Gaylord Specialty Healthcare

# SPINAL CORD INJURY
## EDUCATION MANUAL

*A supplement to the Paralysis Resource Guide*

# Reflections on the Rehabilitation Journey

The experience of recovering from a spinal cord injury is profound and deeply personal. Dr. David Rosenblum, physical medicine and rehabilitation physician at Gaylord Hospital, has captured some of the most powerful emotional aspects of this journey from the perspective of both a patient and physician.

*"I hope that by sharing these impressions, it will help others reflect on the work we do and the impact we have on those in need."*

**- Dr. Rosenblum**

The rhythmic artificial sound of air
Pushed in and out
I can't breathe
A collar ensuring no movement
Where no movement is to be found.
I can't move
A mind betrayed, from the chin down
Senses absent, all but pain.
I can't feel
Tears
Fear, panic, so many questions
I am lost
Unable to talk, even thoughts clouded
Sedatives, needles, tubes, pain
What happened?
What will happen...
Eyes wide open, hoping, praying

Chaos, ambulance, transfer
New place, new people
New routine, uncertainty
Rehabilitation. What is that?
I can't breathe
I can't move
I can't feel
Who are they? Will they help me?
Eyes wide open, seeing, searching

Rehab nurses, rehab physicians,
Internists, pulmonologists,
Lots of therapists and staff
An amazing team
Kindness, support, caring
Ventilator weaning
Learning lots
Pain is less.
Out of bed. Sitting up
With help
Lots of help
I can't breathe
I can't move
I can't feel
But I am here.
Eyes wide open, understanding

Ventilator is off
I can breathe!
I can talk
Bowel programs, bladder programs
Skin care
So much to learn
Directing care
I am helping others help me
Driving a wheelchair
Going when and where I want
Computer access
Environmental control
Family training—they are with me
Tools to help me
Eyes wide open. What do they see?

A mirror. In passing
A moment's glance
A look, then I stare
Beyond the chair, the neck brace
Beyond the muscle atrophy
It takes a moment, but it's clear
Eyes wide open. I see me!


## David S. Rosenblum, MD

**Medical Director, Spinal Cord Injury Program**
**Medical Director, Milne Institute for Healthcare Innovation**
**Associate Clinical Professor, Orthopaedics & Rehabilitation, Yale University, School of Medicine**


### Education

University at Buffalo School of Medicine and Biomedical Sciences, MD
University at Albany, State University of New York, BS

### Post-graduate Education

**Internship** - Millard Fillmore Hospital, Internal Medicine
**Residency** - Columbia Presbyterian Medical Center, Physical Medicine and Rehabilitation

### Board Certification

American Board of Physical Medicine and Rehabilitation
American Board of Physical Medicine and Rehabilitation, sub-specialty Spinal Cord Injury Medicine and Brain Injury Medicine

# TABLE OF CONTENTS

# INTRODUCTION

# Here's to your independence!

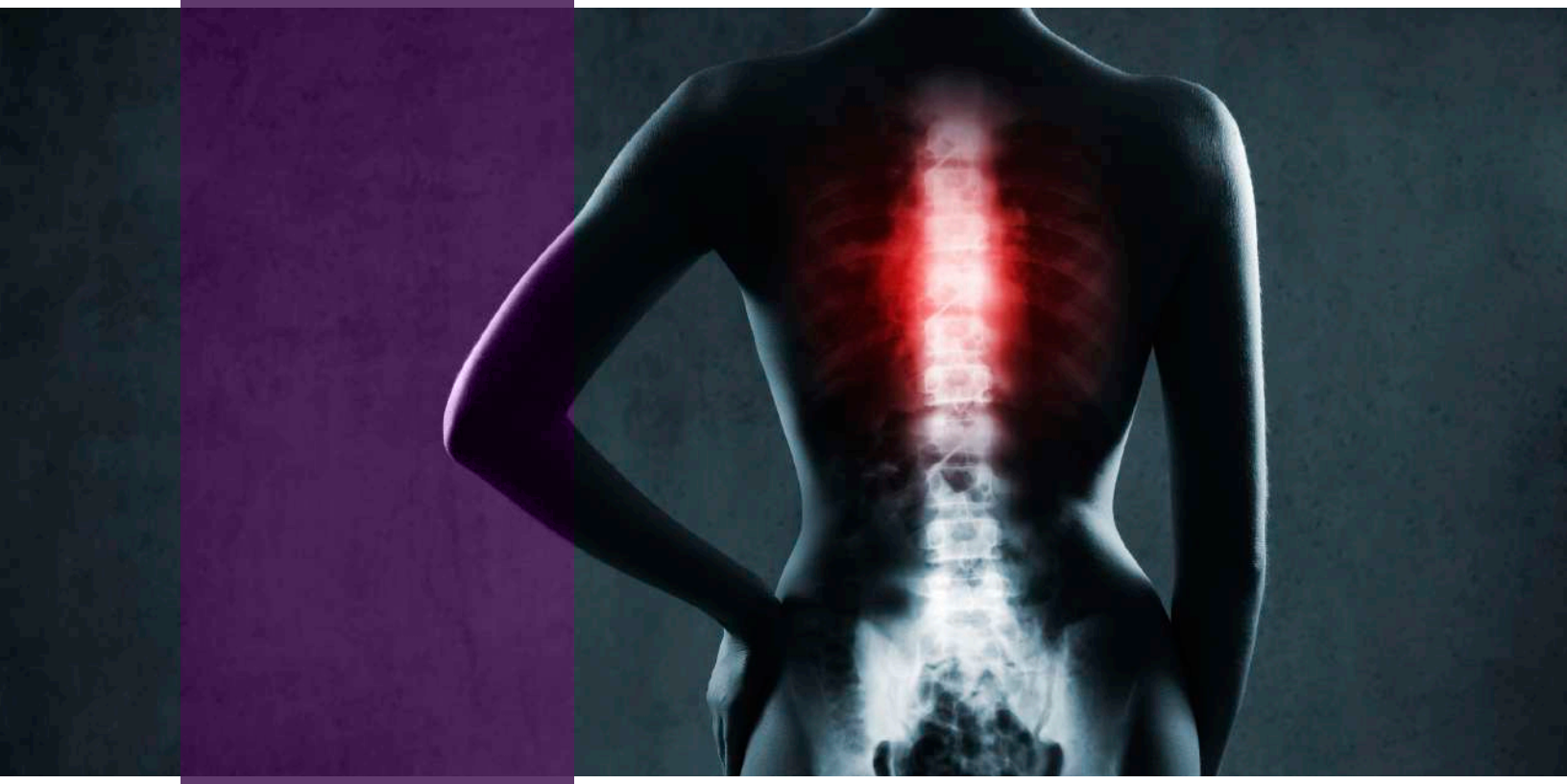
This manual is a vital resource for you and your family as you navigate the journey of rehabilitation after a spinal cord injury. It highlights many of the issues and topics that your Gaylord treatment team will review with you and supplements information that you will find in the Paralysis Resource Guide published by the Christopher and Dana Reeve Foundation.

We strongly encourage you and your family to become familiar with its contents during your hospital stay. All sources of information are important. Take advantage of every opportunity to learn how to best manage your health with spinal cord injury or disease.

After you are discharged, it will serve as a valuable reference for the many questions that may arise. The more knowledgeable you become about managing your health and the adaptations related to your injury, the better prepared you will be to make wise decisions that promote a healthy and fulfilling lifestyle.

SECTION

1



# YOUR GAYLORD SCI REHABILITATION PROGRAM

**A spinal cord injury is a life-altering event, but it does not define your future.**

The path forward is one of learning, adapting, and rediscovering your full potential. The goal of Gaylord Hospital's spinal cord injury program is to empower you with the knowledge, skills, and tools to maximize your functional status and independence as you learn about living with a spinal cord injury. It is about regaining control, building confidence, and creating a new "normal" that is both satisfying and healthy.

Rehabilitation is a collaborative process, and you are the most important member of the team.

## Your Gaylord Team

To help you navigate your recovery, it's essential to understand the role each specialist plays. Knowing who to turn to for specific questions and needs will make you a more active and empowered partner in your own care.

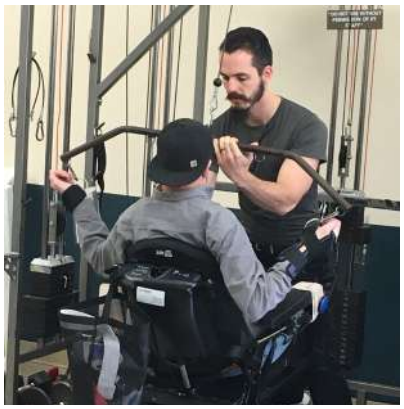
You will work with a dedicated group of specialists to establish realistic goals and monitor your progress. Your team may include, but is not limited to:

A **physiatrist** (fizz-EYE-uh-trist) is a medical doctor who specializes in Physical Medicine and Rehabilitation. They are experts in caring for individuals with spinal cord injuries. Your physiatrist leads the rehabilitation team, helping you achieve your highest possible level of function. They manage your medical care, treat and prevent complications related to SCI, and direct the entire team to optimize your recovery.

Your **Care Manager** is your primary coordinator and advocate. They work with the entire team to ensure your care is appropriate and effective, from admission to discharge. They will help you and your family develop a safe and timely discharge plan, connect you with community resources, and serve as the link between the hospital, your doctors, and your insurance provider.

**Nurses** are central to the care team, providing 24-hour hands-on care, critical patient education, and daily management of vital functions. They bridge the gap between medical care and daily therapies by helping with bowel/bladder routines, preventing pressure injuries, and training families and patients on the intricacies of living with SCI and essential at-home care needs.

**Occupational Therapists** work to improve your ability to perform daily living skills, such as eating, bathing, dressing, and managing your home. Your occupational therapist will teach you new techniques and may fit you with adaptive equipment or splints to increase your independence. They will also explore assistive technology and home modifications to help you thrive in your environment.



**Physical Therapists** work to improve your coordination, strength, range of motion, and balance to maximize your mobility. Your physical therapist will instruct you on how to perform tasks like moving in bed, transferring from your bed to a wheelchair, propelling a wheelchair, and, if your recovery allows, walking. They will also evaluate you for custom braces and wheelchairs.

**Psychologists and neuropsychologists** offer support to help you and your family navigate the emotional and psychological challenges that come with a life-altering injury or illness.

**Respiratory Therapists** are trained to manage the special breathing challenges that can occur after an SCI. They evaluate your breathing, help you manage secretions, provide education on breathing techniques, and assist with any ventilator needs. They are available 24/7 to ensure your respiratory health is maintained at an optimal level.

**Speech-Language Pathology** works to improve your swallowing, communication, and cognitive skills. If you have difficulty swallowing, they will help you safely eat the least restrictive diet possible. They also work to recover speech and language skills or develop alternative communication methods.

**Food and Nutrition (Registered Dietitian Nutritionist or RDN)** evaluates your nutritional status and provides guidance on healthy eating to manage chronic conditions, assist with poor appetite, or manage a tube feeding regimen. Good nutrition is critical for healing and maintaining your overall health, and the RDN works closely with you, your family, and the team to meet your specific needs.

**Therapeutic Recreation** uses leisure and recreation activities to improve your quality of life and enhance your physical, cognitive, social, and emotional function. Your TR specialist will help you discover new and exciting activities, adapt hobbies you already enjoy, and re-engage with your community through sports, games, arts, and community outings.

**Chaplaincy Services** support patients, families, and staff of all faith backgrounds. They help individuals draw upon their own spirituality or religious beliefs as a source of comfort, healing, and strength during the rehabilitation journey.

**Wound Care Specialists** are clinicians with special training and certification in evaluating and treating complex wounds, which may result from an accident, surgery, or pressure. This specialist, often working as part of a multidisciplinary wound care team, will assist your doctor in managing any wounds to ensure proper healing.

This journey is a partnership, and we are here to support you every step of the way.

## A National Leader in SCI Expertise

Gaylord Specialty Healthcare is uniquely qualified to support individuals with spinal cord injuries, holding a number of specialty accreditations that demonstrate our expertise and commitment to the highest standards of care.

- **Only CARF Accredited Spinal Cord Program in Connecticut** for both inpatient and outpatient, adolescent and adult programs.
- **One of two healthcare systems in the world with CARF accreditation** for all inpatient and outpatient rehabilitation programs, including recognition for Spinal Cord Injury.
- **Highly Accredited by the Joint Commission**

## The Gaylord Hospital SCI Model System Partnership: Research-Driven Rehabilitation

Gaylord Hospital is proud to be part of the Spaulding New England Regional Spinal Cord Injury Center, one of only 18 Spinal Cord Injury (SCI) Model Systems in the United States. Gaylord's inclusion in this elite network is a mark of distinction that reflects our deep experience and expertise. Becoming part of a Model System center like Gaylord requires undergoing a highly competitive five-year grant process through the National Institute on Disability, Independent Living, and Rehabilitation Research.

This prestigious, federally funded network of centers is dedicated to providing the highest level of care, conducting groundbreaking research, and improving long-term outcomes for individuals with SCI.

The mission of an SCI Model System is to provide a comprehensive continuum of care, from emergency services through rehabilitation and re-entry into the community. These centers gather critical data for research and are charged with disseminating their findings to patients, families, healthcare providers, and the public to advance the standard of care everywhere.

With data from over 50,000 participants, some of whom are up to 45 years post-injury, this research helps us track long-term trends, identify causes, and evaluate treatments to improve the lives of everyone affected by SCI.

Being part of this national network allows us to offer our patients access to the latest research and the most advanced programs, including specialized care for our younger patients.

Learn more at: **https://msktc.org/about-model-systems/sci**

SECTION

2

# PREPARING YOU FOR SUCCESS AFTER DISCHARGE

## Preparing You for Success after Discharge

Your rehabilitation journey does not end when you leave Gaylord Hospital.

Family support and understanding are incredibly important as you transition back home. Depending on your needs, your team may recommend continued therapy at a sub-acute facility, at home, or on an outpatient basis here at Gaylord Specialty Healthcare.

Upon discharge, you are encouraged to establish a relationship with a primary care physician who can manage your routine medical needs. Your rehabilitation physician will provide them with all necessary information to ensure a smooth transition of care.

We highly recommend periodic follow-up visits with Gaylord's Outpatient Medical Services for specialized care focused on maintaining your long-term function and preventing complications.

**Outpatient Medical Services**
The Outpatient Medical Services Department at Gaylord Hospital provides medical evaluations and follow-up. Our physicians are board-certified physiatrists who are experts in the treatment of individuals with spinal cord injury. Gaylord physiatrists can prescribe specialized treatments for spasticity management. Urologic care appointments are also available at Gaylord.

**https://www.gaylord.org/physiatry**

**Outpatient Therapy Services**
Most individuals with spinal cord injury continue their rehabilitation journey after discharge from Gaylord Hospital.

Gaylord's outpatient clinics in Fairfield, North Haven, and Wallingford are staffed by therapists with specialized expertise in spinal cord injury rehabilitation. Through individualized physical, occupational, and speech therapy programs — combined with advanced rehabilitation technologies — patients receive customized care designed to enhance mobility, manage pain, build independence, and improve overall quality of life.

Our outpatient neurorehab clinics are equipped with specialized and accessible equipment for spinal cord injury rehabilitation and cutting-edge technologies including ZeroG Gait and Balance System, Functional Electrical Stimulation Bicycle, ARC-ex, electrical stimulation units, and Ekso Bionics robotic exoskeleton.

**Call 203-284-2888 to request an evaluation.**

**Outpatient Aquatic Therapy**
Aquatic therapy in Gaylord's accessible therapeutic pool in Wallingford can facilitate movement, reduce pain, and improve function.  Participation does not require the ability to swim.

If you are appropriate for aquatic therapy, your therapist will design an individualized program that may help with:

- Reduction of pain
- Muscle relaxation
- Improved flexibility and range of motion
- Improved endurance
- Pressure relief and improved circulation
- Improved balance and coordination
- Increased strength
- Reduction of spasticity

**Gaylord Wheelchair Assessment Clinic**
Gaylord's outpatient Wheelchair Assessment Clinic in Wallingford is led by a physical therapist who is a certified Assistive Technology Professional and is supported by suppliers of complex rehab technology who assist in advanced equipment selection. They work to identify your goals, your physical capabilities and unique challenges, and environments where the equipment must function.

Other services include computerized pressure mapping assessments, standing frame evaluations, and custom seat cushion and back support shape capture. Proper evaluation improves mobility and quality of life, prevents complications from ill-fitting equipment, and reduces equipment abandonment and cost.

**More at: https://www.gaylord.org/wheelchair-assessment**

**SCI Day Treatment Program**
Gaylord's SCI Day Treatment Program is a comprehensive outpatient program designed to help individuals with spinal cord injuries maximize independence, mobility, and quality of life and continue to progress after inpatient rehabilitation ends.

The only program of its kind in Connecticut, the program provides personalized, goal-driven care tailored to each participant's unique journey.

Offered as an intensive eight-week program on Gaylord's Wallingford outpatient clinic, participants work closely with a dedicated interdisciplinary team focused on helping them strengthen functional abilities, improve confidence, and navigate everyday life more independently at home, in the community, and beyond.

Programming may include individual and group physical and occupational therapy, speech therapy as needed, wheelchair support services, aquatic therapy, caregiver education, return-to-work preparation, and community reintegration activities. Participants also receive education and resources related to adaptive technology, seating and mobility, nutrition, skin care, bowel and bladder management, mental health, driving, and long-term wellness.

**More at www.gaylord.org/sci-day-treatment**

**Outpatient Psychology Services**
The psychology department offers short-term, evidence-based, cognitive-behavioral counseling services with a focus on helping people adjust to catastrophic injury and related mental health concerns.

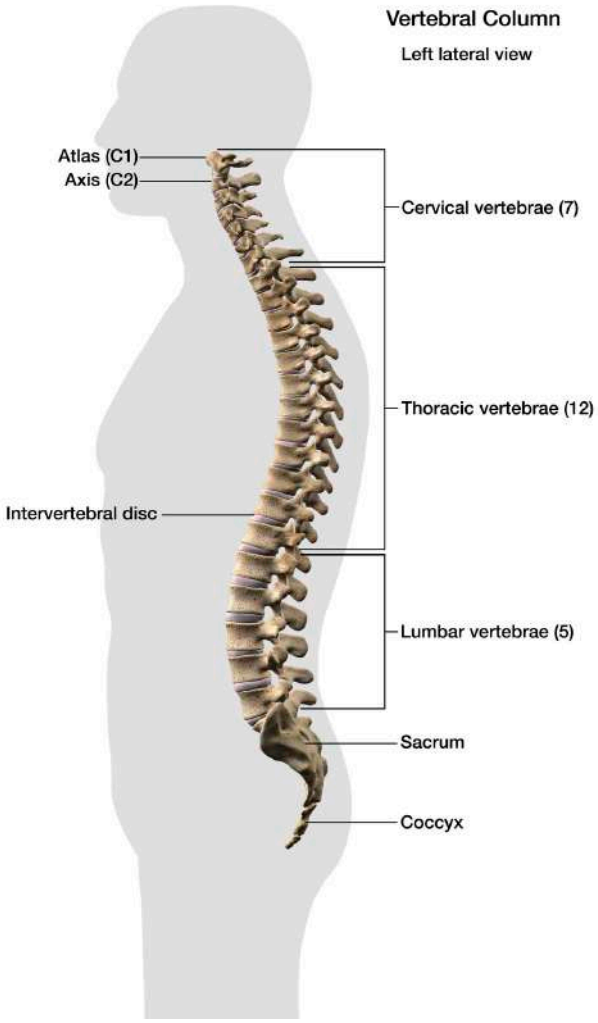
SECTION

3

# SPINAL CORD INJURY ANATOMY

## Spinal Cord Injury Anatomy

Understanding the basics of your spinal cord injury is the first and most important step toward becoming an active participant in your care and recovery. This knowledge empowers you and your family to ask informed questions, understand your treatment plan, and make decisions to promote a healthy and satisfying lifestyle.



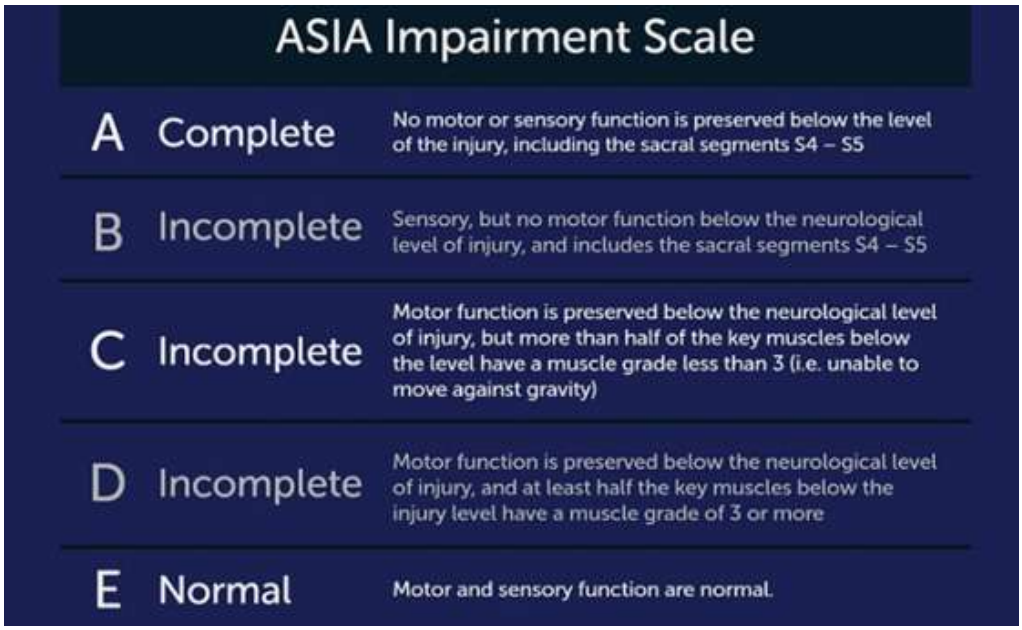

## What is a spinal cord injury?

The spinal cord is a delicate bundle of neurons that acts as the main communication highway between your brain and the rest of your body, sending signals back and forth to your muscles and skin. This cord is protected by the spinal column, a stack of bones called vertebrae separated by jelly-like discs that allow for twisting and bending.

An injury occurs when the spinal column bends or twists too far in one direction, causing the spinal cord inside to be bruised or to swell. This damage blocks the signals traveling from the brain to the muscles, which can lead to paralysis (loss of muscle function) and loss of sensation (feeling) in the skin below the level of the injury.

- **Tetraplegia** refers to an injury that causes weakness or numbness in the arms and legs.
- **Paraplegia** refers to an injury that causes weakness or numbness only in the legs.

In cases where an individual has experienced paralysis, it's helpful to understand the ASIA impairment scale, a tool developed by the American Spinal Injury Association to categorize the degree of damage to the spinal cord. Patients recovering from spinal cord injury are examined using this criteria to determine an accurate diagnosis. The exam is performed at various times post-injury to determine change in neurologic function.




