that reserve space for parking in front of your home (if you live in the city).

<table>
<thead>
<tr>
<th>Type</th>
<th>Indiana</th>
<th>Kentucky</th>
</tr>
</thead>
<tbody>
<tr>
<td>Temporary</td>
<td>$5.00 (6 months)</td>
<td>$4.00 (good for 6 months)</td>
</tr>
<tr>
<td>Placard</td>
<td>No charge (good for 2 years)</td>
<td>$8.00 (good for 6 years)</td>
</tr>
<tr>
<td>Plate</td>
<td>Standard Plate fee</td>
<td>Standard Plate fee</td>
</tr>
</tbody>
</table>

KY Disabled Parking Permit  [www.jeffersoncountyclerk.org](http://www.jeffersoncountyclerk.org)  502 574-5700
IN Disabled Parking Permit  [www.in.gov/bmv/branches](http://www.in.gov/bmv/branches)  812 282-1862

Medicaid Transport by County
Services must be scheduled 72 hours in advance. After hours paging is available on weekends and state holidays for immediate or urgent care transportation needs.

<table>
<thead>
<tr>
<th>Region</th>
<th>Counties</th>
<th>Broker</th>
<th>Address</th>
<th>Phone</th>
<th>Fax</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ballard, Calloway, Carlisle, Fulton, Graves, Hickman, McCracken, &amp; Marshall</td>
<td>LKLP Community Action Council</td>
<td>389 Roy Campbell Drive Hazard, KY 41701</td>
<td>800-245-2826</td>
<td>606-435-1721</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>606-439-2229</td>
</tr>
<tr>
<td>2</td>
<td>Caldwell, Christian, Crittenden, Hopkins, Livingston, Lyon, Muhlenberg, Todd, &amp; Trigg</td>
<td>Pennyrile Allied Community Services</td>
<td>PO Box 582 Hopkinsville, KY 42240</td>
<td>800-467-4601</td>
<td>270-886-1256</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>270-886-1256</td>
</tr>
<tr>
<td>3</td>
<td>Daviess, Hancock, Henderson, Mclean, Ohio, Union, &amp; Webster</td>
<td>Audubon Area Community Service Inc. (GRITS)</td>
<td>1416 West 9th St. Owensboro, KY 42301</td>
<td>800-816-3511</td>
<td>270-684-8714</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>270-684-8714</td>
</tr>
<tr>
<td>4</td>
<td>Breckinridge, Grayson, Hardin, Larue, Marion, Meade, &amp; Nelson</td>
<td>LKLP Community Action Council</td>
<td>389 Roy Campbell Drive Hazard, KY 41701</td>
<td>800-245-2826</td>
<td>606-435-1721</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>606-439-2229</td>
</tr>
<tr>
<td>5A</td>
<td>Butler, Hart, Edmonson, Logan, Simpson, &amp; Warren</td>
<td>Audubon Area Community Service Inc.</td>
<td>1416 West 9th St. Owensboro, KY 42301</td>
<td>800-781-8312</td>
<td>270-684-8714</td>
</tr>
<tr>
<td>Region</td>
<td>Counties</td>
<td>Agency</td>
<td>Address</td>
<td>Phone Numbers</td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>----------</td>
<td>--------</td>
<td>---------</td>
<td>---------------</td>
<td></td>
</tr>
<tr>
<td>5B</td>
<td>Adair, Allen, Barren, Green, Metcalfe, &amp; Taylor</td>
<td>Rural Transit Enterprises Coordinated (RTEC)</td>
<td>PO Box 746 Mt. Vernon, KY 40456</td>
<td>800-321-7832, 606-256-4319</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Bullitt, Henry, Oldham, Jefferson, Shelby, Spencer, &amp; Trimble</td>
<td>Federated Transit Services of the Bluegrass (FTSB)</td>
<td>1460 Newtown Pike Suite 209 Lexington, KY 40511</td>
<td>888-848-0989, 859-233-1668</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Fayette</td>
<td>Federated Transit Services of the Bluegrass (FTSB)</td>
<td>1460 Newtown Pike Suite 209 Lexington, KY 40511</td>
<td>888-848-0989, 859-233-0066, 859-233-1668</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Bell, Clinton, Cumberland, Knox, Laurel, McCreary, Monroe, Pulaski, Rockcastle, Russell, Wayne, &amp; Whitely</td>
<td>Rural Transit Enterprises Coordinated (RTEC)</td>
<td>PO Box 746 Mt. Vernon, KY 40456</td>
<td>800-321-7832, 606-256-4319</td>
<td></td>
</tr>
</tbody>
</table>
Wheelchair Van Transport Services

Vans with wheelchair lifts will provide transportation for specified rates

<table>
<thead>
<tr>
<th>Wheelchair Van Services</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able Care</td>
<td>502 267-1911</td>
</tr>
<tr>
<td>Greater Harvest</td>
<td>502 778-9004</td>
</tr>
<tr>
<td>Mainstream</td>
<td>502 288-1135</td>
</tr>
<tr>
<td>Ready Cab</td>
<td>502 451-4114</td>
</tr>
<tr>
<td>Wheels</td>
<td>502 561-3690</td>
</tr>
<tr>
<td>Wilkerson Transport</td>
<td>502 935-5599</td>
</tr>
<tr>
<td>Valley Medical</td>
<td>502 634-2552</td>
</tr>
<tr>
<td>Yellow Cab Minivan with Ramp</td>
<td>502 214-7505</td>
</tr>
</tbody>
</table>

TARC 3 via the TARC Paratransit Department
1000 W. Broadway                        502 213-3217
Louisville, KY 40203                    TTY 502 213-3240
www.ridetarc.org

To be eligible for TARC 3, individuals must be unable to use fixed-route services due to a disability or functional limitations. TARC 3 costs under $5.00 one way.

| KY Medicaid Members Services            | 800 635-2570       |
| Passport Health Plans (KY Medicaid Health Maintenance Organization) | 800 485-6531 |
| Non ambulance transport                 | 800 296-0517       |
| Ambulance transport                     |                    |

KY Medicaid has cab vouchers for physician or clinic appointments.

IN Medicaid has a transportation service available for physician or clinic appointments

| Mainstream Transport Service           | 812 288-1135       |

Southern Indiana Area
| Lifespan Resources                     | 812 948-9701       |
| Sellersburg Ambulance                  | 812 246-7233       |
Driver's Evaluation

Frazier can provide individuals with disabilities a driver evaluation that is conducted by an occupational therapist. A physician order is typically required. Some insurance plans will cover the evaluation through OT benefit or a person may be eligible for an evaluation through the Department of Vocational Rehabilitation. Once individuals have the appropriate vehicle modifications installed on their vehicle, Frazier staff may provide appropriate driver education/training.

Frazier Rehab Center/Newburg 502 451-6886
3430 Newburg Rd.
Louisville, KY 40218

Travel
Provides free travel information for those with disability.
Able to Travel
www.abletotravel.org 888 211-3635
Access-Able Travel Source
www.access-able.com 303 232 2979
Northeast Passage
http://www.nepassage.org/
Endeavour Safaris
http://www.endeavour-safaris.com/
Accessible Journeys
http://www.accessiblejourneys.com/accessible-travel-resources.htm
SATH
US Dept of Transportation, Aviation Consumer Protection
800 778-4835  TTY  800 455-9880

Vocational Rehabilitation (See employment)