In some cases, surgery may be needed to stabilize the spine with metal hardware. Afterward, you may need to wear a rigid collar or body jacket for 2-3 months to allow the bones to heal properly.

The recovery process after a spinal cord injury can take up to a year or even longer, with most of the functional recovery typically happening in the first 6-9 months.

**Scan to watch Gaylord's SCI Education Series video on Spinal Cord Anatomy**

SECTION

4

# SKIN CARE

After a spinal cord injury, skin care transforms from a simple hygiene task into one of the most critical responsibilities for maintaining your long-term health. Diligent skin care is your first line of defense against serious complications like pressure injuries, which can lead to infection and long periods of bed rest. Learning to protect your skin is fundamental to your independence and well-being.

**The Four Functions of Your Skin**

Your skin is a remarkable organ that serves several vital functions:

- **Protection:** It acts as a shield against bacteria, dirt, ultraviolet rays, and other physical and chemical agents.
- **Sensation:** It provides the sense of touch, pressure, temperature, and pain.
- **Fluid Regulation:** It helps control the body's fluid balance.
- **Temperature Regulation:** It helps maintain a stable body temperature.

Your skin does this for all of the body structures and tissues beneath it including layers of fat, muscles, and bones.

Adequate blood circulation is essential to keep your skin cells alive. When circulation is cut off for a prolonged period, those cells die, and pressure injuries (also called pressure ulcers) can develop.

**How SCI Affects Your Skin**
After an SCI, the loss of sensation means you no longer receive the automatic signals from your brain telling you to move, shift your position, or fix a wrinkle in your clothing. Because you cannot feel discomfort, it is possible to sit or lie in one position for too long, cutting off blood flow to the skin, especially over bony areas.

It is also vital to avoid "shearing motion." Shear is the force that occurs when skin drags/moves against a support surface. One example of shear is body weight not being fully lifted off surface during sliding board transfers.

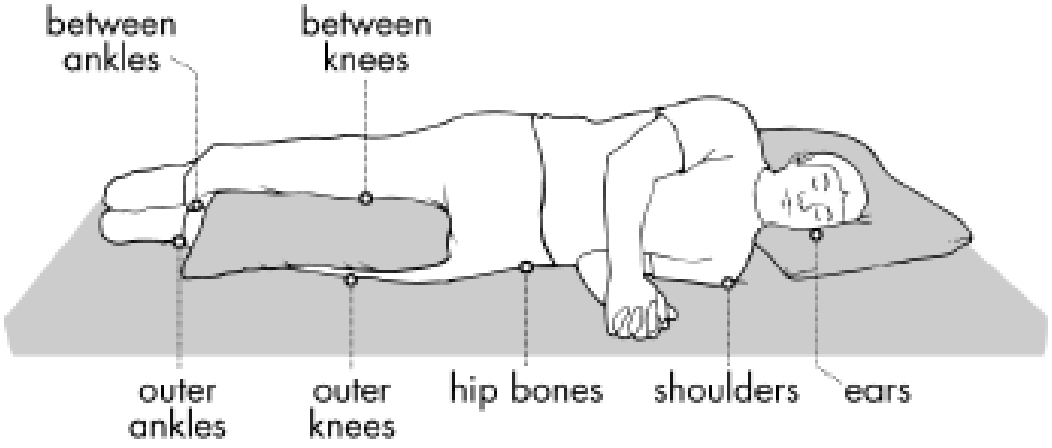
## REMEMBER TO:

- **Look** at how you are positioned
- **Inspect your skin** all over, every morning and every night. Use the inspection mirror given to you or have a caregiver do it for you.
- **Do pressure relief** every 15 minutes when sitting and every two hours when in bed.
- **Keep your skin clean and dry.** Wash daily and check your skin folds. Urine and stool are very irritating and should be cleaned off immediately.
- **Eat a balanced diet and drink plenty of water.** Adequate protein is essential for maintaining healthy skin and healing any breakdown. Drink 6-8 glasses of water a day.
- **Avoid elevating the head of your bed more than 30 degrees** unless medically indicated, as it puts as much pressure on your bottom as slouching in your wheelchair.
- **Perform regular bowel and bladder management** to prevent accidents or wetness

## Common Pressure Areas

Prolonged pressure on your skin will cause pressure injuries. Be extra vigilant about these areas:

- **Back of Head:** From laying on it for a long time
- **Elbow:** From leaning on it, using it as a prop on the armrest of the wheelchair or mattress
- **Coccyx:** (Over the tailbone or tip of the spine)  A sitting sore. It is caused by poor posture (slumping) in the wheelchair or by sitting in a semi-reclining position in wheelchair or bed
- **Sacrum:** (A lying sore) Caused by long periods of lying flat on the back
- **Ischium:** (Over the bones that support the weight of your body when you sit) Sitting in a semi-reclining position in bed or wheelchair can cause pressure. Caused by not shifting your weight often enough while sitting or foot pedals on your wheelchair being set too high. Foot pedals that are too high will tilt the weight of your legs onto the bones in your seat. Even with frequent weight shifting, you could get a pressure sore/ulcer over these bones.
- **Trochanter:** (Side of the hip)  A side-lying sore/ulcer
- **Knee:** Caused by spasms that draw the knees together while sitting. Or caused by side-lying one on top of the other.
- **Ankle:** (Outside part)  A side-lying sore/ulcer
- **Heel:** (Back Part)  A sore often caused by spasms that pull the heel against the foot rest of the wheelchair or by spasms that rub the heels against the bed sheets.  This kind of pressure ulcer can also be caused by lying flat on your back for many hours or ill-fitting shoes.
- **Scapula:** From laying on it for a long time
- **Toes:** Frequently caused by tight-fitting shoes.



## Helpful Hints For Skin Care When You Sit In A Wheelchair

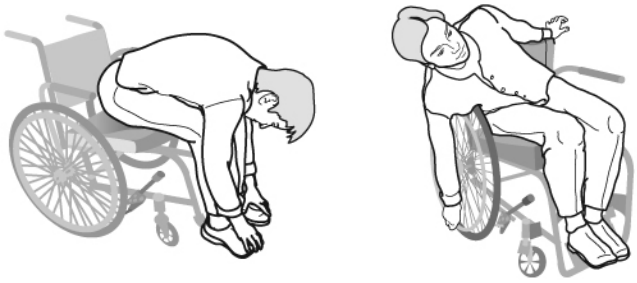
1. Make sure the foot pedals of your wheelchair are adjusted to the right height for you. If in doubt, too low is better than too high. Check with your therapist if you have a question.
2. You must use a special cushion on the seat of your wheelchair. Your physical therapist will help you choose the best cushion for you based on your level of injury, strength, skin integrity, and body weight. Your physical therapist will show you how to use your cushion and keep it maintained.
3. Sit up straight in your chair. Slumping forward or slouching leads quickly to early skin breakdown over the end of your tailbone. Slumping or poor posture over a number of years may cause a severe curvature of the spine, neck discomfort, affect respiratory capacity, and ultimately comfort and mobility.

## In a Wheelchair

**Tetraplegic**

Relieve pressure on your bottom at least every 15 minutes while you are sitting. This is important because the weight of your body over the hips increases the pressure on the skin and muscle over each ischium (seat bone). Your therapist will teach you the most appropriate way for you to relieve pressure.

**A. Leaning side to side.** This technique will relieve pressure over one ischium (seat bone)



- **Park wheelchair near bed (parallel)**
- **Lock brakes**
- **Remove armrest nearest bed**
- **Lean into bed with upper extremity or an elbow to shift weight off of opposite ischium**
- **Hold for at least one minute**
- **Repeat with other side**

**B. Tilting forward.** This will relieve pressure along spine, low back and spine.

- **Lock wheels**

- **Have someone place your feet on the floor**
- **Have someone stand in front of you and pull your trunk forward to unweight your backside**
- **Hold for at least one minute before being assisted to upright**

*Some people are able to do this independently by pulling forward on the armrests. Review techniques with your physical therapist such as leaning forward onto your knees or leaning forward on a table.

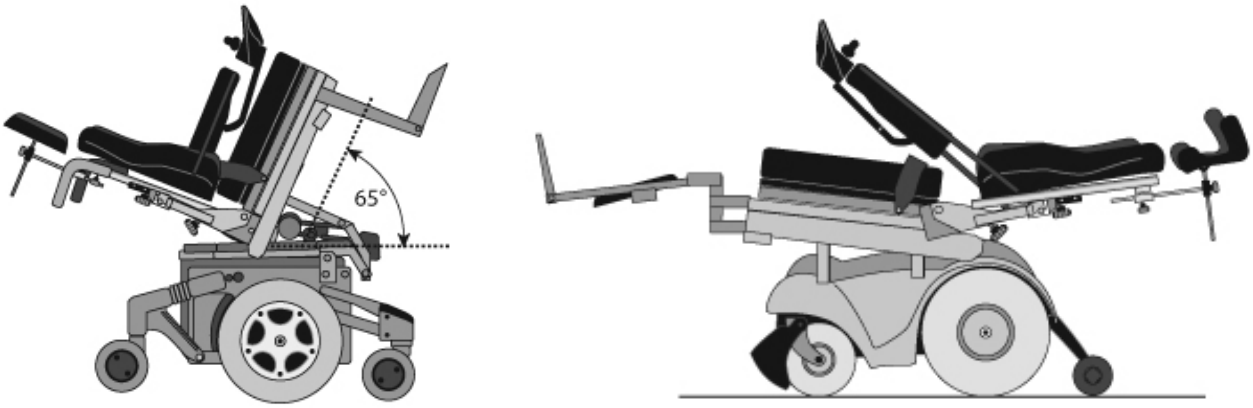
**C. Tilting the wheelchair backward.** This distributes pressure from posterior thigh/buttocks to the back

**Manual wheelchair:**

- **Lock wheels**
- **Have someone tilt your chair backwards resting the push handle grips on a chair or bed**
- **Position pillows to cushion head and shoulders. Be sure your attendant practices this technique with your physical therapist prior to leaving the hospital.**

**Power wheelchair:**

If you have a power wheelchair, go into full tilt and use the power tilt system. Your therapist will show you how to do this.




**Paraplegic**

The above techniques (side to side lean and forward lean) are acceptable. The best type of pressure relief is totally unweighting the bony structures. Therefore a lift is the most optimal choice.

- **Lock wheels**
- **Put hands on the wheels or armrests**
- **Lift yourself off the seat of the wheelchair and hold for 15 seconds**
- **Repeat every 30 minutes**

**In Bed**

Utilize a pressure reducing/redistribution surface if one has been recommended by your rehabilitation team and keep to the turning schedule you have developed during your rehabilitation. You must continue to turn, and not just rely on a mattress to protect you. Depending on your body type, and medical issues, a home-turning schedule of every 2 to 3 hours – turning from side to back to side.

Semisupine position is a variation of supine..

Right lateral position.

SUPINE POSITION

**Other potential threats to your skin include:**

- Thick crotch seams, especially on blue jeans
- Binding in the groin area with pressure on your scrotum
- Tight shoes, especially with swollen feet
- Socks with elastic tops that bind around your lower leg
- Straps that are too tight holding your drainage system
- Condoms that have been applied too tightly or condom catheter left in place longer than 24 hours at a time

**To avoid these problems:**

- If you have clothing that you have never worn before, wash them before wearing and check your skin after one or two hours for redness or chaffing.

- Buy jeans that are designed with low-profile seams (not bulky) in the groin area
- Re-adjust your scrotum as you get dressed and move about.
- Be certain that you are not sitting directly on it.
- Clip the top of tightly fitting socks.
- Check the fit of shoes carefully and watch your feet for signs of edema (swelling)
- Loosen or change the position of your drainage system.
- If using a condom catheter – leave off over night.

## Alcohol use can put you at risk for skin breakdown

Many people drink alcohol. Alcohol use may be a concern when you are taking medications, are consistently drinking more than two or three drinks a day, or if you find you "crave" a drink or need a drink to help you cope with daily hassles. Another indication that alcohol is a problem may be if your job and family are affected by your drinking.

Alcohol and other drugs can damage many organs of the body, especially the liver, kidneys, and brain. **When people are intoxicated, they forget to do pressure relief, so they are likely to get pressure sores/ulcers.** Also, alcohol and drugs may impair your judgment, which may lead to accidents or other activities that can injure your skin.

If alcohol or drug use is difficult to control, consult your SCI clinic, a local mental health center, or a community alcohol treatment program.

## If you are overweight, you can be at risk for pressure ulcers.

Overweight is a relative term. Although there is a large range of weight that is acceptable, we will say that overweight is 10% or more over your ideal body weight.

There are fewer blood vessels in fat tissue than in muscle. Being overweight causes more pressure on your skin when you sit. This increased weight over pressure points increases the likelihood of skin breakdown.

**Solutions:**

1. Discuss with your doctor and see a dietitian. Good diet and adequate water intake is necessary.
2. Keep any areas between skin folds clean and dry. Inspect your skin frequently for reddened areas.
3. Change positions or do pressure releases frequently

## Weight changes can put you at risk for pressure ulcers

It is not uncommon for newly injured individuals to lose weight during their hospitalization. However, after discharge, weight gain (to above and beyond that of prior to the injury) is common. Maintain good nutrition as weight loss can put you at risk for skin breakdown.

This weight gain not only impacts skin condition but also functional mobility and should be avoided.

Any area on your skin where there was a break in it, a scar will form.

All scar tissue has a decreased number of blood vessels when compared to normal skin. So, it cannot withstand the same amount of pressure and will be more likely to break down.

## Accidents can put you at risk for skin breakdown

**Bathing:** Always test the temperature of the water you use for a bath or shower ahead of time. A padded tub bench is preferred.

**Smoking:** Do not smoke or be around smokers. Smoking decreases oxygen in the blood and makes you more prone for sores.

**Cooking:** Don't try to lift boiling pots from the stove or set hot liquids nearby where they might spill on you.

**Heaters:** While riding in a car be careful that your feet are not too close to the car heater. For home space heaters, distance between you and the heater should be at least six feet.

**Transfers:** Be cautious in transferring. Avoid dragging or scraping your bottom when transferring in and out of your chair. Wear some type of clothing over your bottom when using the slide board – simply putting a pillowcase on the slide board does not work. Lift your body as much as possible when transferring. Always wear shoes while in your wheelchair to prevent bumping your toes.

Your bed at home should be the same height as your wheelchair seat with its cushion. This will make it easier and safer for you to transfer from bed to wheelchair.

**Sunburn:** Use sunscreen. You may use a water spray bottle to keep cool. Avoid prolonged sitting in the direct sunlight. Ask your doctor if you need to avoid the sun because medication you are on may cause a harmful reaction.

## Care of Skin Breakdown

***What should you do if your skin does start to show signs of breakdown?***

Keep all pressure (weight-bearing) off the area. If this means you must be in bed to avoid sitting on a pressure spot, then go to bed until the skin looks its normal color. Remember to keep using your turning schedule. Sleeping prone is usually not recommended early on in your recovery. Speak with your doctor about this.

Report pressure areas as soon as possible to your doctor or nurse. If you are home – clean the sore with mild soap and water, cover with a bandage. Make an appointment to be seen by your doctor. If you have a sitting sore, report this when you arrive to see the doctor. Ask to lie down until the doctor is ready to see you. You should not wait in a sitting position.

If you burn yourself and blisters develop, **DO NOT** open them. Remember the broken skin will let

harmful germs enter the body. Leaving the blister unopened will prevent infection. The immediate treatment of minor burns (within 30 minutes), is to soak the burned area in cold water for 20 minutes. Do not apply any medicine or ointment. Cover any blister with a dry, sterile dressing in case it should break. You should gently wash the blister and wide surrounding area with soap and water twice each day. Keep all pressure off the area and report the burn to your doctor or nurse as soon as possible.

## Troubleshooting for Your Skin

Any of the following problems can cause increased spasticity of your arms or legs. Let your spasticity be a clue to your health. If it gets worse, look for a problem.

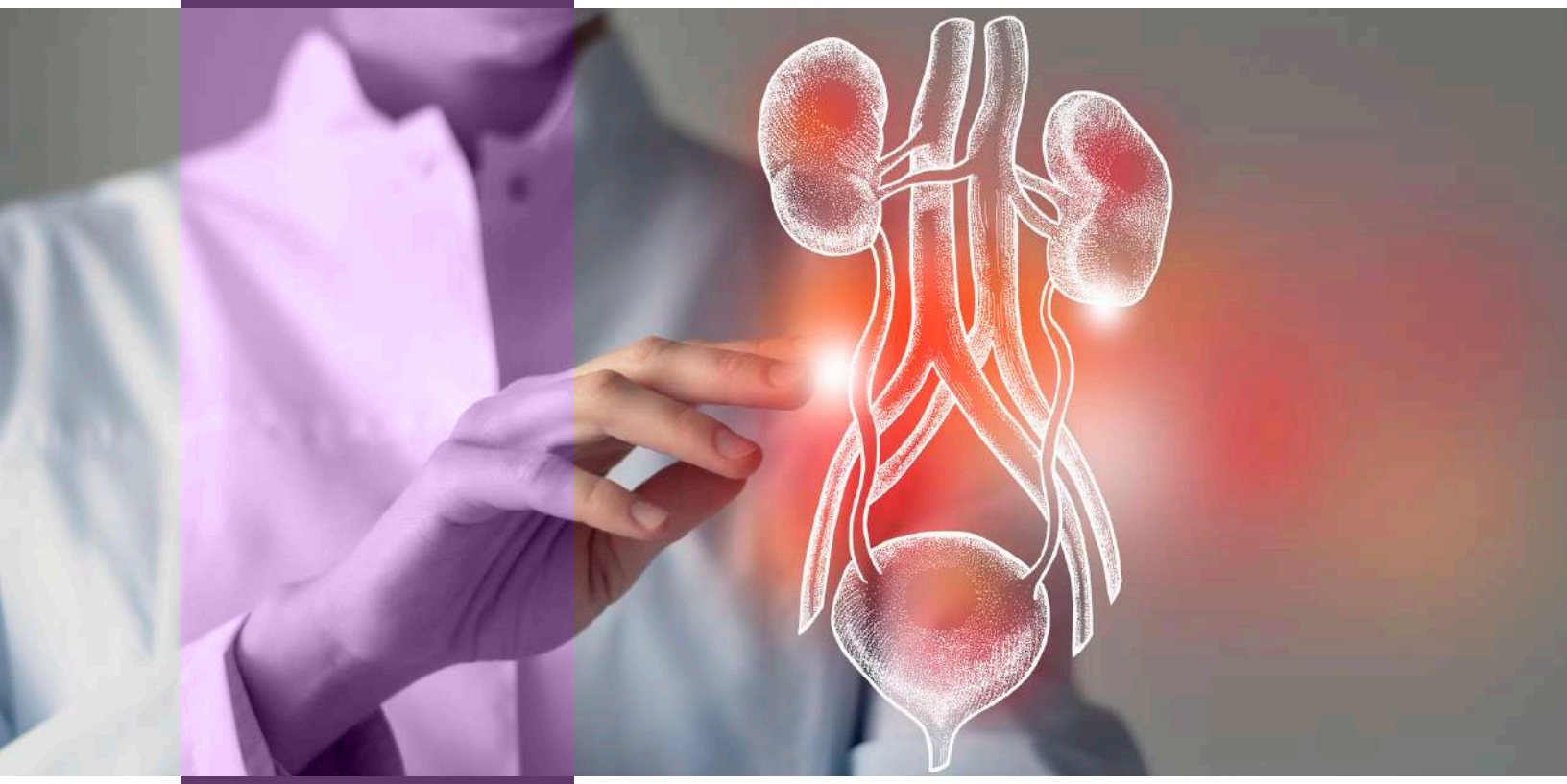
| Problem | What You See | What You Do |
|---|---|---|
| **Blister** | Watery or bloody liquid (fluid) that can be seen under the skin | Do not pop. Keep pressure off of it. If in a pressure area, cover with dry bandage. Call your doctor. |
| **Burn** | Reddened or blistered skin caused by heat. May be an open sore. | Apply cold water soaks immediately, then keep dry. Do not pop blisters. Cover with dry bandage. Contact your doctor. |
| **Frostbite** | Whitened or bluish-black numb skin (usually nose, ears, fingers, toes) as a result of exposure to cold. | Seek emergency care. |
| **Groin rash** | Reddened area in groin and increases and/or all over groin and penis. May be moist and or pimply. | While you are in the hospital, let the doctor know. If you are home, wash with mild soap and water two to three times a day. Rinse and dry well. Spread legs to air dry. Call your doctor as this may be due to a fungal rash. |
| **Ingrown toenail** | Reddened area around toenail, may have pus when pressed. Nail may be cutting into skin. | Contact your doctor immediately as signs of autonomic dysreflexia may occur. |
| **Pressure Ulcer/Sore** | A sore usually over a bony area. | Wash with mild soap, rinse, dry, bandage, if sore is open. Keep all pressure off of the sore. Call your doctor. |
| **Red area** | Red skin over bony area that does not fade in 20 minutes. Does not blanch (turn white when pressure is put on it.) | Do not put pressure on it until redness fades completely. It may take days to improve. If it does not, call your doctor |

**Take good care of your skin. It is one of your most important responsibilities.**

**Scan to watch Gaylord's SCI Education Series video on Skin Management**

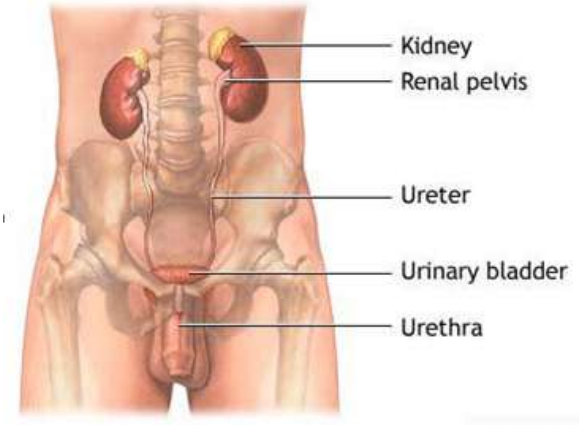
SECTION

5

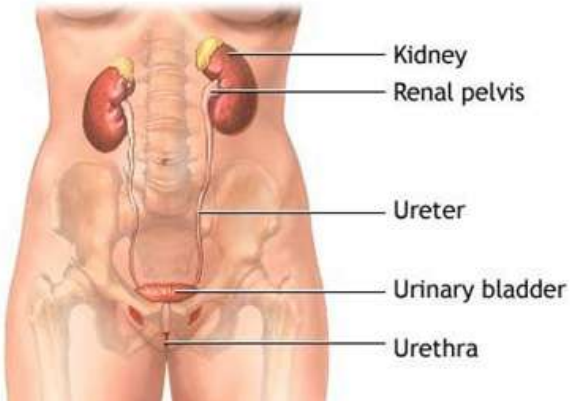


# BLADDER MANAGEMENT

## The Urinary System




Male Urinary System




Female Urinary System

Before your spinal cord injury, you probably did not pay much attention to your urinary system because it worked automatically. After the spinal cord has been injured, you will need to learn how to manage your urinary system. Your urinary system is a very important part of your body and learning to manage it will be vital to your health and confidence in getting on with your life.

After spinal cord injury, it is important to resume regular and complete emptying of the bladder.

## Intermittent Catheterization

Most people with spinal cord injury empty their bladder in this way. A sterile or clean tube is inserted into the urinary meatus (opening) and advanced through the sphincter to the bladder to empty the urine. This will be done every four to six hours to keep your bladder from stretching too much. During your rehabilitation, you, and if necessary, a designated caregiver, will be taught how to do this. This requires patience and practice. Individuals with spinal cord injury have to find the technique for catheterization that is most helpful to them. Your rehabilitation team will assist you in adapting this procedure to your individual function and preference.

Foley catheters, even when changed once a month, are not recommended to manage the bladder for most people because of the possible complications- such as infection or increased pressure from the catheter. Some patients may be able to initiate emptying of their bladder by crede or tapping on the lower abdomen over the bladder or by applying pressure to this area. Tapping and crede may only be initiated after a urologist has completed a urodynamic evaluation and recommended them.

You and your physician will discuss various bladder emptying options and decide which one is most appropriate for you.

## Intermittent Catheterization (General Information)

Purpose: Intermittent catheterization is recommended as the preferred alternative to a permanent

indwelling Foley catheter in the bladder for all patients with spinal cord injury or disease who are unable to pass urine on their own when the bladder is full. The technique may be one of intermittent self catheterization for paraplegics and those tetraplegics who have sufficient hand function to perform their own catheterization. The advantages of this technique are:

- Empties the bladder every few hours in a pattern typical to most individuals.
- Decreases the likelihood of bladder infections and stones which may occur with a permanent catheter lying in the bladder.
- Eliminates the need and inconvenience of bedside and leg urine bags.

## General Instructions **(A clean rather than sterile technique is described)**

The volume of urine obtained with each catheterization should not exceed 500 ccs. (2 cups or 16 ounces). Any more than this over-stretches the bladder, interferes with blood circulation through the bladder and is likely to result in a bladder infection. Do not stop emptying your bladder at 500 ccs. If you are still draining, continue to empty your bladder. Catheterization on schedule is more important than sterility and must be performed even if conditions are not ideal. Remember to always carry spare (extra) clean catheters.

Ideal catheterizations yield 300-500 ccs. of urine. This may require catheterization every four to six hours, depending on the patient, the fluid intake, level of activity and bladder muscle function. A daily fluid intake of approximately 2 liters (2,000 ccs.), is recommended and should be spaced throughout the waking day with restricted fluid intake between dinner and retiring. This may eliminate awakening during the night to catheterize. Your schedule should be established by the time you are discharged from the hospital; however, times may be changed to fit your lifestyle.

The maximum amount of ccs. drained each time should not change. Certain medications may be prescribed to prevent urine leakage between catheterizations. These are described on the medication sheet.

## Intermittent Self-Catheterization for Men

When the bladder cannot empty itself or cannot do so completely, intermittent catheterization (IC) becomes necessary. This is a procedure that you do yourself or a caregiver of your choice can be taught by nursing. To avoid introducing germs and possible infections into the bladder, it is important that you are careful to follow clean procedure taught to you by nursing. In general the goal is to have a cath volume of less than 500cc or 2 cups.

**Equipment** (Before you begin, make sure you have everything you need)

- Catheter (and optional extension) cath. kit or loose catheters
- Water soluble lubricant jelly
- Urinal or other container or you can be seated on the toilet
- Soap

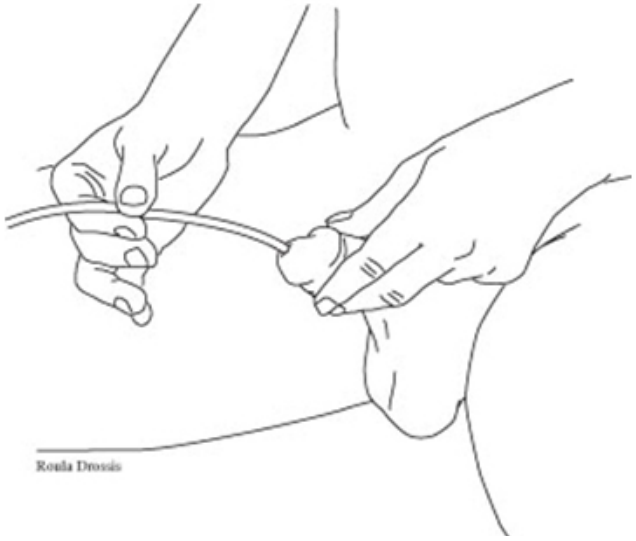
**Procedure**

Catheterization may be performed while sitting on the toilet, commode, wheelchair, bed, or while standing.

- **Wash your hands thoroughly with soap and water**
- **Wash the penis and surrounding area with soap and water. Rinse with the rinse cloth.**
- **Wash hands again**
- **Open the lubricant jelly**
- **Open the catheter package, take out the catheter, and lubricate the catheter the way you were taught by nursing or your therapist.**
- **Put one end of the catheter in the collection container or toilet. Do not let the catheter touch any other surface or water. Hold your penis outward in one hand and with the other gently insert the catheter through the urinary opening. As you push the catheter in, pull outward on your penis to help the catheter slide in more easily.**
- **Continue pushing the catheter in until urine begins to flow. Hold the catheter in place until all of the urine has drained into the container or toilet.**

To make sure your bladder is empty, take some deep breaths or press on your lower abdomen and withdraw the catheter slowly to allow bladder to completely empty.

- **When the urine flow stops, pinch the catheter closed to avoid spillage and slowly remove it.**
- **Empty the collection container and rinse it.**
- **Wash your hands.**
- **You should have a supply of individual catheters or kits. Be sure to have extra catheters on hand at all times, if a catheter appears cracked or damaged in any way throw it away.**
- **Clean catheters are the key to avoiding infection.**



## Intermittent Self-Catheterization for Women (Clean Technique)

When the bladder cannot empty itself or cannot do so completely, intermittent catheterization (IC) becomes necessary. This is a procedure that you can do yourself or a caregiver of your choice can be taught by nursing. To avoid introducing germs and possible infections, it is important that you are careful to follow the procedure taught to you by nursing. In general the goal is to have a cath volume of less than 500cc or 2 cups.

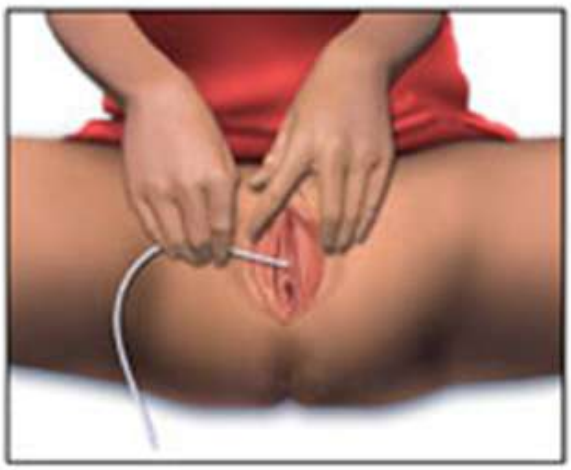
**Equipment** (Before you begin, make sure you have everything you need)

- Catheter (and optional extension) cath. kit or loose catheters
- Water soluble lubricant jelly
- Urinal or other container for collecting urine or you can be seated on toilet
- Soap

**Procedure**

Catheterization may be performed while sitting on the toilet, commode, wheelchair, bed, or while standing.

- Wash your hands thoroughly with soap and water
- Wash the urinary area (urethral opening) and the surrounding area with soap and water. Use downward strokes and avoid the anal area.
- Wash hands again
- Open the lubricant jelly
- Open the catheter package, take out the catheter, and lubricate the catheter the way you were taught by nursing or your therapist.
- Put one end of the catheter in the basin or over the seat of the toilet. Do not let the catheter touch any other surface or water. With the index finger and ring finger of one hand, spread the lips of the vulva apart, and with the middle finger, locate the urethral opening. With the other hand, gently insert the catheter into the urinary opening.
- Continue pushing the catheter until urine begins to flow. Hold the catheter in place until all of the urine has drained into the collection container or toilet. To make sure your bladder is empty, take some deep breaths or press on your lower abdomen and withdraw the catheter slowly to allow bladder to empty completely.
- When the urine flow stops, pinch the catheter closed to avoid spillage and remove it.
- Empty the collection container and rinse it.
- Wash your hands.
- You should have a supply of individual catheters or kits. Be sure to have extra catheters on hand at all times. If a catheter appears cracked or damaged in any way throw it away.
- Clean catheters are the key to avoiding infection.



## Fluid Intake and Output

Adequate intake is very important in helping prevent urinary tract infection, as it keeps the system flushed out well. You should drink approximately 2 liters (2,000 ccs.) of liquid per day. Remember that soups, ice cream, sherbets, and Jell-O, account for a portion of that fluid intake. During hot weather, you may have to drink slightly more fluids to compensate for fluids lost by sweating. Urine output will generally be about one pint or so less than intake. You may have to adjust your amount of fluid intake depending on the volumes obtained by your intermittent catheterizations.

Normal urine is a clear, pale, yellow with little or no sediment. Urine is normally a darker color first thing in the morning when it is concentrated due to lack of fluid intake during the night. A dark color during the day may indicate an inadequate fluid intake or an infection. An increased fluid intake will cause the urine to be a lighter color.

Please refer to the Christopher Reeves Spinal Cord Injury Resource for additional information about bladder complications and signs/symptoms of urinary tract infections.

## Signs of Overstretching Your Bladder

- Consistently high volume times. If you find you have a peak time, catheterize more frequently during that time of the day. Evening is a peak time for many patients.
- Taking in more fluid than usual, possibly in a social situation or due to hot weather.

**Incontinence**

If your bladder begins to empty on its own or you leak in between scheduled emptying, you may need to wear an incontinence product or external drainage device to keep the urine contained and off of your skin.

## Male External Collection System

These urine collectors have many names depending on the brand you choose. These condom type

collectors are a thin rubber or latex sheath; ending in a rubber tube that is attached to a drainage bag. The sheath and bag are applied according to the instructions you received at Gaylord. They are easy to apply and staff will work with you to learn proper use of the device. The drainage bag used under your clothing will be smaller than the one you use at night. You will be taught how to empty each bag so you can do this alone or instruct someone to do it for you.

Some external devices are applied with double back tape and many now have built-in adhesive and can simply be rolled onto the penis. Tubing that is free of kinks and angled downhill is essential for proper drainage. Always apply on a clean, dry penis. Self-adhesive elastic tape may be applied on the outside of the sheath for added security. Never apply too tightly. Check the penis often for swelling or constriction. Change the sheath if there is a problem. You may apply the device while you have an erection.

Wear loose clothing to prevent constriction of the device or tubing. Check your tubing each time you change positions and each time you transfer from one place to another.

Remember: The most important factor is the use of an external collector is good skin care. The collector should be changed daily and the penis washed well with soapy water and dried thoroughly. Exposure of the penis to the air for one to two hours will help keep the skin healthy. Always inspect the penis daily for evidence of skin breakdown as this may temporarily prevent the use of the external catheter.

**If you find a sore or cut on your penis:**

- Clean the area with soap and water and dry thoroughly.
- Check with your doctor
- Place a piece of stoma adhesive or thin Duo-Derm over the sore to protect the area and allow healing and protection from urine.

**Common Medications**

See medication section

## Urodynamics

A urodynamics evaluation consists of a series of studies that provide information about the mechanics of voiding. It is done by a urologist.

These tests give information on sphincter activity and urethral pressures during bladder filling and emptying. This aids in planning the best bladder management program for you.

Ask your doctor or nurse for more information about this test. If urine is being forced back towards the kidneys (reflux), this test is the only way to find this out. This back pressure will eventually cause permanent kidney damage. Your doctor will put you on appropriate medicine to prevent this from happening and causing your kidneys to be damaged. This test is pain free and takes about 20 minutes.

## Glossary of Terminology for Bladder Function

**BVI:** Bladder volume indicator, ultrasound machine shows the amount of urine in the bladder. This is a non-invasive procedure.

**Cath:** Slang for catheterization

**Catheter:** Flexible rubber or plastic tube used to drain the bladder

**Catheterization:** Insertion of clear or sterile tube to empty the bladder

**Coude':** Type of catheter with curved tip, easier to advance through sphincter for some patients.

**Crede/tapping:** Method of emptying the bladder with pressure or tapping of hands, only used with physician approval.

**Cystogram:** X-ray of the bladder, dye or gas may be inserted via a catheter for viewing and later removed.

**Cystoscopy:** Viewing the bladder via a scope inserted into the meatus.

**Dyssynergia:** Uncoordinated opening of the sphincters. This causes ineffective emptying of the bladder.

**Foley:** A catheter that stays in the bladder and attaches to a drainage bag.

**Dydronephrosis:** Stretched kidney from excess reflux urine.

**IC or ICP:** Abbreviation used by some professionals to mean intermittent catheterization or intermittent catheterization program.

**Incontinence:** A bowel or bladder accident

**IVP:** X-ray of the urinary system. Dye is injected into a vein.

**Reflux:** Backflow of urine from the bladder to the kidney, urine is flowing the wrong way.

**Residual:** Urine left in the bladder after voiding without a catheter or if a catheter is removed before full emptying occurs.

**Sphincterectomy:** Surgical cutting of sphincter muscles to eliminate spasticity and related voiding problems.

**Stones:** Solid mass that becomes stuck in the urinary tract, blocking normal urine flow.

**Suprapubic cystostomy:** Small opening through abdomen into bladder in which a catheter is placed for continuous draining of urine.

**Ultrasound:** Non-invasive test used to view many parts of the body for example: the bladder, used in conjunction with urodynamics.

**Urinanalysis:** Sample test of urine to check for any problems.

**Urodynamics:** A series of studies that give important information about voiding, kidney condition, and urethral pressures.

**Void:** To empty the bladder

**Scan to watch Gaylord's SCI Education Series Bladder Management with SCI**

SECTION

6

# BOWEL MANAGEMENT

## How SCI Affects the Bowel

A spinal cord injury interrupts the nerve signals between your brain and your bowel, causing what is known as neurogenic bowel. This means you may no longer feel the urge to have a bowel movement or be able to voluntarily control the anal sphincter muscle. The injury also tends to slow down peristalsis, the natural wave-like muscle contractions that move stool through the intestines.

There are two main types of neurogenic bowel, depending on the level of your injury:

- **Reflex Neurogenic Bowel (Upper Motor Neuron):** This typically occurs with injuries at the T-12 level or above. The reflex that triggers a bowel movement remains intact. When the rectum fills with stool, it triggers a reflex emptying. A bowel program for a reflex bowel focuses on stimulating this reflex at a scheduled time.
- **Non-Reflex Neurogenic Bowel (Lower Motor Neuron):** This is common in injuries at T-12 or below, where the reflex center for defecation may be damaged. The anal sphincter muscle may remain relaxed, and the rectum loses its ability to empty by reflex. This can lead to leakage or impaction. The program for this type of bowel often involves manual removal of stool.

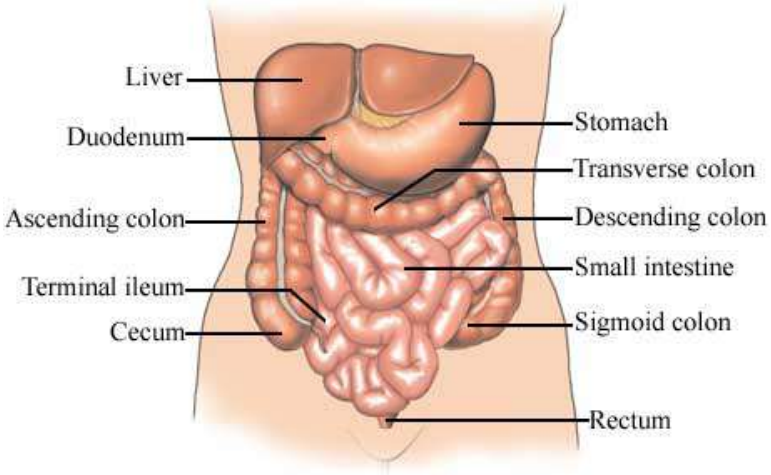
Following spinal cord injury, bowel control can be limited or completely lacking, depending on the amount of damage to the spinal cord. Learning how to manage a bowel program that will work well for you may take time but it is vitally important to your health and general sense of well-being. It can be a major factor for many individuals in returning to school, work, or social activities.

The bowel is part of the digestive tract. Part of its action is automatic, and part is under voluntary control. With spinal cord injury, the body's voluntary control over elimination is usually lost.

The muscle at the end of the bowel (anal sphincter) is the one that is relaxed when having a bowel movement. This allows intestinal and abdominal muscles to force out the feces (stool). A spinal cord injury may reduce the ability of both voluntary and automatic muscles to move the stool. Stool generally moves along the intestines more slowly and as water is reabsorbed, it may become hard. Initially, you will not be able to tell when your bowels are full when the automatic muscles will empty them. Therefore, it is necessary to begin a program of emptying the bowels on a regular basis. Establishing a program will prevent bowel accidents, diarrhea, constipation, and impaction.

Whether a bowel program is begun to establish voluntary control or to have a controlled pattern of elimination, regularity is important. Medications and other aids may be used to achieve this.

The type of control you will have depends on the level of your injury and how much damage was done. Fortunately, most people with spinal cord injury are successful in regulating their bowel through training and can have movements on a convenient schedule. Work with your medical team to find the routine that is best for you.



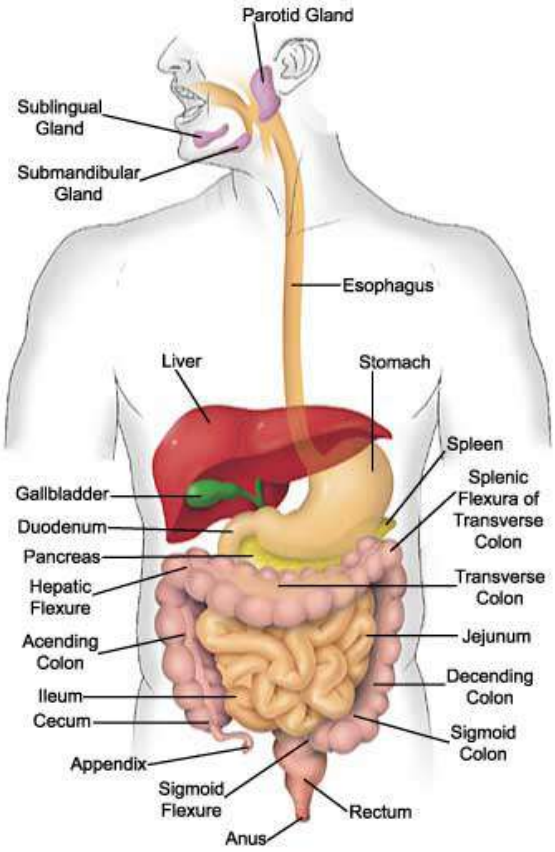
## Goals of a Bowel Management Program

- Bowel movement at regularly scheduled time (every 24 to 48 hours).
- Avoid bowel accidents (incontinence) between planned bowel routine
- Complete routine in less than 45 minutes
- Prevent constipation, impaction, diarrhea
- Prevent hemorrhoids or anal fissures (tears)

## How Will Bowel Functions Be Affected by Spinal Cord Injury?

In the very early part of your injury (hours or days), a period of spinal shock occurs. During this stage, bowel function is absent. You may have been receiving food and fluids through IVs. This is because your system was not working properly and the peristalsis was slowed down. If you have eaten foods, they would not have been broken down and nutrients would not have been properly absorbed.

Slowly, as shock subsides, your digestive system function and peristalsis return, but they are weaker than before due to damaged nerves at the level of your injury.




- The passage of food through the mouth, esophagus and stomach continues in the normal way, but peristalsis in the intestines is often slower than normal.
- Messages that travel to and from the brain and spinal cord are interrupted, resulting in the inability to feel the urge to have a bowel movement and the inability to control when the stool comes out.
- Messages will continue to travel between the rectum and the spinal cord if the reflex center is intact (it may not be in very low injuries). An intact reflex center results in a reflex or automatic emptying of the rectum (reflex neurogenic bowel).
- If the reflex center has been damaged (some low injuries below T-12), the rectum loses the ability to empty automatically, resulting in a non-reflex neurogenic bowel (independent of external influences) and an increased likelihood of impactions. Also, the anal sphincter (muscle) may remain relaxed, causing a leakage of stool.

## What is a Bowel Program?

A bowel program is a plan to provide you with a consistent, practical, and convenient means of clearing your bowel on a regular predictable basis. It is important that your program fits your own schedule and meets your own needs.

The kind of bowel program that is best for you is determined by your level of injury and how complete it is. Habits or schedule prior to spinal cord injury are often not helpful in determining the best program after a spinal cord injury.

## Why Do a Bowel Program?

After food is broken down into material that can be absorbed by the body, the relatively liquid waste is transformed into solid waste (feces) and excreted. Development of firm waste is important; stools should be soft but well formed.

- If waste remains in liquid form, a great deal of water will be lost from the body. Very loose bowel movements, or diarrhea, can lead to dehydration. For many persons with spinal cord injury, loose bowel movements are also the cause of skin breakdown on the buttocks.
- On the other hand, if too much water is removed, the stool may remain in the bowel too long, become hard and result in constipation. Even intermittent (and unnoticed) hard stool can upset a bowel routine.
- If your bowels do not move regularly and completely, there is an increased chance of leakage of loose, watery stools from behind the blockage. The most common cause of diarrhea in persons with spinal cord injury is a blockage called a fecal impaction (the stool becomes so hard it cannot move through the rectum). You may lose your appetite, feel nauseous, and become extremely uncomfortable. Your stomach may swell (become distended). You may require a liquid or oral laxative to break up the impaction and clear the system. Once the “blockage” is relieved, re-evaluation of the bowel medications should be considered to prevent future hard stools or constipation.

Again, the key to avoiding any of these complications is prevention. A specific bowel management routine is of vital importance both physically and socially to persons with SCI. The right routine for the right person can give confidence and new freedom, thus enabling you to live a full, satisfying life.

## Training Your Bowels

Beginning a bowel training program during rehabilitation is important in order to avoid problems and prevent bowel accidents, which are embarrassing and can lead to skin problems. It will take time to get your bowels regulated (probably several weeks). During that time, you will need a lot of patience and determination especially when your bowels don’t do what you want them to when you want them to. As time goes on, you will gain more control and confidence in your ability to regulate your bowels.

**Procedure for Digital Stimulation**

- Insert gloved, lubricated finger into the rectum past the anal sphincter (muscle)

- Rotate the finger in circular motion several times. Wait for results for at least 15 minutes.
- Report any bleeding to your doctor. It may be caused by hemorrhoids.
- If no results and the lower bowel is empty, repeat the program. If poor or no results two days in a row, rectal and/or oral laxatives should be considered.
- If stool remains in the rectum but digital stimulation is not effective, gently remove stool with a gloved, lubricated index finger (utilizing a circular motion and waving your finger toward the anus). Non-Reflex Bowel (usually for injuries at T-12 or below)

The procedure is same as for reflex bowel without the digital stimulation procedure

## Adjusting Medications and Schedules

Modifications to the bowel program require educated, gradual change and patience. If change is necessary, change only one element at a time and allow at least 3-7 days to evaluate results.

**Medication Adjustments**
Stool softeners may need to be adjusted according to stool consistency. Increase with hard stools or constipation. Before decreasing or stopping a stool softener, discuss with your doctor. The neurogenic bowel usually takes longer to respond to medications than the normal bowel does.

**Schedule Adjustments**
If you have no or poor results on an every other day schedule, change to an every day program temporarily until good results are achieved. Never go more than three days without a bowel movement. When making a change in the schedule, allow at least two weeks for a successful adjustment.

Bowel accidents may occur during this transition and the bowel medication schedule will need to be changed accordingly.

Remember, only you can make your program work well by following the recommendations and procedures described and adjusting them to your particular situation. Although difficult at first, with adjustments and patience, regulation of the bowel is possible.

## Factors That Promote Successful Bowel Management

Depending on the location of your injury, you may have a bowel that easily responds to rectal stimulation and a well planned bowel program that includes the following:

- **Regularity and timing**
- **Physical activity**
- **Position**
- **Diet and fluid intake**
- **Medications (as necessary)**

**Regularity and Timing**

- Consider pre-injury bowel movement schedule. It may or may not be helpful to maintain the same pattern at the time of discharge. Lifestyle and availability of assistance, if needed, are other important factors to consider.
- An evening program is usually followed during rehabilitation so that is does not interfere with therapies, and also because gravity and increased activity during the day help promote bowel emptying. However, you may switch to a morning schedule prior to discharge if you wish.
- Regularity is important in order to achieve best results, since the bowel is being trained to empty on command. Plan to do your program at approximately the same time every day or every other day (the bowels will tend to respond to a schedule of every 24 hours or 48 hours better than to a schedule of Monday/Wednesday/Friday with 72 hours without emptying on the weekend).
- Taking advantage of the gastro colic reflex can aid evacuation. This reflex occurs approximately 30-60 minutes after eating and is especially strongest after the first meal of the day.
- Bowel movements should never be more than three days apart. If stool stays in the lower bowel for longer than 48-72 hours, changes in consistency may lead to constipation and eventually incontinence.

**Physical Activity**

- You should get as much physical exercise as possible, even if you are on bed rest. Stretch and move every muscle you can. Contract and relax your abdominal muscles by breathing deeply and tightening your abdomen periodically. Do range of motion exercise and change your position frequently.
- Perform as much of your own care as you can. If possible, wash you, feed and dress yourself, and do your own transfers, as well as bowel and bladder program.

**Position**

- The best position is sitting erect on a toilet or commode with feet flat on the floor or on a small stool. This allows gravity to help the process. Assist by rubbing the abdomen up the right side, across and down the left side, following anatomy of the large intestine.
- Use a padded toilet seat, and never stay seated on a toilet or commode more than 30-45 minutes at a time because of the risk of developing a pressure area. Do pressure reliefs while waiting for results.
- If you cannot maintain a sitting position, or are unable to use a commode, lie on your left side in bed. Do not make a habit of doing your bowel program in bed. Sitting up is the more natural, and therefore, more effective way.
- Do not use a bedpan. A bedpan can injury your skin if you sit on it too long, or if you forget to do weight shifts on it.

**Diet**

- Your diet greatly affects your bowel program. Eating regular meals and maintaining a well-balanced diet helps develop a good bowel routine and decreases the chances of unexpected bowel movements.
- Eating roughage (fiber) adds to the bulk necessary to move stool. It helps the stool to become larger and softer by absorbing water. This allows it to move more easily through the intestines.
- Certain foods pass through the intestines at a slower rate. Overeating these foods increases the likelihood of constipation. These foods include: dairy products, white bread, and white rice.
- Certain foods and fluids irritate the intestinal tract. Overeating these foods can cause diarrhea. They include: alcohol, caffeine, spicy or gassy foods.
- Everyone is different. It is important to experiment with different kinds of foods to learn how your body reacts to them and then individualize your diet accordingly.
- For a guide to recommended daily food choices seek advice from a nutritionist.
- Adequate fluid intake is necessary to maintain stool consistency and increase effectiveness of softeners and bulk formers. It is important that you have enough fluid in your diet for the fiber or laxative to do their job. If fluid intake is too limited, dehydration of fiber in stool may lead to extreme constipation.
- http://sci.washington.edu/info/forums/reports/nutrition.asp

**Medications**

- Usually, medications such as suppositories and stool softeners are needed to help establish a proper bowel program. Although bowels can become reliant on laxatives and enemas, it is important to note that under use of medications may lead to more significant complications. Appropriate treatment is best established with advice from a medical doctor familiar with SCI bowel management.
- There are two phases of bowel evacuation. The first phase moves the stool to the rectum. Oral medications may be needed to assist this process. The second phase moves stool out of the rectum. Assistance with this phase may require the use of suppositories or enemas, along with digital stimulation and/or manual evacuation.

## Doing Your Bowel Program

If for any reason you cannot do your bowel program for yourself, you must know the procedure so that you can teach someone else to do it for you. The following steps outline the recommended methods for doing your bowel program for both reflex and non-reflex bowel.

**Reflex Bowel**

- Lying on your left side with padding under your buttocks, check for stool in the rectum by using a gloved index finger.
- Remove any stool you may find. If no stool is felt, you may be able to move higher stool down to your rectum with digital stimulation (see below).
- Insert suppository as directed. Wait 10-15 minutes for the suppository to begin working, then transfer to the commode or toilet. If you are able, you can insert the suppository while sitting on the commode.

1. Once up on the commode, use assistive techniques (prior to performing digital stimulation) to assist the passage of stool for complete evacuation.
2. Rub the abdomen, right to left following the intestine
3. Push or grunt (Valsalva maneuver). This is not recommended for individuals with cardiac history, unless you first consult with your doctor.
4. Lean forward and rock back and forth.
5. Complete deep breathing
6. Take a warm drink such as coffee, tea, warm apple juice or warm water with lemon.

- If you have no results after 15-20 minutes, do digital stimulation, repeat as necessary. Do no sit longer than 30 minutes without pressure relief. If you are not getting results, go back to bed and lie on your left side to finish your program.
- Digital (rectal) stimulation: Recommended method for evacuating reflex neurogenic bowel (for injuries above T-12)
- Causes the rectal sphincter (muscle) to relax and open up so that the stool will be able to pass out.
- This process stimulates a reflex (automatic response) that move the stool out of the rectum

## Potential Problems

The following are the most common problems you may have with your bowel program.

- Autonomic dysreflexia
- Constipation
- Impaction
- Diarrhea
- Hemorrhoids
- Excessive gas/abdominal distention

When you suspect a problem:

1. Try to confirm the signs and symptoms of the problem.
2. Check for possible causes.
3. Know how to handle a problem when it happens.

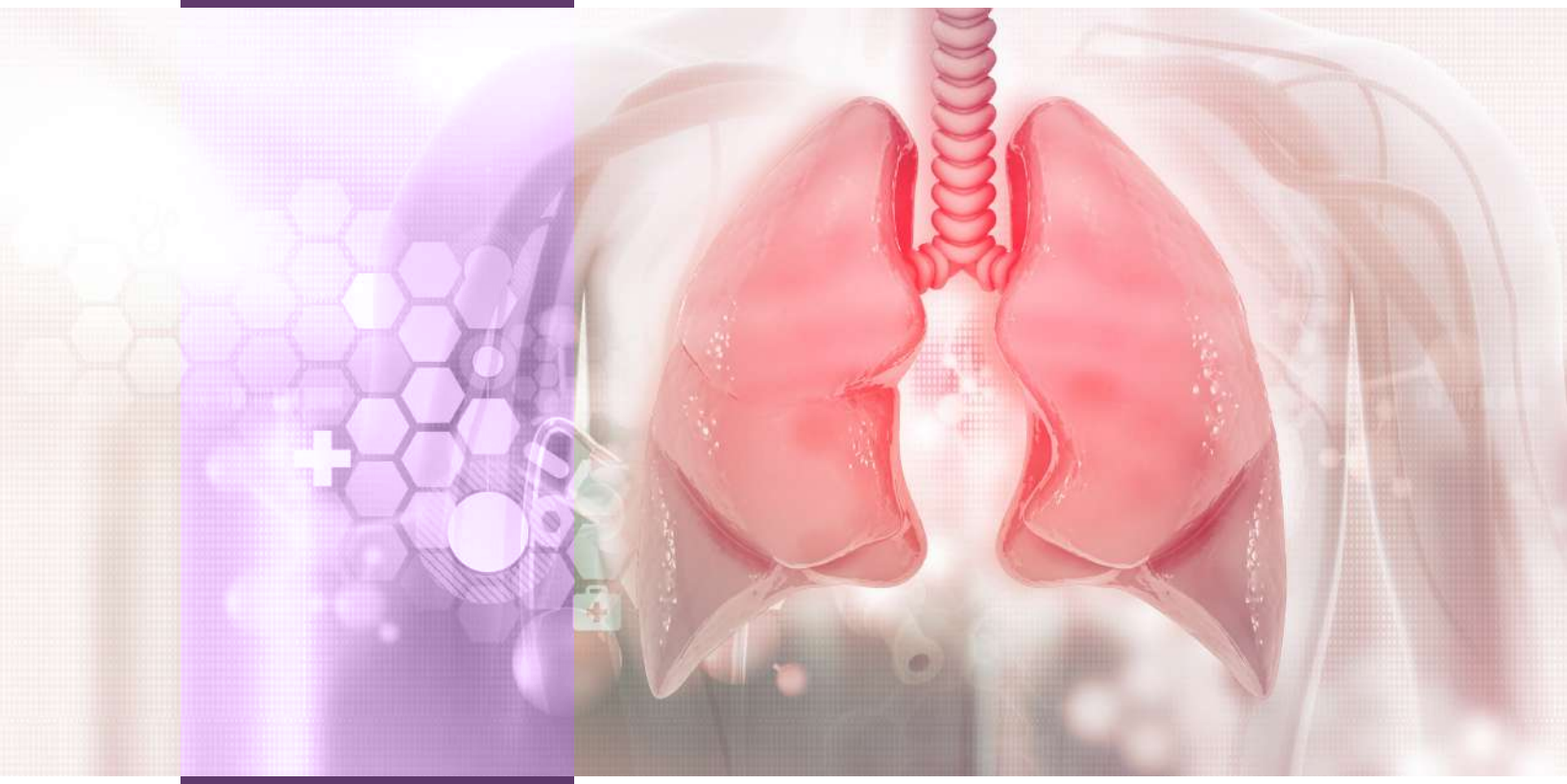
Above all, if you have other problems, contact your doctor right away.

Please see the Paralysis Resource Guide for additional information.

**Scan to watch Gaylord's SCI Education Series Bowel Management with SCI**

SECTION

7



# RESPIRATORY (BREATHING) MANAGEMENT

Your lungs are just like big air bags that fill and empty on a routine cycle. Each lung has a branch of your windpipe that keeps branching off all the way down to very tiny branch ends—it looks like a big, flourishing, upside down tree.

1. Blood vessels run all throughout the walls of your lungs like wiring in the walls of your house. These blood vessels pick up the oxygen you breathe into your lungs and disperse it throughout your body. Every single part of your body requires this oxygen brought in from your lungs to live. That's why good, clear breathing is so important to your health and life.

2. While the blood vessels around the lungs take oxygen away from the lungs, these vessels also "drop off" carbon dioxide into the lungs. Carbon dioxide is like a waste product that must get out of the body or it will poison it. The way it gets out is by being exhaled by your lungs when you breathe out.

**NEITHER SECRETIONS, FOOD NOR POLLUTANTS BELONG IN YOUR LUNGS**

Smoke is a pollutant to the lungs, so you should not smoke or be around people who are smoking. If you are a smoker there are ways your team can help you quit. Ask your respiratory therapist or medical provider for help.

When anything that is foreign to your lungs (like food or dirt in the air), starts to go down your windpipe, your reflex is to cough until it comes up.

If secretions run down your windpipe they end up in your lung. It is especially hard to get rid of the sticky secretions that come with a cold or from smoking. If these materials are not coughed up, they can go from the airways down to the lung. There they can become lodged in the windpipe and build up in your lungs. They become a great place for bacteria to grow. Bacteria can cause pneumonia. Pneumonia is an infection within a part of the lung. This bacteria may be killed by taking antibiotics. Your body's defense against this is a good, hearty cough reflex.

## What does Spinal Cord Injury do to Breathing Muscles?

A spinal cord injury in the thoracic region of the spine can effect your ability to breathe.

**T12 level or above**

Your ability to breathe is decreased because your breathing muscles may be effected. The higher the level of injury, the more muscles around your rib cage become paralyzed. Ribs that expand only a little cannot pull your lungs open enough for a good breath of air. Weak abdominal muscles (stomach muscles) make it hard to cough strongly.

A spinal cord injury in the neck or cervical region effects your breathing muscles.

**C4 level or above**

With these injuries, there may be weakness of the diaphragm as well. The diaphragm is the most important muscle for breathing and being

able to perform a strong cough.

Some people may need a ventilator. Some people may need an artificial airway – tracheostomy – which is a hole in the neck to help them breathe.

Not all persons with a tracheostomy need artificial breathing. They may need the tracheostomy to help get rid of their secretions. Also, not all persons will need artificial breathing all the time. It is important that you speak to your medical provider if any of this applies to you.

## Testing Your Breathing Muscles

Tests may be performed to help your doctor to know how much effect your spinal cord injury has had on your breathing muscles. Some simple methods are used to see how well these muscles are working.

**Respiratory Rate**
This counts how many times you breathe in a minute. It shows how much work you have to do or how fast you have to breathe in order to keep a high enough level of oxygen and low enough level of carbon dioxide in your blood.

**Oxygen Saturation**
Also known as an 02 SAT, this measures the amount of oxygen in your bloodstream. It lets us know if there is an adequate or healthy level of oxygen in your body. This test is performed by placing a clip to your fingertip or earlobe which is connected to a small piece of equipment that looks like a box.

**Maximum Inspiratory/Expiratory Pressure**
This is a non-invasive, straighforward way to measure respiratory muscle strength. MIP is the strongest breath in you can take and MEP is the strongest breath out you can blow. Respiratory therapists may use a manometer to measure your inspiratory and expiratory strength.

## Guidelines To Successful Breathing

To prevent lung collapse and pneumonia in a spinal cord injured person with poor breathing capacity, certain measures **MUST BECOME HABIT**:

**Deep Breathe and Cough**
Several times a day this should be done to improve lung strength. Your lungs' ability will increase by doing this exercise the same way your arm muscles may strengthen by lifting weights.

**Practice Breathing with an Incentive Spirometer**
You will be taught how to use this by your Respiratory Therapist.

Other helpful options may include:

**Drink a lot of Water and other Fluids** – if it is okay with your doctor.
Fluids help thin out normal secretions in your body so it doesn't take so much diaphragm strength to cough them out and so that they are easier to get rid of.

**Exsufflation (Cough Assist)**

A fancy word that is another way to help stimulate a cough in someone who is unable to do it on their own. Coffolator is a mechanical devise that stimulates a cough. It blows air into your lungs and pulls it back out helping to move the secretions and assists you to cough.

**Positive Expiratory Pressure Therapy**
The use of a small device that is often called an Acapella or flutter valve. It is used when you blow out the air. It causes a vibration in the windpipe to help loosen and cough up secretions.

**Chest Physical Therapy (Chest PT)**
To do chest PT, another person helps your weakened chest muscles. This is done by a vibrating vest that is placed on you for a short period of time and helps to loosen secretions. Also can be completed manually by lightly clapping and vibrating their hand over your chest and back, lung secretions are loosened and cleared. Please note that chest PT should be done before meals or 1-2 hours after a meal.

**Expiratory Muscle Strengthy Trainer (EMST)**
EMST is used for patients with weakness in respiratory function, swallowing, cough, and voice. Using this device targets external and internal obliques, intercostals and supra hyoid muscles. EMST has shown to reduce risk of respiratory complications.

**Assisted Cough**
Lung secretions need a good strong cough to be brought up from the lungs so you can expectorate or "spit" them out. If, however, your cough is not strong enough, you may need a little extra help. This is the role of the "ASSISTED COUGH".

When someone helps you cough, all they are doing is giving the force of your own cough a little extra "umf". Follow these steps:

1. Your helper should place one hand on top of the other on the part of your abdomen between your belly button and the lower tip of your breastbone (that's the first bone you run into as you go up from your belly button to your neck).
2. Take a deep breath and hold it for one second before you cough.
3. At the same time you cough, your helper pushes firmly UP and INTO your diaphragm. Each time your cough, your helper should push in this way.

Make sure you and your family are trained by your therapist or nurse before trying this.

Assisted cough as well as the guidelines mentioned on the previous pages, allow the spinal cord injured person to have "clear" lungs for good respiratory health.

***Watch Gaylord's SCI Education Series: Breathing & Pneumonia***

Scan to Watch

**DO NOT SMOKE OR BE AROUND SMOKERS**

Smoke is a pollutant to the lungs. Therefore, if you are currently a smoker there are ways to assist you in quitting. Ask your Respiratory Therapist or Medical Provider for information.

SECTION

8

# MEDICAL CONSIDERATIONS WITH SPINAL CORD INJURY

A spinal cord injury can lead to a number of secondary health conditions that require ongoing awareness and management. This chapter serves as a quick-reference guide to help you understand, prevent, and respond to these common issues. Being knowledgeable is the first step toward proactive self-care.

## Autonomic Dysreflexia

You are at risk for Autonomic Dysreflexia if your level of spinal cord injury is at or above T6, although it has been known to occur as low as T10. Autonomic Dysreflexia, or AD, is a potentially life threatening medical emergency.

AD occurs in response to a stimulus below your level of injury, such as an overstretched bladder. The sympathetic (emergency) nerves of your autonomic system kick into action and cause your blood pressure to go up quickly, and potentially to a dangerous level.

**What are the causes?**
Anything that can irritate your body, such as on overfilled bladder, constipation, ingrown toenail, or clothes too tight.

**What are the symptoms?**
May include sweating, pounding headache, stuffy nose, flushed face, goosebumps above the level of SCI.

**What can happen if I don't stop the AD?**
The blood pressure can go very high, and cause severe damage such as a stroke.

**What do I do?**

1. First thing you do is sit up or raise your head to 90 degrees. If you can lower your legs, do so.
2. Find the source of the problem- empty the bladder.
3. Clean out your bowels with a bowel program using Lidocaine jelly to help numb the nerves. Remove any painful stimuli.
4. If you are having sex, stop immediately.
5. Loosen any clothes.
6. Look for ingrown toenails, skin sores, and signs of infection.
7. Medications can be used if the cause cannot be identified.

## Orthostatic Hypotension

Orthostatic hypotension is a sudden drop in blood pressure that occurs when changing position from lying down to sitting up or from sitting to standing. With this quick position change gravity causes blood to rush down to your legs. Since your muscles are not working as effectively as they did before your spinal cord injury, they do not pump the blood back up towards your heart as effectively as they did prior to your injury.

**Symptoms of orthostatic hypotension:**

- Lightheadedness or dizziness
- Nausea
- See “stars” or blurred vision
- Ringing in your ears
- You could pass out/faint.

**What should you do when this happens?**
When you first begin to get symptoms have someone raise your legs up and/or tip you back. This can help to prevent you from passing out. If you still have symptoms after this you may need to return to bed and lie flat with your legs elevated.

**How can you help to prevent orthostatic hypotension?**

- Get up slowly. Raise the head of your bed up 15-20 min. prior to getting out of bed. Dangle your legs off the edge of the bed for a few minutes prior to transferring.
- Get out of bed every day, bed rest increases your risk of getting orthostatic hypotension.
- Wear elastic stockings (TEDS) and an abdominal binder.
- Drink plenty of fluids.
- If you have tried all of the above and are still having problems with orthostatic hypotension consult with your doctor. Your doctor may need to make medication changes to help reduce your symptoms.

## Deep Venous Thrombosis

***Watch Gaylord’s SCI Education Series: Deep Venous Thrombosis***

**Scan to Watch**

Deep Venous Thrombosis, or DVT, is a blood clot. When blood pools in the legs, blood flow can slow down and a clot, or blood blockage, can form.

The biggest risk for DVT is within the first few weeks after a spinal cord injury, but they can develop later. People with SCI are at risk for DVT in their legs, especially if they are not as mobile. In other words, the less active a person is, the more risk they have for DVT.

**What should I watch out for?**

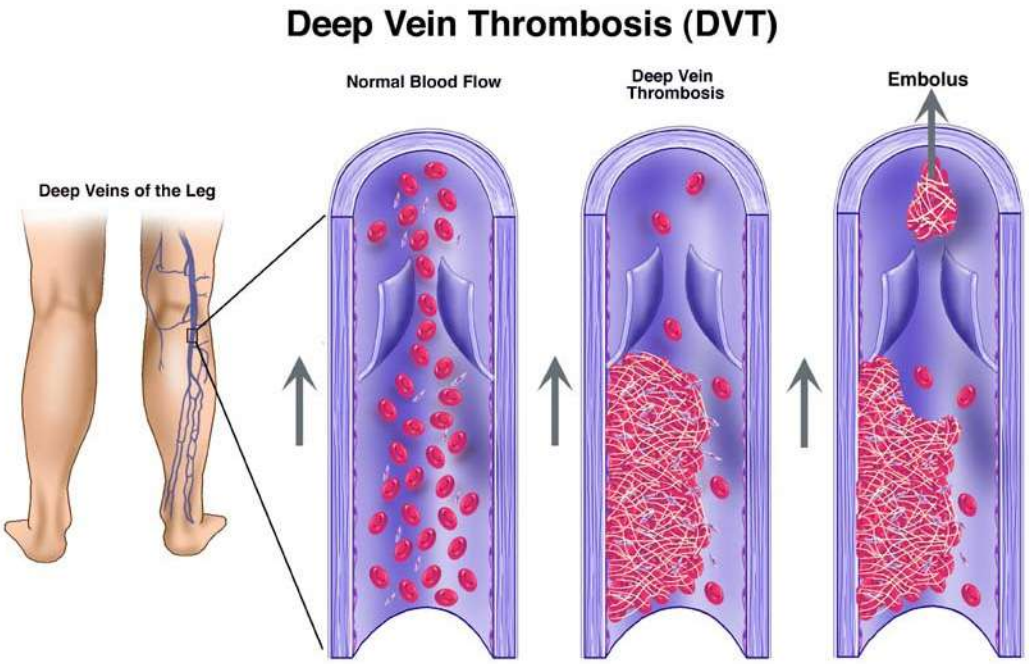
- Swelling in the leg and or calf
- Increased warmth or redness in the legs
- Tenderness in the leg
- Fever

If you have any of these symptoms, your doctor may order an ultrasound of the leg. This test is quick, painless, and helps determine if you have a DVT

**Prevention**
Keeping as mobile as possible is important. Compression socks when out of bed may help as well.

Sometimes a medication is used, such as a blood thinner, to help prevent clots.

**Why is a DVT serious?**
Blood clots can be dangerous because they can break off and move through the blood system to your lungs. A clot in the lung is a Pulmonary Embolism. The clot blocks blood that is going to the lungs to pick up oxygen. If the blood can't pick up oxygen, the oxygen can't get to the rest of the body. Symptoms of a pulmonary embolism can include trouble breathing and chest pain




**What is the treatment for a DVT?**
In those people that can safely have their blood thinned, a medication is used. If not, an "IVC Filter", or Inferior Vena Cava filter may be placed: this device, placed into a major deep vein, helps catch any clots that may form in the legs or deep vessels so they don't get to the lungs.

Medication may be used to help prevent the clots from forming. These medications are often injected. Some people may need to continue using these medications at home for a while, after their discharge from Gaylord.

## Heterotopic Ossification

Sometimes after spinal cord injury, bone can grow in places it normally doesn't. This is called heterotopic ossification. This most commonly involves the major joints such as hips, knees, shoulders and elbows. This can lead to a decrease in range of motion surrounding the joint, and the joint can become hot and swollen. This is usually diagnosed by your health care provider with an x-ray. Your provider may track labs and x-rays to follow the progress of this bone. You will work with your therapists to develop a stretching program to help improve your range of motion.

## Pain

There are many different types of pain seen in spinal cord injury. People with SCI can certainly have acute pain, such as stubbing a toe, or hitting a fingernail with a hammer. Those with SCI may also experience what is called visceral pain, or organ pain, such as that seen in appendicitis.

Depending on the level of SCI, different people will experience different degrees of these types of pain. Some of the most concerning types of pain are chronic pain and nerve pain. Pain can be caused from overuse of joints, inflamed joints, muscle pain, spasticity, overuse syndromes, and other types. Your doctor can help sort out the different types of pain, their potential causes and treatments.

After SCI, there may be changes in the central nervous system that lead to a pain often described as burning, aching, tingling, pressure, or a "tight band". This pain can often be treated with nerve pain medications, such as Neurontin, Lyrica, Cymbalta, Elavil, Pamelor, and others. Psychotherapy, relaxation, biofeedback, behavior modification, and other interventions used in therapy may be helpful.

## Spasticity

Immediately after a SCI, the muscles are usually loose and flexible- not stiff, even if they cannot be moved on their own. This is called spinal shock. When the shock is over, usually after 2-6 weeks, the reflexes return and spasms may occur.

Spasticity is a side effect of paralysis and usually involves muscle stiffness and involuntary muscle contractions. It can be seen in SCI as well as other conditions, such as multiple sclerosis and brain injury. Most people with SCI have some degree of spasticity.

**What causes spasticity?**
After spinal cord injury the normal flow of nerve signals to the area below the injury is interrupted. Parts of the spinal cord lose their normal signals, some of which are inhibitory, and the muscles then become overactive, or spastic, and "jerking"

**Why is it important?**
Spasticity can interfere with comfort, and the spasms may make rehabilitation more difficult by interfering with function. However, at times the spasms may in fact be useful. Some people may use their spasms for function. So spasms, and spasticity are not necessarily a bad thing.

**What makes it worse?**
In general, anything stressful to the body  such as  infection, injury, or skin sores, can cause an increase in spasticity.

**How is it treated?**
Treatment usually consists of medications. See medication section. The more common medication choices include baclofen, tizanidine, and sometimes diazepam. Non-pharmalogical treatments may also be helpful when treating spasticity. The use of stretching, electrical stimulation, and other treatments may help. Botulinum toxin may be used to treat selected muscles; the injection usually lasts 3-4 months. The body may build antibodies to it which may reduce its effectiveness. At times, surgery is used to release tendons that have become shortened over time due to spasms.

## Edema

Edema is swelling that occurs when extra fluid accumulates beneath the skin's surface. Edema is commonly found in areas of the body such as the legs and feet. This type of swelling often occurs when your legs have been dangling down for long periods of time, as when sitting in a wheelchair.

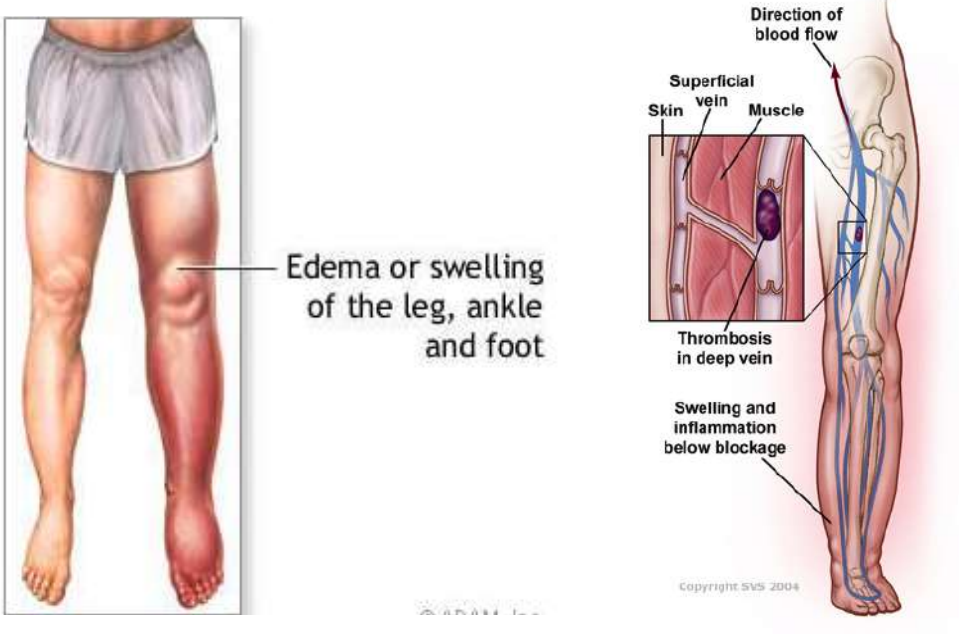
The muscles in the legs are responsible for pumping fluid from the feet back up towards the heart. A person with spinal cord injury has weakness in their legs and the ability to create this pumping action is impaired. As a result, fluid commonly collects and pools in the legs, ankles and feet.

What can you do to prevent this type of swelling?

1. Elevate your feet above your heart for periods of time during the day, whether it be elevating your legs while in the wheelchair or lying down.
2. Monitor your salt intake. Salt can cause you to retain water.
3. Wear compression stockings (TEDs) when out of bed.
4. If you are able, perform ankle pumps while in bed. This helps fluid move away from the legs and feet.

Make sure to monitor your skin carefully if you have any swelling. When there is swelling, your shoes or socks may fit tighter and rub on the skin, causing skin breakdown and even autonomic dysreflexia.

If swelling is not relieved with the use of the above prevention techniques, extends into the upper thigh, or if you experience shortness of breath or chest pain, make sure to contact your doctor right away. If your swelling has a sudden onset, or you notice a significant change in the amount of swelling, you should contact your doctor.



## Thermoregulation

You may find that the temperature of your environment affects you more than it did before your spinal cord injury. After a spinal cord injury, the nerves that travel to the blood vessels are interrupted and your body changes the way that it adapts to cold or hot environments. Using too many blankets may cause your temperature to go up. Not wearing enough clothes in a cold room can cause your temperature to go down. Try to dress in layers so that if you start to get hot you can remove a layer and vice versa. This is more common in people with SCI at or above T8.

SECTION

9

# MEDICATIONS

Medications are an important part of the treatment of spinal cord injury. They may help your body adjust to the chagnes that have occurred since your injury. Below are examples of some common medications for peole with SCI.

**Note: Do not drink alcohol with these medications**

## Spasticity

**Baclofen: (Lioresal)**

- **How it works/what it is:** Muscle relaxant that acts on the central nervous system to reduce muscle spasms.
- **Side effects:** Drowsiness, dizziness, weakness, headache, nausea.
- **Important information:** Do not stop suddenly; taper under medical supervision to avoid withdrawal symptoms.
- **Additional:** May be used with some other antispasticity medications.

**Tizanidine (Zanaflex)**

- **How it works/what it is:** Muscle relaxant that works by blocking nerve signals to relax muscles.
- **Side effects:** Drowsiness, dizziness, dry mouth, weakness, low blood pressure.
- **Important information:** Do not stop suddenly; do not use with alcohol or other CNS depressants.
- **Additional:** Can cause liver enzyme changes; monitor liver function

**Diazepam (Valium)**

- **How it works/what it is:** Benzodiazepine that calms the nervous system to treat anxiety, seizures, and muscle spasms.
- **Side effects:** Drowsiness, dizziness, confusion, muscle weakness, headache, dry mouth.
- **Important information:** Do not stop suddenly; taper to avoid withdrawal. Avoid alcohol and other CNS depressants.
- **Additional:** Can be habit-forming; use only as prescribed.

**Dantrolene Sodium (Dantrium)**

- **How it works/what it is:** Muscle relaxant that acts directly on skeletal muscles to reduce spasticity and spasms
- **Side effects:** Drowsiness, dizziness, weakness, fatigue, diarrhea, nausea, constipation, muscle weakness
- **Important information:** May cause liver damage-monitor liver function.
- **Additional:** May cause photosensitivity—protect skin from sunlight.

## Bladder Management

**Oxybutynin (Ditropan)**

- **How it works/what it is:** relaxes bladder muscles to treat overactive bladder
- **Side effects:** Dry mouth, constipation, blurred vision, dizziness, drowsiness
- **Important information:** Has a long acting formultion and short acting formulation
- **Additional:** increased risk of confusion in older people

**Tolterodine (Detrol)**

- **How it works/what it is:** reduces bladder muscle contractions for overactive bladder
- **Side effects:** Dry mouth, headache, constipation, dizziness, blurred vision
- **Important information:** Short acting and long acting formulations
- **Additional:** Avoid alcohol and other CNS depressants

**Tamsulosin (Flomax)**

- **How it works/what it is:** relaxes bladder neck muscles to improve urine flow
- **Side effects:** Dizziness, headache, abnormal ejaculation, runny nose
- **Important information:** Take at bedtime to minimize dizziness
- **Additional:** Monitor blood pressure

**Mirabegron (Myrbetriq)**

- **How it works/what it is:** relaxes the bladder muscle to treat overactive bladder
- **Side effects:** High blood pressure, headache, cold symptoms, urinary tract infection, dizziness
- **Important information:** Monitor blood pressure regularly
- **Additional:** may be used with other bladder medications

## Nerve Pain

**Amitriptyline (Elavil)**

- **How it works/what it is:** increases certain neurotransmitters to treat nerve pain
- **Side effects:** Drowsiness, dry mouth, constipation, blurred vision, weight gain
- **Important information:** Do not stop suddenly; taper to avoid withdrawal
- **Additional:** may be helpful for sleep; typically given at night

**Nortriptyline (Pamelor)**

- **How it works/what it is:** increases certain neurotransmitters to treat nerve pain
- **Side effects:** Drowsiness, dry mouth, constipation, blurred vision, weight gain
- **Important information:** Do not stop suddenly; taper under supervision
- **Additional:** Typically less sedating, but still may help sleep

**Pregabalin (Lyrica)**

- **How it works/what it is:** reduces nerve pain by affecting calcium channels.
- **Side effects:** Dizziness, drowsiness, weight gain, swelling in hands/feet.
- **Important information:** Do not stop suddenly; taper to avoid withdrawal.
- **Additional:** There are specific dosing options for spinal cord injury

**Gabapentin (Neurontin)**

- **How it works/what it is:** reduces nerve pain by affecting calcium channels.
- **Side effects:** Dizziness, drowsiness, weight gain, swelling in hands/feet.
- **Important information:** Do not stop suddenly; taper to avoid withdrawal.

- **Additional:** Watch for swelling

**Duloxetine (Cymbalta)**
- **How it works/what it is:** antidepressant that increases serotonin and norepinephrine to treat depression and nerve pain
- **Side effects:** Nausea, dry mouth, dizziness, fatigue, constipation
- **Important information:** Do not stop suddenly; taper to avoid withdrawal
- **Additional:** May be used with other nerve pain medications

## Blood Thinners

**Warfarin (Coumadin)**
- **How it works/what it is:** Anticoagulant that prevents blood clots by inhibiting clotting factors
- **Side effects:** Bleeding, bruising, nausea, hair loss
- **Important information:** Requires regular blood tests (INR monitoring)
- **Additional:** Avoid sudden changes in diet (especially vitamin K-rich foods)

**Apixaban (Eliquis)**
- **How it works/what it is:** Direct oral anticoagulant that inhibits factor Xa to prevent blood clots.
- **Side effects:** Bleeding, bruising, nausea, anemia
- **Important information:** No routine blood monitoring required, but report any unusual bleeding
- **Additional:** Do not stop suddenly except on doctor's advice; risk of stroke if stopped abruptly

SECTION

10

# EMOTIONAL ADJUSTMENT

# I Am Lost

*By: David Rosenblum, M.D.*
*Gaylord Hospital*

I hardly know what happened, it was so fast-
Pain, hospital, and now I cant move.
Cant feel.
My body isn't working- and I don't know why.
I am angry.
I am confused.
I am lost

They sent me here to work on my "rehab"
But I cant do anything.
Paralyzed.
They tell me my bladder isn't working.
My bowels, too.
They try to turn me like a pancake every two hours
Something about my skin
They try to get me out of bed, to the gym.
I push them away.
They keep coming back.
I hate it
I am lost

I can't sleep. The room is dark. I am alone
They come to take my blood. A needle.
I say no.
They try to give me pills. And a shot.
I say no
I push them away.
Hard.
I use words that hurt.
Because I hurt.
I am lost
I am afraid.

The staff comes in, and I yell at them.
Go away.
I know them better now, so I know which words hurt more.
I feel my anger.
And I feel my loss.
My words say I hate you.
And worse.
Brave bravado, unkind, hostile, aggressive
Hiding fragile thoughts that I could never say:
I hope you wont leave me
Even as I push you away.
I am lost.
I want to give up.
I hope you wont give up on me.

I am learning more about my body
More about what I need
More about what I can do
And more about how to cope.
Its hard.
I don't like it.
I still push away
I am starting to feel safer- but my anger flows freely
Especially to those I care for the most
And those that try to help me
But I am starting to talk about it.
A little.
Despite what I say, I don't hate you.
I hate what happened.
I hate being lost.

A quite moment.
The staff comes in my room to help
A reminder of what I have lost.
I am trying. Do they see that?
I build up my courage
And try to find the right words
To say what I'm feeling:
Please, help me find my way

“Adjustment” is how you adapt to, or become used to new situations. This is a continuous and at times difficult process. We recognize that it takes time to adjust to a new “normal” routine after injury, and you will adjust to life after a spinal cord injury in your own way and in your own time frame. There is no “one way” to adjust to life after a spinal cord injury. You may feel “different” in your body in the early weeks and months after your injury.

It is common to experience a sense of loss or grief following your injury, and there are several factors which can impact this including:

- Role reversal/dependency
- Stigmatization (what will people think”)
- Loss of job/financial security
- Changes in sexual functioning
- Social contact/isolation
- Loss of activities
- Additional health complications
- Changes in level of social/family support

While there is no “one size fits all” for how to adjust to a spinal cord injury, we do know that there are thoughts and feelings that are common. These include:

## Denial/Disbelief

This is a normal reaction to deal with overwhelming emotions and to help with copings. You block out the words and hide from the facts. This is a temporary response that carries us through the first wave of pain.

## Anger

Some people react to their injury with strong feelings of anger. This occurs as the denial wears off and you are not ready to accept what has happened. You may feel resentful and/or angry with yourself and with others for not preventing the loss injury. If properly handled, anger can be helpful and useful tool for motivation in the rehabilitation process. However, if handled incorrectly, anger can be destructive. By recognizing and expressing anger in a positive way, it can motivate you to deal with problems and achieve goals. If you need assistance in effectively coping with anger, members of the rehabilitation team can help you.

## Sadness

Feeling sad is normal after your injury,no matter what level or severity your injury is. Sadness is “feeling down” or “feeling blue” when something bad happens, and should be openly discussed with your rehabilitation team.

## Depression

Depression is a medical condition that is beyond “feeling down or blue” and sadness. Depression may cause some, or all of, the following physical and psychological symptoms:

- Changes in sleep (too much/too little)
- Feeling down or hopeless
- Loss of interest or pleasure in activities you once enjoyed
- Changes in appetite (over or undereating)
- Decreased energy
- Difficulty concentrating
- Feelings of worthlessness or self-blame
- Thoughts of suicide or death

If you are experiencing symptoms of depression, it is important to speak with your rehabilitation team for help. It is important to treat the depression as early as possible to avoid further complications, including decreased motivation towards the rehabilitation process.

## Acceptance

Reaching this stage of loss/grief is a gift not afforded to everyone. When acceptance is reached, there is usually more motivation to set/meet long and short term goals. These goals are different for everyone and often change throughout life.

It takes time to grieve your loss and come to accept the realities of your injury. It is important to believe that you will regain a sense of control and that all of your feelings are legitimate. Using available resources, including professionals, family and friends to deal with your thoughts and feelings is extremely important to your overall adjustment and well-being.

## Support and Resources

The department of psychology/social work provides support and counseling for patients while both inpatient and outpatient. The support can be individual or with family, friends and members of your identified support system. There are a variety of programs offered by Gaylord as well as community resources that can assist with coping and adjustment. These include a prayer service coordinated by a Gaylord chaplain, a referral to a peer mentor program, and information on community support groups. Please reach out to our social work/psychology for additional information.

SECTION

11

# SEXUALITY & SPINAL CORD INJURY

Sexuality is a natural and important part of life that continues after a spinal cord injury. While an SCI can change how your body responds physically, it does not diminish your capacity for intimacy, pleasure, and fulfilling relationships. Discussing your questions and concerns about sexuality with your care team is a normal and encouraged part of your rehabilitation. This chapter provides information and resources to help you explore and understand sexuality after your injury.

## Sexuality for Women with Spinal Cord Injury

**Sexuality**
Sexuality is an expression of one's self as a woman or man. It is intimate in nature, which means it is personal and private. Sexuality is commonly expressed through physical and emotional closeness. Most people consider sexual activity as a means to express physical intimacy. However, physical intimacy is more than sexual intercourse. Holding hands, hugging and kissing are good examples of ways to express physical intimacy. Likewise, emotional intimacy is more than feelings that result from physical contact. Emotional intimacy can be a connection with one's self that results in feelings of self-satisfaction, confidence and self-worth. It may also be a feeling of trust in another person and an openness to share private thoughts and feelings.

**After Spinal Cord Injury**
As a woman with spinal cord injury (SCI), you will discover that sexuality is still an important part of your life. It may take some time for a newly injured woman to become comfortable with her body and resume natural feelings of sexuality. Healthy adjustment begins with knowing the facts about the impact of SCI on sexual issues.

**Sexual Function**
In actuality, there are few physiological changes after injury that prevent women from engaging in sexual activity. Some women have decreased vaginal lubrication. This problem is likely the result of the interruption in normal nerve signals from the brain to the genital area.

Typically, lubrication occurs as a mental and physical reflex response to something sexually stimulating or arousing. Lubrication is a sign of sexual arousal and generally results in easier vaginal penetration and more pleasurable sexual activity. While most women with SCI maintain some degree of lubrication, those who wish can utilize a water-based lubricant such as K-Y Jelly, (never use oil based lubricants), to facilitate sexual activity.

Depending on your level and completeness of injury, you may experience a change in surface sensation and ability to contract your muscles. This may lead you to try sexual positions or activities different from those prior to your injury. Talking to your partner about your need and/or desire for these new activities and positions is also a way to improve your relationship.

One of the changes that you may notice after SCI is that it takes longer for an orgasm to occur and/or it feels different. While the majority of women with SCI are able to experience orgasm, it may take more stimulation than prior to injury. Also, many of the medications that women take can make it more difficult to achieve orgasm.

If you are having difficulties, the use of a vibrator may help women with an injury below the T6 level. It may also be helpful to speak with your physician to see if your medications could be adjusted to minimize their impact on your sexual responses.

**Fertility**
It is normal for most women to experience a brief pause in their menstrual cycle after SCI. This pause may last as long as six months after the injury. However, a study from the UAB Model SCI System (Jackson, 1999) showed that the ability of women to have children is not usually affected once their period resumes. If your period does not resume, talk to a doctor about possible options for treatment.

**Sexual Adjustment**
Women who know the facts about living with SCI understand that the loss of movement or sensation does not mean a loss of pleasure. Women with SCI can, and do, resume active, enjoyable sex lives after injury.

Issues with body image can be a primary area of concern (see Table 1). It is important because how you feel about yourself will influence your desire to engage in sexual activity, and your partner's desire as well. A positive attitude and a little humor will naturally attract others to you and will help you feel good about yourself.

One of the main keys to adjustment is learning to manage impairment related issues of everyday life. All women have doubts, concerns and questions, so it is normal for women with SCI to feel the same way. However, the facts are simple. Women with SCI:

- Are desirable
- Have the opportunity to meet people, fall in love, and marry
- Are sexual beings
- Have sexual desires
- Have the ability to give and receive pleasure
- Can, and do, enjoy active sex lives
- Can become pregnant and have children

Women who accept these facts as true will find it easier to achieve a satisfying and happy sexual relationship.

**You and Your Partner**
Many women worry about whether or not they can maintain a relationship after injury. In reality, it is impossible to predict the success of any relationship. Lasting relationships depend on a number of factors such as personal likes and dislikes, common interests and long-term compatibility. All relationships take hard work, dedication and commitment.

Women with SCI need to help their partners understand the issues of spinal cord injury and the areas of concern. Communicate clearly and work together to solve problems. This is a great way to build physical and emotional intimacy.

**Areas of Concern about Sexual Activity**
- Urinary Accidents
- Bowel Accidents
- Not satisfying a partner
- Feeling sexually unattractive
- Others viewing me as sexually unattractive
- Not getting enough personal satisfaction
- Preparation too much trouble

- Hurting self
- Loss of interest
- Not liking methods for satisfaction

The above list ranks ten common areas of concern for women with SCI. While these concerns may be more common right after injury, these are life-long issues that may always need special attention. The best way to feel good about these concerns are to discuss them with your partner ahead of time, be aware of what could happen and be prepared to deal with any problems that arise. In time, you and your partner will become more at ease in dealing with these issues.

**Bladder management** is a concern for most women with SCI. There are a number of ways to reduce the chance of urinary accidents during sexual activities. First, women might limit fluid intake if they are planning a sexual encounter. Drinking too much fluid increases urine output and causes the bladder to fill more quickly. Women who use intermittent catheterization for bladder management can empty their bladder before engaging in sexual activity. Women who use a Suprapubic or Foley catheter may have concerns about the tubing. The Foley can be left in during sexual intercourse because the urethra (urinary opening) is separate from the vagina. If the catheter tube is carefully taped to the thigh or abdomen so that it will not kink or pop out, it should not interfere with intercourse. Women also have the option of removing the Foley catheter before sexual activities, but the catheter needs to be properly reinserted following sexual activities.

**Bowel management** is another concern for women with SCI. The best way to avoid accidents is to establish a consistent bowel management program. Once a routine is established, an accident is much less likely to occur. For added confidence, empty your bowel and avoid eating before sexual activity.

**Sexual satisfaction** may be an issue for some women who wonder whether or not they can be sexually satisfied or satisfy a partner. Talking to your partner, experimenting with new ideas and working together will help you find mutual satisfaction.

**Sexual exploration** can also help couples enhance their physical pleasure. The goal is to find sexual activities that are interesting, enjoyable and mutually pleasurable. As couples work together, it may help to try different methods of giving and receiving physical pleasure. Some couples may find that methods for gaining sexual satisfaction are the same as before injury. However, those “old” methods may not be satisfying. Sexual exploration can help you and your partner enhance your physical pleasure. The goal is for both you and your partner to gain mutual satisfaction. Hopefully, you will then find that sexual activity is interesting and enjoyable.

It may also be necessary for some couples to explore a variety of sexual positions to find comfort during sexual intercourse. This exploration may be needed especially if spastic hypertonia (muscle spasms or contractures) or pain occurs during sexual activities. If spastic hypertonia or pain is a problem, it is
recommended that you talk to a doctor for advice on treatment.

**Sexual arousal** is the emotional and physical process of stimulating excitement and readiness for sexual activity. Emotionally, you will likely find that you are still aroused by the same things as before your injury. These emotionally stimulating activities might include dressing up, a romantic dinner, showering together or an erotic film. This is another opportunity for sexual exploration. It may help to know what other women with SCI find physically arousing. Also, it is often helpful to “explore” your body and see what works before being sexually active with a partner. Women have reported they

can achieve arousal through their mouth and lips, neck and shoulder, clitoris, stomach, vagina, thigh, breasts, buttocks, ears and feet.

**Other Potential Problems**
Autonomic Dysreflexia (AD) is a life-threatening condition for women at the level of T-6 injury and above. Although sexual activity normally results in a rise in blood pressure, which is one sign of AD, women at risk and their partners should be watchful for other signs such as irregular heart beat, flushing in the face, headaches, nasal congestion, chills, fever, blurred vision, and/or sweating above the level of injury.

While AD has not been noted in lab studies of sexual response in women with SCI, if you experience multiple signs of AD during sexual activity stop immediately. If symptoms continue after stopping, it is crucial to contact a doctor immediately for advice.

**Verbal and physical abuse** is an unfortunate reality in some relationships. Women who are in an abusive relationship can talk to friends, family, doctors or clergy to find local agencies that help women escape abusive relationships. Seek help from the agency of your choice. However, if needed, the National Domestic Violence Hotline is 1-800-799-SAFE (7233) or text BEGIN 88788 or chat online at https://www.thehotline.org

**Sexual Dysfunction** in women is gaining interest in the medical community. For women with SCI, dysfunction is most often a lack of desire to participate in sexual activities or a failure to achieve satisfaction. There are treatment options available, so talk to your doctor if you think sexual dysfunction might be impacting the quality of your sex life.

**Aging** can impact sexuality. Many women have a decline in sexual interest and a decrease in vaginal lubrication after menopause. It is worthwhile to discuss these issues with your doctor because in some cases medications may be prescribed to assist with these problems. Although it is natural to experience some changes in sexuality over time, there is no reason why you cannot continue to enjoy an active sex life as you age.

**Conclusion**
Sexuality does not have to change after spinal cord injury. Women with SCI can still express sexuality both physically and emotionally. However, it is important for women to learn how their injury may have changed their mind and body. When you prevent potential problems and properly manage areas of concern, you will feel comfortable in exploring, expressing, and enjoying all aspects of sexuality regardless of your level of injury.

If needed, women with SCI should not hesitate to get professional advice if they experience problems related to sexuality. For example, a professional counselor can help resolve problems with self adjustment and relationship issues. A physiatrist (doctor who specializes in rehabilitation medicine) can be an educational resource for women and help them manage medical issues. Plus, a physiatrist can likely recommend a urologist and gynecologist knowledgeable on issues related to sexual and reproductive health for women with spinal cord injury.

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**Resources**

*Secondary Conditions of Spinal Cord Impairment Health Education Video Series - Sexuality and Sexual Function (2006)*
Free video from the University of Alabama at Birmingham Model SCI System. Online at: https://www.youtube.com/watch?v=Wk6ruAZ2ztc&feature=youtu.
A 3 DVD series, sold only as a set, is available by mail. Total cost is $30. Make check payable and send to:
UAB Office of Research Services
619 19th St S, SRC 529,
Birmingham, AL 35249-7330
(205)934-3283

*Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities (and the People who Care About Them)*
By Ken Kroll and Erica Levy Klein, book, approx 220 pages, available for purchase online, $15.95 plus S&H: https://www.newmobility.com bookstoreromance. cfm?type=REG&order_id=new
Or contact No Limits Communications, Inc. at (888)850-0344

*SexualHealth.com*
This website provides information about the ways in which different kinds of spinal cord injuries can affect sexual relationships and functioning.
http://www.sexualhealth.com/ channel.php?Action=view sub&channel=3&topic=11

*Spinal Cord Injury Manual*
A free online publication from the Thomas Jefferson University Regional Spinal Cord Injury Center of Delaware Valley (includes a section on Sexuality).
Available online at: https://jdc.jefferson.edu/cgi/viewcontent.cgi?article=1016&context=spinalcordmanual_eng
To inquire about mail service call (215) 955-6579

*Spinal Cord Injury: Sexuality*
Article from the Rehabilitation Institute of Chicago LIFE Center, reviewed November 2006. Available free online at: https://www.sralab.org/lifecenter/resources/spinal-cord-injury-sexuality or contact (312) 238-LIFE (5433)

*Sexuality Reborn*
Video available for purchase from Kessler Medical Rehabilitation Research & Education Center. Online order form at: https://www.kflearn.org/courses/sexuality-reborn or call (973) 243-6812

*Through the Looking Glass*
A nationally recognized center that has pioneered research, training and services for families in which a child, parent or grandparent has a disability or medical issue.
http://lookingglass.org
2198 Sixth Street, Suite 100, Berkeley, CA 94710-2204
1-800-644-2666 (VOICE)

*The National Domestic Violence Hotline*
http://www.ndvh.org
If something about your relationship with your partner scares you and you need to talk, call the National Domestic Violence Hotline at:
1-800-799-SAFE (7233) or 1-800-787-3224 (TTY)

*Dating & Relationships after SCI*
Free online SCI Forum Report from the University of Washington NW Regional SCI System. Available online at:
http://sci.washington.edu/info/forums/reports/dating.asp
Or contact (206) 685-3999

Visit the Spinal Cord Injury Information Network at
**spinalcord.uab.edu**

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## Sexual Function for Men with Spinal Cord Injury

**Introduction**
Many men with spinal cord injury (SCI) experience changes in their sexual function and ability to biologically father children. In addition to these physical changes, most men also experience emotional issues that often affect their overall sexuality. It is very important for men and their partners to understand and address these issues as a part of the overall adjustment to life after injury.

**Normal Sexual Function**
Men normally have two types of erections. The brain is the source of psychogenic erections. The process begins with sexual thoughts or seeing or hearing something stimulating or arousing. Signals from the brain are then sent through the nerves of the spinal cord down to the T10-L2 levels. The signals are then relayed to the penis and trigger an erection. A reflex erectionoccurs with direct physical contact to the penis or other erotic areas such as the ears, nipples or neck. A reflex erection is involuntary and can occur without sexually stimulating thoughts. The nerves that control a man's ability to have a reflex erection are located in the sacral nerves (S2-S4) of the spinal cord.

**Sexual Function After Injury**
For men with SCI, the ability to have a psychogenic erection depends on the level and extent (complete or incomplete) of injury. Generally, men with low level incomplete injuries are more likely to have psychogenic erections than men with higher level incomplete injuries. Men with complete injuries are less likely to experience psychogenic erections. However, most men with SCI are able to have a reflex erection with physical stimulation regardless of the extent of the injury if the S2-S4 nerve pathways are not damaged. Because each SCI is different, the impact of injury on sexual function can also differ.

Although many men with SCI are capable of gaining and maintaining an erection sufficient for sexual activity, erectile dysfunction (ED) is also common. ED is the inability of a man to achieve or maintain an erection sufficient for his sexual needs or the needs of his partner. ED can be a problem for men who are
newly injured, or it may develop at any time after injury. Men with SCI who are experiencing ED should have a thorough physical exam by a doctor familiar
with SCI.

**Medications for ED**
The first treatment option for ED is almost always an oral medication of phosphodiesterase inhibitors such as Viagra® (sildenafil), Cialis® (tadalafil) or Levitra® (vardenafil HCl). These pills are self-administered by mouth and work by increasing blood flow to the penis to improve erectile function. Men will not get an erection just by taking the pill. Sexual stimulation is also required for an erection. Once a man has completed sexual activity, blood flow to his penis should decrease and his erection should go away.

Differences in study populations, primary end points, and measurement tools make comparisons of all three drugs difficult. However, studies show that all three medications appear to be equally effective in treating ED and are generally well tolerated by men in SCI.

Remember, it is essential to talk to a doctor prior to taking any medication. ED medications can be harmful if taken by men with certain medical conditions. Some men may prefer or respond better to one medication over the others. Proper dosage varies among the three medications, and men taking the same medication may respond to different dosages. Because level of injury and possible side-effects are other factors to be considered, it is probably best for men with SCI and their primary care doctors, if needed, to first talk with a doctor familiar with ED and SCI.

**Alternative for ED**
Other treatment options are available for those who do not respond to, or cannot take, oral medications. These treatment options also have associated risks to consider, so it is important to talk

to a doctor for more information.

*Penile injection therapy* involves injecting a single drug or a combination of drugs into the side of the penis. This produces a hard erection that can last for
one to two hours. These drugs must be used exactly as prescribed by the physician. This method is not recommended for use more than once a week. A penile injection is a difficult option for a man with limited hand function due to SCI. Therefore, he must have assistance in getting the injection.

*Medicated Urethral System Erection (MUSE)*, or transurethral therapy, is a medicated pellet placed into the urethra where it is absorbed into the surrounding tissue. This causes the blood vessels to relax and allows blood to fill the penis. The drug, alprostadil, is the same as used in penile injection therapy.

The *vacuum pump* is a mechanical option for producing an erection that, for most men, is sufficient for intercourse. The penis is placed in a vacuum cylinder and air is pumped out of the cylinder causing blood to be drawn into the erectile tissues. The erection is maintained by placing a constriction ring around the base of the penis. This ring also prevents urinary leakage that some men with SCI experience. It is important to remove the ring after intercourse to avoid prolonged pressure and the risk of sores. A battery operated model is an option for those with limited hand function, and another model requires good hand function to press the pump against the skin to create the necessary vacuum.

*Surgical implantation* is often the last treatment option for ED because it requires a permanent penile prosthesis. The procedure involves inserting an implant directly into the erectile tissues to obtain an erection.

Three types of implants are available: semi-rigid or malleable rods, fully inflatable devices, and selfcontained unit implants.

**ED Treatment Risk Factors**
*Priapism* is a prolonged erection. Priapism occurs if the blood fails to drain from the penis. This can damage the penile tissue and be extremely painful. Men need to seek immediate medical attention if an erection lasts more than 4 hours. Priapism must be treated as soon as possible or lasting damage can happen to the penis can occur, including the inability to have erections.

*Autonomic Dysreflexia (AD)* is a life-threatening condition for men with SCI at level T6 and above. Signs of AD include flushing in the face, headaches, nasal congestion and/or changes in vision. These symptoms are also possible side-effects of oral medications, so it is very difficult to know if the symptoms are for AD or a common side-effect of the medications. Men at risk for AD will need to consult with their doctor about what to do in the case of developing symptoms. It is usually recommended for men to stop sexual activity if they experience symptoms.

A check of blood pressure is needed to determine if symptoms of AD are occurring. Higher than normal blood pressure is associated with AD.

**Fertility**
The fertilization process typically begins during sexual intercourse as the sperm is ejaculated into the woman's vagina. Motile sperm then move through the cervix, uterus, and into the fallopian tubes. Pregnancy results when the man's sperm fertilizes the woman's egg.

Many men with SCI and their partners want to have children. Although there are some couples who have little or no difficulty with fertility, many men with SCI are unable to father children through sexual intercourse.

Ejaculation problems are the primary issues to be resolved for men who want to become fathers. About 90% of men with SCI experience anejaculation, which is an inability of men to ejaculate on their own during intercourse. Another potential problem is retrograde ejaculation, which is a condition wherein semen is deposited in the bladder instead of exiting the body through the urethra.

Poor semen quality can also make it very difficult for men with SCI to fertilize the egg. Men with SCI make normal numbers of sperm, but the average number of motile sperm in semen from men with SCI is 20% compared to 70% in men in the general population. It is not know why there is abnormally low sperm motility, but it does not seem to be related to level of injury, age, years post injury, or frequency of ejaculation.

**Fertility Treatments**
Men who experience fertility problems must rely on alternative methods to improve their ability to father children. There are potential risks that need to be considered with all treatment options, so men with SCI need to talk to a doctor experienced in fertility issues related to SCI.

Semen quality is varied, but the exact cause of poor semen quality is unknown. Some recent research has shown that normal semen can be obtained for about 6-12 days after in injury. This may allow some men to have their normal semen frozen in an effort to improve fertility rates at a later date. Some men who have a large number of dead sperm (necrospermia) may see improvements through repeated ejaculation. Otherwise, there is little that can be done to improve poor semen quality.

Because of problems with ejaculation, most men with SCI must rely on alternative techniques to achieve parenthood. Penile vibratory stimulation (PVS) can be used to achieve an erection, but its main purpose is to produce an ejaculate for those who wish to become fathers. A variety of vibrators/ massagers are available for this purpose. Some are specifically designed with the output power required to induce ejaculation in men with SCI. Estimations are that 55% of all men with SCI can expect to respond to a high amplitude vibrator, and 80% will respond if their injuries are above T10. PVS is usually recommended as a first treatment option because of the low investment of time and money. Although research suggests that the better quality semen is obtained with PVS, Rectal Probe Electroejaculation (RPE) is an option if PVS is not successful. With RPE, a doctor inserts an electrical stimulation probe into the rectum, and the controlled electrical stimulation produces an ejaculation. When sperm cannot be retrieved using PVS or RPE, minor surgery can be performed to remove sperm from the testicle. Collected sperm are used in artificial insemination techniques.

**Sexual Adjustment**
Pre-injury life was probably routine, familiar, and comfortable. Following injury, however, things can suddenly change. Pre- and post-injury routines are usually very different, and men who are newly injured will likely face a lot of physical and emotional changes as they adjust to life after injury. It takes some time to rebuild a life following SCI and learn about SCI and self-care issues such as bowel, bladder and skin care. Once those daily self-care issues are managed, sex usually becomes an issue of importance.

Most everyone has established views of what is considered a “normal” sexual relationship prior to injury. Following injury, changes in views and established routines may be needed. Sexual adjustment

is essential to the overall adjustment to life for men following injury. It is common for men with SCI to be unsure as to whether or not they can give or receive physical pleasure. They may experience a loss of self-satisfaction, confidence, and self-worth.

As time passes, many men with SCI begin to experience a greater appreciation for sexuality as a whole. Hopefully, they will regain any lost feelings of self-satisfaction, confidence, and self-worth as they become more comfortable with their bodies. They often find pleasure in holding hands, hugging and kissing in addition to sexual intercourse. Many men also experience a greater emotional closeness with loved ones.

**Relationships**
Men who are single may wonder about meeting potential partners. The reality is that there is no difference before and after injury. Men who put themselves in positions to meet new people have a greater opportunity for meeting potential partners. If you meet someone and ask that person on a date, the answer will be "yes" or "no."

It is common for men to take time to become comfortable with their bodies following injury, and partners will likely need time to adjust too. Partners need to understand about SCI and health-related issues such as bowel, bladder and skin care.

Open, honest communication is essential for couples. They need to work together to manage heath-related issues if needed. Couples need to talk about how each person feels about those issues. Couples can talk about, explore and experiment with different ways to be romantic and intimate. Together, both men and their partners can discover how to best give and receive pleasure and satisfaction.

For men or couples who have difficulty with relationships, a professional counselor can help in processing feelings that are common after injury. This may include working through feelings of anxiety over establishing or continuing a healthy relationship after a spinal cord injury. A counselor also can work with couples on healthy ways to communicate.

**Smart Sex**
The risk of sexually transmitted disease (STD) is the same both before and following SCI. Therefore, men need to take precautions to protect against STD such as gonorrhea, syphilis, herpes, and AIDS.

Men who are able to ejaculate should also protect against pregnancy if they do not want to father children. Protection is needed even if men have poor semen motility or numbers.

For men who engage in sexual intercourse and want to prevent unwanted disease and pregnancy, a male or female condom (Latex/Polyurethane) is recommended even if the partner is using another form of birth control. However, a condom is not 100 percent reliable and most reliable only when used correctly.

**Conclusion**
Men with SCI can be both romantic and intimate with their partners. This information sheet cannot address in detail all the issues related to sexuality for men with SCI. Please contact your doctor for information on sexual issues.

**Resources**

*Guide and Resource Directory to Male Fertility following Spinal Cord Injury/Dysfunction.*
www.scifertility.com

*Sexuality and SCI*
http://www.pvamagazines.com/pnnews/magazine/article.php?art=232
Paraplegia News

*Sexuality, Fertility, & Parenting*
http://sci.washington.edu/info/forums/reports/report_subject.asp#sexuality

*First Times*
http://www.newmobility.com/
review_article.cfm?id=332&action=browse New Mobility

*How Sexy is Your Brain?*
http://www.newmobility.com/
review_article.cfm?id=1253&action=browse New Mobility

*Aging & Sexuality*
http://www.pvamagazines.com/pnnews/magazine/ article.php?art=709 Paraplegia News

**Watch Gaylord's SCI Education Series: Sexuality After a Spinal Cord Injury**

Scan to Watch


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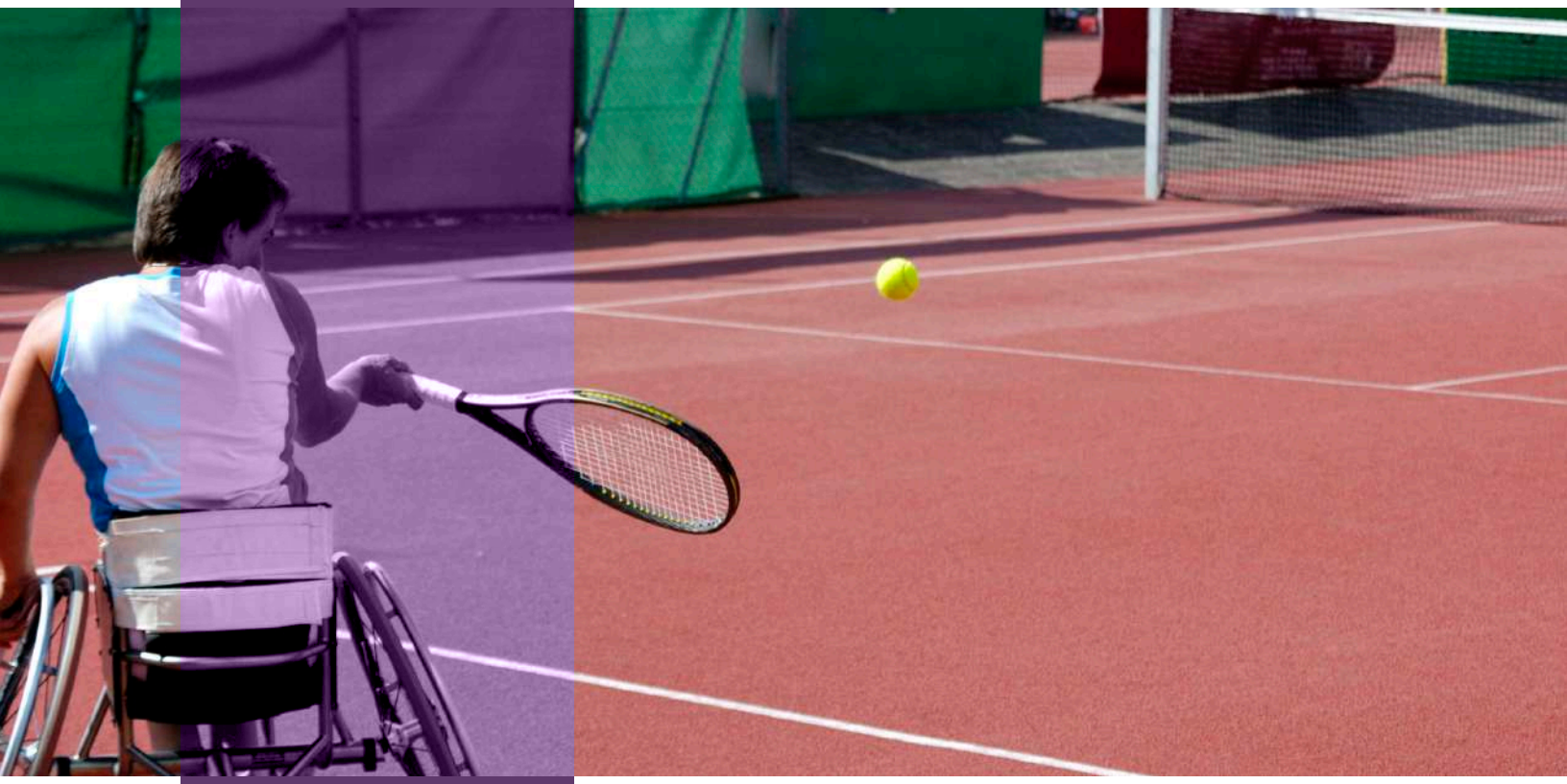
SECTION

12



# WHEELCHAIRS

Mobility is important to your quality of life and is necessary for functioning at home, work, school and play. Good mobility can help your self-image, social interaction, and health. If you have a spinal cord injury, regardless of your level of injury or completeness of injury, you may require a wheelchair to achieve mobility. It is important that you work closely with your doctor and therapist to determine which type of wheelchair is most appropriate for you.

## Types of Wheelchairs

**Manual mobility devices**
A manual wheelchair is a wheelchair with four wheels. Typically, you need good upper body strength to use a manual wheelchair. You also need to be able to perform independent pressure relief and positioning while seated in a manual wheelchair. There are many types of manual wheelchairs. The most common manual wheelchair used by an individual with a spinal cord injury is called an ultra-lightweight wheelchair.

**Ultra-lightweight manual wheelchair**
An ultra-lightweight manual wheelchair is a wheelchair that is made with light weight components. It has significant ability to be customized. It can accommodate components to improve your positioning and posture in the wheelchair. An ultra-lightweight wheelchair can have a folding frame, which allows the wheelchair to fold in half, or a rigid frame that has a frame that is welded in a set position.

Other types of manual wheelchairs that can be used if you have a spinal cord injury include:

**Reclining wheelchair**
A manual reclining wheelchair is a wheelchair in which the seat back of the wheelchair can be reclined, much like a car seat. This typically is a heavy wheelchair with a long frame making it difficult for you to propel yourself. A reclining wheelchair is used if you have a problem with low blood pressure, have range of motion limitations in your hips, have respiratory or orthopedic problems that require you to recline, or require a method of pressure relief. This type of wheelchair is often used during the initial phases of recovery from spinal cord injury.

**Tilt-in-space wheelchair**
A manual tilt-in-space wheelchair is a wheelchair in which the entire seat of the wheelchair can be tilted forward or backward. This typically is a heavy wheelchair with a long base making it difficulty for you to propel yourself. A tilt-in-space wheelchair is used to allow you to perform pressure relief by shifting your weight from the seat cushion to the back support. It is also used to give you increased trunk stability, to prevent changes in your posture or to decrease your tone. This type of wheelchair is often used during the initial phases of recovery from spinal cord injury.

**Standing manual wheelchair**
A standing manual wheelchair is a wheelchair that has a standing frame built into the frame of the wheelchair. It allows you to propel to a location and come to a supported standing position or propel in a standing position. This type of wheelchair has many functional applications in the home and workplace and allows you to receive the medical benefits of standing.

**Transport wheelchair**
A transport wheelchair is a manual wheelchair with four small wheels that you are unable to propel yourself. Someone must push you in this wheelchair. This wheelchair does not have any custom seating options. This type of wheelchair is not typically used with spinal cord injury, unless you can walk and only infrequently require the ability to be pushed in a wheelchair.

**Standard weight, or lightweight manual wheelchair**
A standard or lightweight manual wheelchair is a wheelchair that is manufactured with components that are heavier than an ultra lightweight wheelchair. This type of wheelchair has limited ability to be customized for you. This type of wheelchair is often used upon discharge from Gaylord while you are waiting for your custom wheelchair to be delivered. This type of wheelchair is only used as a permanent wheelchair if you can walk and only infrequently require the ability to propel yourself in a wheelchair.

## Power mobility devices

A power mobility device, including power scooter, power wheelchair, and power assist system, is typically used if you cannot push or propel a manual wheelchair due to arm weakness, pain, or poor endurance, or if you cannot perform independent positioning and pressure relief in a manual wheelchair.

**Scooter**
A scooter is a power mobility device with three or four wheels and a tiller style steering mechanism. There is no custom seating available on a scooter. This is primarily used if you require a wheelchair for long distance mobility only, do not require any custom seating or positioning, and cannot propel a manual wheelchair.

**Power Add On Unit/Power Assist System**
A power assist system is an electronic system that can be added to most manual wheelchair bases. In a system with motorized wheels, the motors multiply the force applied to the wheels by the user to give the user more power during propulsion. These wheels can be removed for transport or when not needed, however they are extremely heavy. This system is appropriate for you if you can complete independent positioning and pressure relief in a manual wheelchair but experience some difficulty with manual wheelchair propulsion. This system also allows you to have the portability and maneuverability of a manual wheelchair. Another type of system is a power add-on unit. This unit attaches to the wheel axle and functions like cruise control in a car. It is lighter than the motorized wheels and is a great option for independent community mobility, particularly if you do not have access to a wheelchair accessible van.

**Power wheelchairs**
A power wheelchair is a wheelchair that consists of a battery powered, motor-propelled base and a seating system. A power wheelchair is used if you are unable to propel a manual wheelchair or perform independent positioning and pressure relief in a manual wheelchair. Three drive configurations for power wheelchairs exist: front wheel drive, mid/center wheel drive, and rear wheel drive. Many options exist to allow you to operate a power wheelchair, including joysticks and switches to operate with your fingers, hands, chin, head, tongue, breathing, feet or legs.

Several power seating systems can be added to a power wheelchair as appropriate. These include:

**Power tilt system**
This system tilts your entire seat backwards and returns you to upright. This assists with pressure relief, changes the affects of gravity on your body, can inhibit pain and fatigue, can help with your posture, can increase your trunk stability, and can decrease edema in your legs (if used in conjunction with elevating leg rests).

**Power recline system**
This system reclines your seat back, much like a car seat. This can allow you to catheterize seated in the wheelchair, can assist with pressure relief, can accommodate range of motion limitations, and can help decrease pain, fatigue and edema.

**Power elevating leg rest system**
This system raises and extends your legs while seated in the wheelchair. This accommodates range of motion limitations, and can help decrease pain, edema and spasticity.

**Power seat lift**
This system raises the seat height of the wheelchair. It can increase independence and safety with transfers and can increase independence with performance of home management and self care tasks. It also has many benefits in social settings and work environments.

**Power standing system**
This system is a power standing frame system that is built into the power wheelchair. This allows you to attain the physiological benefits of standing while using your wheelchair.

## Manual and Power Wheelchair Accessories

Most components of wheelchairs have many options and are customizable, from seat size to arm rests, foot supports, wheels/tires and electronics.

**Seat cushion**
A seat cushion must be added to all wheelchairs. The role of a seat cushion is to provide pressure relief, positioning, and comfort. Many types of cushions exist, including foam cushions, gel cushions and air cushions. Proper cushion selection can prevent skin breakdown and changes in posture.

**Back support**
A back support must be added to all wheelchairs. The role of a back support is to provide stability to the trunk. Many options exist, including sling upholstery, adjustable tension upholstery, rigid, and custom molded. Proper back support selection can provide trunk stability and help with proper posture.

## Wheelchair Evaluations

It is important that you be properly evaluated for your wheelchair to ensure that the appropriate equipment is selected. Selection of the right equipment should:

- Improve your independence with mobility
- Provide equipment that is functional, safe and comfortable
- Improve your posture and function in the wheelchair
- Help you to prevent secondary complications caused by poorly fitting ormalfunctioning equipment, including deformity, skin breakdown, pain and depression

A wheelchair evaluation should consist of a comprehensive evaluation by an occupational or physical therapist of the following components:

- Your goals and needs
- Current and previous equipment
- Functional abilities
- Environments in which you will use the equipment, including home, work and school
- Physical Assessment, including: skin and soft tissue, range of motion, tone, active movement, pain, posture, balance, sensation, and endurance

A wheelchair evaluation can be done while you are an inpatient, a skilled nursing facility resident, a home care patient or an outpatient. If you are an inpatient, your custom wheelchair can only be ordered by the facility that will directly discharge you to home. If you are going to a skilled nursing facility after leaving Gaylord, that facility will order your wheelchair. It typically takes several months after your evaluation to receive your custom wheelchair. You might receive a standard weight or lightweight wheelchair as a loaner wheelchair until your custom wheelchair is available.

After you receive your wheelchair, it is important that the wheelchair be adjusted to fit you properly; small adjustments to your wheelchair and seating system can make a significant difference in your mobility. You should be instructed in safe and effective use and maintenance of your equipment. You should also be able to perform or direct wheelchair management. Remember that successful wheelchair use requires training and practice.

**Scan to learn more about Gaylord's outpatient Wheelchair Assessment Services**

SECTION

13

# TECHNOLOGY

Assistive technology (AT) is any item, piece of equipment, or product system, that is used to increase, maintain, or improve your functional capabilities. Assistive technology can be off the shelf, modified or customized.

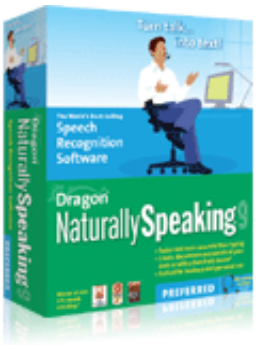
Assistive technology enables you to fully participate in meaningful activities and fulfill life roles. Trained therapists work collaboratively with individuals to determine the most effective and efficient piece of assistive technology to meet your needs.

Therapists may recommend devices to help you be more independent with feeding, bathing, dressing, communicating, cooking and/or accessing their home environment. Assistive technology also includes devices that increase your mobility, computer access and communication.

Assistive technology may be considered 'low tech' or 'high tech'. Low tech equipment may include a long handled reacher or a leg strap. High tech equipment may include an environmental control unit that can control lights and simple appliances in your home.

Therapists work with both you and your family to determine specific goals and objectives. Therapists are able to evaluate your skill level and make recommendations as appropriate. Assistive technology also includes making adaptations to existing equipment to increase your level of function.

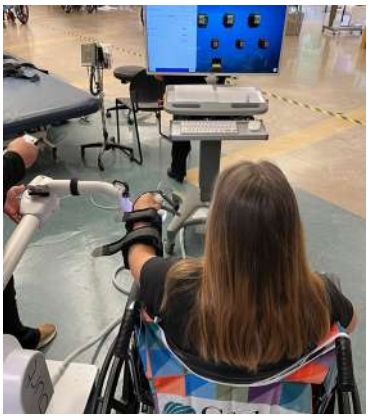
During your inpatient stay, your therapy and medical team will begin to introduce you to a variety of assistive technology that meets your needs. We will be able to provide you with a number of resources and trial assistive technology products if appropriate.




**Meta Quest 3**

The Meta Quest 3 is a virtual reality system that immerses the patient into a new virtual environment. The patient can experience total immersive simulations (fully simulated experience) or mixed reality simulation (view of the real world with an overlay of digital elements). It is a wireless modality that can be utilized in any location with connection to wifi. Patients can choose the intervention or experience they wish to engage in – archery, guided meditation, job simulation, exploration, and learning new skills are all options. Benefits include patients working on functional skills such as balance, strength, and skill development through sports or movement, improve executive functioning and problem solving, and coping and adjustment to the disability or returning to a career

through simulation. Experiences can be guided by a therapist in a 1:1 session or in conjunction with other therapies. These experiences can be performed from a seated or standing position.



**BURT**
BURT is our upper extremity robotic device intended to treat shoulder and elbow weakness, motor control and proximal upper extremity range of motion. BURT is targeted for many different neurological diagnoses including stroke, brain injury, spinal cord injury, brachial plexus injuries, multiple sclerosis and Parkinson's disease. It has helped numerous patients regain strength and function in their affected upper extremity. Patients enjoy the interactive games and are constantly motivated to beat their prior scores. Patients have fun playing the games while simultaneously getting in multiple repetitions in all functional planes. BURT has been a great addition to our patients recovery process

**Omnicuff**
Omnicuff is a versatile assistive device designed for individuals with adaptive hand needs, empowering them to securely hold and use everyday objects with ease.  Patients can more easily switch between various ADL items such as utensils, grooming tools, electronics, etc." Patients have the opportunity to trial this device during their inpatient stay and their therapist can assist patients with ordering a custom set for home prior to discharge

**ZeroG® Gait & Balance System®**
The ZeroG Gait and Balance System protects patients from falls while providing dynamic body-weight support as patients practice walking, balance tasks, sit-to-stand maneuvers and even stairs. Because ZeroG is mounted to an overhead track, there are no barriers between the patient and therapist. With the only ZeroG in Connecticut, inpatients can begin rehabilitation as early as possible in a safe, controlled environment.

**AlterG® Anti-Gravity Treadmill®**
AlterG Anti-Gravity Treadmills use NASA-developed Differential Air Pressure (DAP) technology that enables unprecedented unweighting therapy and training capabilities. This unique unweighting with air pressure comfortably lifts the user and allows him/her to walk or run at a fraction of their body weight. Gaylord has AlterG treadmills in all outpatient locations.

## Ekso Bionics ™

**What is Ekso™ ?**
Ekso™ is a wearable robot or exoskeleton that enables people with lower-extremity paralysis or weakness to stand and walk. It is a ready to wear, battery powered, bionic device that is strapped over the user's clothing.

**How does it work?**
Ekso is an adjustable, portable, bionic exoskeleton designed to help people with lower-extremity paralysis or weakness stand up and walk. With the individual providing the balance and proper body positioning, Ekso allows them to walk over ground with reciprocal gait. The physical therapist uses the control pad to program the desired walking parameters, such as step length and speed, as well as control when the Ekso stands, sits, and takes a step. It is powered by two high-capacity lithium batteries which drive the hip and knee motors.

**How much does the device weigh?**
The device weighs approximately 50 pounds (23 kg). The user doesn't support the weight of the device as it is transferred into the ground through the Ekso structure.

**How is a person evaluated to use Ekso?**
In order to be eligible for Ekso the individual needs to bring a medical release. Then, a comprehensive physical evaluation is conducted, which typically takes one hour. During this evaluation, a physical therapist examines key requirements for use including range of motion, muscle strength and spasticity.

**How long does it take to fit Ekso after initial evaluation?**
The fitting of the individual and the adjustment of Ekso typically takes ten minutes. Ekso can be adjusted to fit most people between 5'2" and 6'2" who weigh 220 pounds or less.

**How fast can a user don and doff Ekso?**
An experienced user can transfer to/from their wheelchair and don or doff the Ekso in less than 5 minutes. The torso and leg straps are designed to enable the user/patient to easily get in and out of the device with none or minimal assistance.

**Who is it for?**
Ekso is for people with lower-extremity paralysis or weakness who would like assistance to stand up and walk. The user needs near normal range of motion, arm function and adequate arm and hand strength to manage crutches or a walker, as determined during the evaluation. If you can transfer independently from a wheelchair to a chair, are between 5'2" – 6'2" (150-190 cm) tall and weigh 220 lbs (100 kg) or less, you are most likely a candidate.

**How fast can someone walk in it?**
The walking speed of Ekso depends on the individual's aptitude and condition. Ekso allows walking speeds up to 1 mph.

**Will users always use a walker? When can they use crutches?**
All users complete a training program when learning to use Ekso. The learning curve is quite user specific and can depend on many factors. Usually, individuals begin using a walker and progress to crutches.

**How does the physical therapist assist a user?**
The physical therapist operates the Ekso with a remote control. This allows the PT to teach the user when to take a step, how to position their body for proper balance, and how to shift their weight in preparation to take another step. The PT also has the ability to modify Ekso's walking pattern (i.e. step speed and length) as the individual progresses.

## Functional Electrical Stimulation

Electrical stimulation is the clinical use of electrical current to cause a contraction in a muscle.

When electrical stimulation causes the muscles to contract in a purposeful way, this is called functional electrical stimulation or FES. The most common application of functional electrical stimulation is to pedal a stationary lower extremity bicycle, called an FES bike.

When using an FES bike, electrodes are applied to the muscles in your legs. Your legs are then secured to the pedals of a special bicycle. A computer then sends electrical stimulation to your muscles, making them contract in the right sequence to pedal the bicycle. The computer monitors the strength and duration of your muscle contractions.

**The benefits of using an FES bike are:**

- Maintaining or increasing muscle mass
- Maintaining or improving lower extremity circulation
- Maintaining or improving lower extremity range of motion
- Maintaining or improving cardiovascular status

You might be appropriate to use an FES bike if you have a spinal cord injury that results in leg weakness. Your physician must clear you to use an FES bike. X-rays might be needed prior to FES bike use. Use of the FES bike is usually started as an outpatient.

Some possible reasons you might not be able to use the FES bike include:

- Discomfort or pain from the electrical stimulation
- Impaired skin integrity
- Cardiac or respiratory problems
- Unstable or healing fractures or orthopedic problems

If you do get trained in use of the FES bike and want to continue using one, the Connecticut Chapter of the Spinal Cord Injury Association has several FES bikes available for use throughout the state.

Contact the Chapter office for information at (203)-284-2910 or read about it at www.SCIACT.org/FES.asp

**Bioness® L300 Go System**
The Bioness L300 Go system is a FES or Functional Electrical Stimulation device that is used with individuals post SCI, stroke or ABI that present with foot drop and/or impaired strength in the knee extensors and flexors. It works by stimulating the nerve that controls the movements that assist in lifting the foot or supporting the knee to assist with improving walking.



**Onward ARC$^{EX}$ System**
The Onward ARC-EX is the first system approved for non-invasive spinal cord stimulation for people with spinal cord injuries. Onward ARC-EX can be applied externally to the areas where the spinal cord has been damaged, in an attempt to activate dormant nervous system pathways to restore and optimize functions previously affected by the injury. The ARC-EX is intended to improve hand sensation and strength for those with a chronic cervical spinal cord injury.

## Standing Frame

A standing frame is a piece of medical equipment that allows you to be supported in a standing position if you have weakness in your trunk and legs. A standing frame can be a separate piece of medical equipment or can be built into a manual or power wheelchair. You can attain a standing frame for use in your home. Use of a standing frame does not substitute for therapy, but can be an important part of your rehabilitation and health maintenance.

Research has shown that passive or supported standing has many benefits if you have a spinal cord injury. It is important that a therapist and physician be involved with the use and selection of a standing frame. You must use caution when using a standing frame to avoid injury.

Regular use of a standing frame may minimize many complications that you can experience due to prolonged sitting in a wheelchair. The potential benefits of using a standing frame include:

- Maintaining range of motion in your hips, knees and ankles
- Improving posture and spinal alignment
- Reducing pressure on your internal organs, which can improve respiratory, bowel and bladder function

- Decreasing the occurrence of urinary tract infections, due to improved bladder function
- Preventing loss of bone density by allowing you to bear weight through your legs
- Improving circulation in your legs and decreasing swelling in your legs and feet
- Reducing muscle spasms
- Providing good pressure relief to your skin
- Reducing fatigue
- Increasing confidence and improving mood

If you have a standing frame that is built into your manual or power wheelchair, additional benefits include:

- Increasing your ability to reach items in your home, workplace or community
- Improving your ability to perform activities of daily living
- Improving your ability to perform vocational tasks and recreational activities
- Increasing the ease of use of a standing frame system

Your physician must clear you to initiate and perform a standing program. You might not be appropriate for a standing program if you have:

- Existing contractures
- Skeletal deformities
- Existing bone mineral density loss and osteoporosis.
- Postural hypotension
- Skin breakdown

The frequency and duration of your standing program must be determined by your therapist and physician.

Above adapted from the RESNA Position on the Application of Wheelchair Standing Devices, March 2007.

SECTION

14

# AQUATIC THERAPY

Aquatic therapy may be a part of your rehabilitation process on an inpatient, or more typically, on an outpatient basis. Aquatic therapy or therapeutic exercise in water, provides a soothing and efficient method of exercise for achieving movement. Gaylord's Aquatic Therapy program includes treatment provided by physical and occupational therapists with advanced training in aquatic therapy techniques. The ability to swim is not necessary to participate in aquatic therapy. After discharge, you the opportunity to get a membership to aquacize, Gaylord's independent, community-based acquatic program.

## Benefits of Aquatic Therapy

The physical properties of water diminish the effects of gravity, allowing for:

- Earlier movement of the limbs and functional mobility training
- Reduction of pain
- Muscle relaxation
- Improved flexibility
- Improved endurance
- Pressure relief and improved circulation
- Improved balance and coordination
- Increased strength

Water-based therapy is beneficial because of the water's buoyancy, warmth and hydrostatic pressure. Water diminishes the effects of gravity, allowing for decreases pain and increased mobility. When you particiapte in acquatic PT or OT treatment, you will recieve an individualized exercise program that may include:

- Strengthening and flexibility exercises
- Endurance training
- Gait training
- Relaxation
- Modified swimming instruction
- Pain reduction
- Balance and coordination activities
- Spasticity reduction

About the Therapeutic Pool

Gaylord's 75-by-25 foot therapeutic pool is specially designed for people with disabilities. The water is maintained at a temperature within a therapeutic range averaging 90 degrees F. Features include:

- Hydraulic lift
- Ceiling lift
- Stairs with rails
- Transfer ledge with wheelchair access
- Adaptive exercise and swimming equipment
- Bench in the water for seated exercise
- Accessible locker rooms and showers
- Heated towels and bathing suit spin dry
- Separate customized changing area for those needing caregiver assistance
- Temperature controlled observation room

The following conditions would prohibit participation in Aquatic Therapy:

- Open wounds
- Bowel incontinence
- Bladder incontinence
- Urinary Tract Infection in initial stages
- Uncontrolled seizures
- Isolation precautions
- Skin infections
- Fever
- Tracheostomy

There may be other medical circumstances that may require discussion with your physician or therapist prior to participation in aquatic therapy. If you are interested in Aquatic Therapy, discuss if it is an appropriate exercise method with your physician.

SECTION

15

# EXERCISE & NUTRITION

## Nutrition and Spinal Cord Injury

**Healthy Diet and Weight Management**
Good eating habits are an important part of staying healthy after spinal cord injury. For a short time after injury, your nutritional needs are usually increased. This is because your body is under a lot of stress to repair damage and to fight off infection. Often, you are told during this time to eat as much as possible, eat more protein, or take high calorie, high protein supplements.

As your body heals, your need for extra calories and protein decreases. To avoid too much weight gain, you will most likely need to eat less than you did before your injury. Excess weight gain can put you at higher risk for skin breakdown, heart disease, diabetes, and high blood pressure. Extra weight can also make mobility and transfers harder.

While there is no one eating plan that is right for everyone, most nutrition experts agree that the best approach is to eat more vegetables, fruits, and whole grains, with moderate amounts of lean protein, dairy products, healthy fats, and less saturated fat, sugar, and salt. Some examples of health eating plans to consider are:

- USDA's My Plate plan (ChooseMyPlate.gov)
- Mediterranean Diet (Mayoclinic.com or Heart.org)
- DASH (dietary approaches to stop hypertension) diet (Dashdiet.org)

**Health Risks**
Having a spinal cord injury may put you at higher risk for heart disease and diabetes. You can help lessen this risk by eating a healthy diet, keeping your weight down, and staying as active as possible. Having your blood sugar levels, blood pressure, and lipid levels (triglycerides, cholesterol, HDL and LDL cholesterol) checked regularly are important ways to monitor and manage your risk. A healthy diet to help manage these risks should include:

- Choose healthy fats (canola or olive oil, nuts, seeds, avocado, fatty fish such as salmon) instead of saturated fats (animal fats, butter, shortening, hydrogenated fats, coconut, palm & palm kernel oil).
- Choose whole grains (whole wheat breads, oatmeal, brown rice, whole wheat pasta) over refined grains (such as white bread, white rice, and white pasta).
- Try adding more plant based foods such as tofu, tempeh, edamame, quinoa, nuts, and legumes such as lentils, chickpeas, split peas and black beans.
- Limit added sugars (sugar sweetened drinks, candy, sweet treats, sweetened cereals). To satisfy a sweet tooth, choose fresh fruit instead.
- Limit sodium intake to no more than 2300 milligrams per day. Watch out for high sodium foods such as soups, frozen meals, processed meats, and condiments. Choose lower sodium alternatives by reading nutrition facts labels and focus on foods that are naturally lower in sodium (fresh fruits and vegetables, fresh meat/poultry/fish and grains).

**Nutrition for Skin Health**
Eating a balanced diet with plenty of fluids is important for keeping your skin healthy. If skin

breakdown does occur, you will need to pay extra attention to proper nutrition to help your skin heal. A balanced diet with foods from all food groups will help you to get the vitamins, minerals, protein, and calories needed for healing. Protein is very important because it provides the building blocks for healing. Good sources of protein from food include:

- Meat, fish, and poultry
- Eggs
- Nuts and nut butters (peanut butter, almond butter, cashew butter)
- Dried beans and peas (such as kidney beans, navy beans, lentils, split peas, chickpeas)
- Dairy products, especially milk, cheese, and yogurt. Be aware of fats and added sugars.

You will also need enough calories from healthy carbohydrates and fats to help your body use the protein for healing. Your doctor, dietitian, or other health care provider may suggest high calorie, high protein supplements (available in liquid or powder form) and/or vitamin and mineral supplements. These supplements may help with healing if your diet does not provide enough of these nutrients.

**Nutrition for Bowel and Bladder Health**
A diet high in fiber can help you to maintain good bowel function. Fiber is found only in plant foods. It acts like a sponge, pulling water into the intestines, creating a softer stool. Drinking enough fluid is important to help the fiber work properly. At least half your body weight in ounces per day. Although water is the best fluid for most, other fluids count towards this amount. Have awareness of fluid intake if you are intermittent cathing

Good sources of fiber include:
- Vegetables
- Dried beans and peas (legumes)
- Fruits (especially fresh)
- Whole grains
- Nuts and Seeds

The recommended fiber intake for most people is 25 to 38 grams per day. When trying to eat more fiber, it is best to do so gradually. Fiber supplements are also available if it is hard to get enough fiber in your diet (ask your health care provider). Adequate fluid intake is also important for keeping your bladder and kidneys healthy. Drinking plenty of fluid can decrease your risk of urinary tract infections and kidney or bladder stones.

**Key Points:**

- Eat a healthy and balanced diet, including fruits, vegetables, whole grains, nuts and seeds, lean protein, dairy products, and healthy fats.
- Prevent too much weight gain by being mindful of portion sizes, limiting “empty calories” (foods and drinks that give you a lot of calories without much nutrition) and keeping as active as possible.
- Monitor risk factors for heart disease and diabetes—get blood sugar, lipid levels and blood pressure checked regularly. Follow the recommendations of your doctor for keeping these risks under control. Choose heart healthy fats, higher fiber carbohydrates, and lower sodium foods.
- If you have skin breakdown (pressure sores), eat a healthy diet with plenty of lean protein. Use

high calorie, high protein supplements or vitamin and mineral supplements if suggested by your health care provider.

- To keep skin healthy, eat a balanced diet, including half your body weight in ounces of fluid daily. Consider a basic multivitamin and mineral supplement if there is a chance your diet is not well balanced.
- Include plenty of fiber and fluid for bowel, bladder, and kidney health.

## Behavioral Changes

**Planning Meals**
Take a moment to think about how you prepare for a meal. You probably think about your meal when you are ready to eat. Few people actually plan for upcoming meals. However, people who have a good meal plan tend to make healthier food choices, have lower stress levels, and save time and money.

**When you plan meals, you should consider 6 factors:**

**1) What is your lifestyle?**
Before you actually write anything in your meal planner, think about how your meals can best fit your lifestyle. How much time do you have to prepare meals? Are you able to prepare your own food or do you rely on someone to assist you? What days do you want to eat at home and dine out? Are you planning meals for yourself or family? How often do you pick up food to bring home? What is your food budget? How much variety of foods do you want? What are your favorite foods or recipes?

**2) Stick to a schedule.**
Your body works best on a regular schedule. Ideally, you should eat something about every three to four hours each day. You want to plan your meals at around the same time every day whenever possible. You can plan healthy snacks between meals. Spreading your food intake throughout the day will help you avoid skipping meals, overeating and maintain blood sugar levels.

**3) Set aside planning time.**
Pick a day that is your least stressful and allows you plenty of time to think without distractions. If you plan your meals immediately before you grocery shop, you will have an idea of what foods you need to buy. If you shop for groceries every two days, you might plan your meals two days at a time. If you shop for groceries weekly, you might plan your meals every week. At first it may seem like a big task to plan out all of your meals at one time. After a few weeks, however, you will find a menu planning method that works for you.

**4) Choose healthier foods.**
Again, you want to eat plenty of fruits and vegetables. Eat 100% whole wheat grains, healthy fats and lean meats. Cut saturated/trans fats from your diet by avoiding snack foods such as cookies, chips, and cakes. If you choose foods that are not the most nutritious, you simply limit how much you eat.

**5) Plan for the unexpected.**
Thoughts, feelings, and even events can trigger an “urge” for food when you are not actually hungry. You might have a habit of eating when you feel sad or lonely. You might want something to eat at a ball game or movie. You can avoid being caught off guard by recognizing your triggers and developing a plan to deal with urges.

**6) Choose foods that you like to eat.**
Generally the more you enjoy food, the less you really need to feel satisfied.

**Shopping**
In general, groceries have a similar layout. The outer perimeter of the store has fresh foods, which are usually the healthiest. Foods are usually not as healthy on inside aisles. Therefore, you want to buy most of your foods from the outer perimeter. You might also buy convenience foods to keep on hand for quick meals. You might like healthy "ready made" meals that are easily cooked in the microwave. You might buy canned beans, vegetables, fruits, soups and tuna. However, you want to buy pre-cooked and canned foods with little or no salt and sugars added and avoid those foods with preservatives. You need to compare Nutrition Facts labels of similar products to make healthier choices. In general, it is best to buy foods lower in cholesterol, fats, sugars and sodium. Compare labels and choose foods higher in the healthier monounsaturated and polyunsaturated fats and lower in the unhealthiest saturated and trans fats.

**Cooking**
The key to healthy cooking is to reduce the fat and limit added sugars and processed foods. While some fats are healthier than others, all fats are high in calories. The healthiest way to reduce fats is by eating more fruits and vegetables and less meats and dairy products. When cooking, you can substitute oil or butter by using a small amount of water, wine, flavored vinegar, or fruit juice. Fat-free chicken, beef, or vegetable broth is a great alternative for flavor. When oil must be used, olive, avacado and canola oils are more nutritional choices. Bake, broil, grill, roast, steam and sauté your foods. You might also use a rack or broiling pan when roasting meats and poultry to allow excess fats to drain away from meat. Microwave cooking can also reduce fat. You can cook foods quickly without losing a lot of nutrients. You can cook healthy precooked meals or create your own microwave dishes. When you create great tasting dishes, write down and reuse your recipes.

**Dining Out**
Some foods are healthier than others no matter what restaurant you visit. One key to healthy dining is to avoid over eating. Many people like to visit familystyle restaurants that feature food buffets. However, people who eat from buffets have a tendency to over eat. You want to also limit portion sizes when dining out. If possible, you might reduce your portion size by ordering an appetizer or lunch portion. You might split a main course with someone or eat half and have the rest wrapped up to take home. Never "up-size" meals!

It is best to order from the menu. Ordering from the menu allows you to ask questions about how a food is prepared. You can ask for healthier changes if needed. For example, you can request that meats or sides be grilled instead of fried. Ask to have your food prepared without butter or have sauces served on the side. Ask for a substitute item such as a vegetable in place of fries, or you can ask the server not to bring items that you do not want to be tempted to eat.

The average fast food meal contains about 1200 calories! It is best to limit your meals to approximately 500 calories and 15 - 20 grams of fat. You should ask for the nutritional guide and select foods lower in calories, cholesterol, fat, sugar, and salt. Add flavor and bulk to sandwiches with lettuce, tomatoes, sprouts, pickles, peppers, or onions. Choose grilled chicken, baked potato, or salad instead of hamburgers and fries. You also want to make healthy beverage choices. Water is best. You might try 1% or fat-free milk, low-calorie soft drinks or unsweetened tea or coffee. Avoid high calorie soft drinks, milkshakes and drinks with alcohol.

Sample of How Portion Sizes Have Changed

| Food Item | Calories per Portion 20 yrs Ago | Calories per Portion Today |
|---|---|---|
| Bagel | 140 Calories (3” diameter) | 350 Calories (6” diameter) |
| Fast food cheeseburger | 333 Calories | 590 Calories |
| Fast food french fries | 210 Calories (2.4 oz) | 610 Calories (6.9 oz) |
| Bottle soft drink | 85 Calories (6.5 oz) | 250 Calories (20 oz) |
| Turkey sandwich | 320 Calories | 820 Calories (10 “ sub) |

**Improving Self-Talk**
The way you think directly impacts how you feel and what you do. If you feel good about yourself, you are more likely to take care of your overall health. On the other hand, your self-talk can hold you back. This happens when we have thoughts like:

- “I can’t exercise because I’m in a wheelchair”
- “I’ll never be healthy because of my condition.”

Self-talk is a learned process based on personal beliefs developed through life experiences. Because self-talk is a learned process, you can re-learn and improve your self-talk. The goal is to have your self-talk work for you, not against you. For example:

- “I can be healthy by eating nutritional foods and being active.”
- “It may take time and hard work to reach my goals but I can do it.”
- “I didn’t accomplish everything today but I will work harder tomorrow.”

In addition to your own thoughts, outside influences can impact your weight control program. Friends and family can be a wonderful source of reinforcement if you give them suggestions on ways they can support you. Ask for feedback, praise and comments on changes they notice in you. A diet partner can be another source of support. A partner can be a friend, co-worker, or family member. You can encourage each other while you shop and exercise together. Ultimately, it is really up to you to take control of your life. With practice, you can improve your self-talk to improve your overall health.

- Be honest with yourself.
- Do not try to be perfect.
- Avoid over exaggerations.
- Do not try to predict future.
- Keep a positive attitude.
- Do not be self-critical.
- Recognize the good with the bad.
- Pat yourself on the back for a task well done.

**Reducing Stress**
Managing stress is an important key to maintaining healthy behaviors because your eating behaviors often change when you’re under stress. People who constantly experience symptoms of stress are often at higher risk for serious health problems including illness, addiction and depression. No one is going to be stress free, but you can minimize the impact of stress. There are many things you can do to feel better emotionally and physically.

- Get enough sleep.
- Get outdoors and enjoy the sunshine.
- Eat regular, healthy meals and snacks.
- Participate in regularly physical activities because your body can fight stress better when it is fit.
- Cut down or cut out use of caffeine and tobacco.
- Seek a balance of work and leisure.
- Hug somebody!
- Be assertive with your feelings, opinions, or beliefs instead of becoming angry, defensive, or passive.
- Be socially active with friends and family.

### Symptoms of Stress

- Anxious
- Scared
- Irritable
- Moody
- Low self-esteem
- Fear of failure
- Inability to concentrate
- Embarrassing easily
- Worrying about the future
- Forgetfulness
- Grinding your teeth
- Increasing smoking
- Increased drug/alcohol use
- Acting impulsively
- Loss of appetite or overeating
- Startling easily
- Crying for no apparent reason
- Trembling
- Perspiration /sweaty hands
- Increased heart beat
- Nervous ticks
- Tiring easily
- Dryness of throat and mouth
- Sleeping problems
- Diarrhea/indigestion/vomiting
- Butterflies in stomach
- Headaches
- Premenstrual tension
- Neck and or lower back pain
- Susceptibility to illness

**Setting Goals**
Realistic goals help give you direction and purpose. Short-term goals usually take no more than a couple of weeks to achieve, and long-term goals can take months to years.

Losing weight is difficult, especially for individuals with SCI. It is not reasonable to expect to lose 20 pounds in 2 weeks. In fact, losing weight too quickly puts you at risk for health problems such as gallstones, electrolyte imbalance, and lean muscle loss. Instead, you need to set realistic short-term weight loss goals,such as losing one or two pounds a week. It may take 6 months or a year to lose 20 pounds.

Research also shows that carrying extra fat around one's midsection can have a negative effect on health. Because most everyone with SCI has a loss of some or all use of their abdominal muscles, you probably have more fat in your midsection. However you can still set a goal to reduce your waist size. A healthy waist size for men is below 40 inches and below 35 inches for women.

Body Mass Index, or BMI, describes your weight in relationship to your height. You can find your BMI using the BMI table below. At the bottom of the BMI table, you can see that your BMI is classified as normal (healthy), overweight (at risk for health problems) or obese (at high risk for health problems). If your BMI is 25 or higher, you can improve your health by setting a goal to lower your BMI.

**Body Mass Index**

| | BMI | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 35 | 40 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | WEIGHT IN POUNDS | | | | | | | | | | | | | |
| HEIGHT | 5′ 0″ | 97 | 102 | 107 | 112 | 118 | 123 | 128 | 133 | 138 | 143 | 148 | 153 | 179 | 204 |
| | 5′ 1″ | 100 | 106 | 111 | 116 | 122 | 127 | 132 | 137 | 143 | 148 | 153 | 158 | 185 | 211 |
| | 5′ 2″ | 104 | 109 | 115 | 120 | 126 | 131 | 136 | 142 | 147 | 153 | 158 | 164 | 191 | 218 |
| | 5′ 3″ | 107 | 113 | 118 | 124 | 130 | 135 | 141 | 146 | 152 | 158 | 163 | 169 | 197 | 225 |
| | 5′ 4″ | 110 | 116 | 122 | 128 | 134 | 140 | 145 | 151 | 157 | 163 | 169 | 174 | 204 | 232 |
| | 5′ 5″ | 114 | 120 | 126 | 132 | 138 | 144 | 150 | 156 | 162 | 168 | 174 | 180 | 210 | 240 |
| | 5′ 6″ | 118 | 124 | 130 | 136 | 142 | 148 | 155 | 161 | 167 | 173 | 179 | 186 | 216 | 247 |
| | 5′ 7″ | 121 | 127 | 134 | 140 | 146 | 153 | 159 | 166 | 172 | 178 | 185 | 191 | 223 | 255 |
| | 5′ 8″ | 125 | 131 | 138 | 144 | 151 | 158 | 164 | 171 | 177 | 184 | 190 | 197 | 230 | 262 |
| | 5′ 9″ | 128 | 135 | 142 | 149 | 155 | 162 | 169 | 176 | 182 | 189 | 196 | 203 | 236 | 270 |
| | 5′ 10″ | 132 | 139 | 146 | 153 | 160 | 167 | 174 | 181 | 188 | 195 | 202 | 207 | 243 | 278 |
| | 5′ 11″ | 136 | 143 | 150 | 157 | 165 | 172 | 179 | 186 | 193 | 200 | 208 | 215 | 250 | 286 |
| | 6′ 0″ | 140 | 147 | 154 | 162 | 169 | 177 | 184 | 191 | 199 | 206 | 213 | 221 | 258 | 294 |
| | 6′ 1″ | 144 | 151 | 159 | 166 | 174 | 182 | 189 | 197 | 204 | 212 | 219 | 227 | 265 | 302 |
| | | NORMAL | | | | | | OVERWEIGHT | | | | | OBESE | | |

*Source: National Heart, Lung and Blood Insitute*

**Participating in Physical Activities**

Physical activity is any bodily muscle movement that uses energy. When you increase your energy output, you burn calories quicker and lose fat while gaining muscle mass. People who participate in regular physical activity usually feel better, have more energy, and are healthier than people who do not.

No matter what your level of impairment, do not limit your physical activities solely based on the fact that you have limited mobility. You can get substantial health benefits from 150 minutes per week or 30 minutes five times a week of moderate physical activity. Moderate activities require some physical exertion, but you should be able to comfortably carry on a conversation while participating. Moderate activities include aerobic activity and weight training.

There are many ways to get a moderate amount of physical activity. Some activities are available through local and national organizations and foundations that offer activities such as hunting, fishing, shooting, fitness classes, seminars, and competitive athletics. In fact, wheelchair sports are another way to get physical activity. The number of sports offered to participants who are disabled has grown to rival that of sports offered to non-disabled participants. You can participate in everything from traditional wheelchair basketball to power wheelchair soccer. In some cases, organizations and foundations will even provide the adaptive equipment that you need to participate.

Physical activity can also be a part of your everyday life. For example, you may have a job that keeps you physically active by regularly lifting or pushing. Even adding some routine activities around the house beyond what you are currently doing can go a long way in improving your overall health. Such activities include cleaning, gardening and playing with children. You might have physically active hobbies such as art, fishing and hunting. You can even stay physically active by biking or pushing a wheelchair.

**Maintaining Long-Term Success**

When you reach your goals, you need to re-evaluate your situation. For example, you may reach a goal of losing 10 pounds and decide to simply work to maintain your weight. You may need to set a new goal. Again, it depends on what you want.

You may have problems with your transition from weight loss to weight maintenance. The common problem is that people fail to properly adjust their daily calorie intake. For example, you might lose weight with a daily intake of 1,800 calories but swing to 2,500 calories per day after you reach your weight loss goals. Instead, you need to gradually increase your daily calorie intake. You can do this by adding between 200 and 250 calories per day to your diet. If you continue to lose weight after a week, you can increase your daily intake by another 200 calories. When you increase your calorie intake to a level where your weight is stable, you can stop increasing your calorie intake.

As an individual with SCI, you need to also visit your doctor at least once per year. Your body changes as you get older. You may experience other health concerns, which may mean you need to change or modify your nutritional needs. Your doctor can best prevent and manage problems if you are seen regularly.

This InfoSheet briefly outlines the EatRightTM Home-Based Weight Management Program for Individuals with Spinal Cord Impairment funded by the PVA Education Foundation and developed by the UAB Department of Physical Medicine & Rehabilitation in cooperation with the Department of Nutrition Sciences. EatRightTM is a comprehensive program on the 12 proven elements of effective weight management. The home-based program utilizes video lessons and workbook assignments to guide consumers through the 12-week weight management program. It can be purchased from the UAB Office of Research Services at 205-934-3283. This information sheet is not intended nor implied to be a substitute for professional medical advice. Always ask a physician or other qualified health professional about any matter concerning individual health prior to starting or changing any medical treatment. Nothing contained in these columns is intended for medical diagnoses or treatment purposes.

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Information used with permission by University of Alabama at Birmingham Spinal Cord Injury Model System (UAB-SCIMS).

## Before You Begin Exercise

**Introduction**
There are many benefits of regular physical activity and exercise, and no matter what your level of injury is, exercise is for everyone. Staying active is often considered a key factor in maintaining and improving overall health. Benefits of moderate physical activity can be even greater for individuals with a disability since they have a tendency to live less active lifestyles. Inform your primary care physician prior to beginning a new exercise routine to make sure there are no medical issues you need to consider once you start to exercise. If possible, consult a trained exercise professional for an individualized exercise prescription.

***Benefits of regular physical activity and exercise:***

- Weight control
- Improved strength and endurance to perform activities of daily living
- Decreased anxiety and depression
- Enhanced feeling of well-being
- Protection against development of chronic diseases such as diabetes
- Prevention of secondary conditions such as cardiovascular disease, pressure sores, hypertension and respiratory distress
- Increased cardiac (heart) and pulmonary (lung) function
- Lowered cholesterol and blood pressure

**Types of Exercise**
There are several different types of exercise that may benefit you in different ways:
Cardiovascular Exercise- Primarily benefits your heart, circulatory system and lungs. Examples of cardiovascular exercise are:

- Aerobic exercise
- Circuit training
- Arm ergometry
- Wheelchair ergometry
- Sports (tennis, basketball, swimming, quad rugby, cycling, etc.)

The American College of Sports Medicine (ACSM) recommends that adults participate in moderate-intensity aerobic exercise for at least 30 minutes on at least 5 days of the week, which may include housework/chores, brisk-paced wheelchair propulsion, and exercise during which you can still talk easily.

ACSM also recommends that adults participate in high-intensity exercise for at least 20 minutes on at least 3 days per week, which may include playing sports and exercise that makes you feel out of breath. The exercise does not need to be all at once. Two 10 minutes sessions of exercise can be just as beneficial as one 20 minute session, since you are active more frequently. It is always a good idea to start slow and gradually increase the amount of time and days per week you exercise. The Spinal Cord Injury Information Network recommends starting with 10 minutes of exercise every other day and then slowly increasing the time you

exercise.

There are many ways that you can incorporate cardiovascular exercise into your daily life. If you use a manual wheelchair, try parking a little farther from the store entrance and using a ramp instead of an elevator.

The best way to get active is to get your family and friends active as well. Even shopping trips to the mall can add some aerobic exercise to your daily routine.

Resistance exercise- Primarily benefits you by making you stronger (improving muscular strength) and/or giving you better endurance so you can perform activities longer (improving muscular endurance). Examples of resistance exercise are:

- Weight machines
- Free weights
- Exercise bands
- Body weight exercise/push-ups & pull ups

There are two ways to resistance train: for muscular strength or for muscular endurance. If your goal is to increase muscular strength, you should use a heavier weight (one that is difficult for you to lift more than 6-8 times). Perform 6-8 reps 3-5 times, with at least 3-5 minutes of rest between sets. If your goal is to increase muscular endurance, you should use a lighter weight (one that you can lift at least 12-15 times). Perform at least 12-15 reps 2-3 times, with 1-2 minutes between sets. It is important to keep on breathing while resistance training. Exhale while pushing the weight up or out and inhale while letting the weight down or in. Resistance training sessions should be held 3-4 times per week with at least one day of rest between sessions.

Flexibility exercise- Primarily aimed at giving you greater range of motion in joints and more flexibility in your body. Examples are:

- Self-Stretching
- Stretching with assistance of another person
- Yoga
- Pilates

Flexibility training should be incorporated before and after every cardiovascular and strength workout. Be sure to hold stretches (without bouncing) for 30-60 seconds and progress slowly. Remember, stretching should never be painful.

**Spinal Cord Injury Related Considerations When Exercising**

- **Incontinence-** Make sure to empty your bowel and bladder before exercising
- **Spasticity-** Stretch spastic muscle groups and avoid exercises that cause excessive spasticity.

- **Orthostatic hypotension** (drop in blood pressure)- Monitor blood pressure throughout exercise, avoid quick movement and make sure you drink enough water.
- **Thermoregulation** (irregular body temperature)- Make sure you wear appropriate clothing in warm vs. cold climates, and drink plenty of water.
- **Skin Integrity/Pressure Sores-** Make sure you maintain your pressure relief guidelines while exercising, and get out of sweaty clothes as soon as you're done exercising. Perform skin checks after exercising.
- **Joint Strain-** Stop exercising if you experience any pain in your joints while exercising. Consult your doctor before beginning exercise if you have a history of joint pain, particularly in your shoulders. If you do experience joint pain, certain exercises may need to be avoided. Consider consulting a trained exercise professional for an individual exercise program that is designed to avoid exercises that will cause you joint pain.

**Important Safety Considerations**

- Stop exercising if you experience pain, discomfort, nausea, dizziness, lightheadedness, chest pain, irregular heartbeat, shortness of breath or clammy hands.
- Check medications and their effects during exercise.
- Drink plenty of water.
- Wear appropriate clothing
- Set realistic short-term and long-term goals
- Find and follow an exercise program that meets your specific goals

RRTC on Secondary Conditions in the Rehabilitation of Individuals with Spinal Cord Injury

MedStar National Rehabilitation Network



## Exercise and Spinal Cord Injury

**Introduction**

For important fitness benefits, adults with a spinal cord injury should engage in exercise five times per week (aerobic exercise 3-5 times a week, strength traning 2-3 times a week). Experts recommend that all healthy adults with spinal cord injury set aside time to be physically active. This part of your day should be enjoyable, so choose activites that you like to do and make it fun. Try to incorporate both aerobic activity and strengthening activity. If you are newly injured, are pregnant, prone to autonomic dysreflexia, or have other medical conditions, you should talk to your health professional to find out what types and amount of physical activity are right for you. A health professional might include a doctor, a physiotherapist, or a qualified exercise professional.

**Aerobic Activity**

Moderate means somewhat hard, and you feel like you could

continue for a long time. You can talk, but not sing your favorite song, during the activity. Using a 0 to 10 scale, moderate-intensity physical activity is usually a 5 or 6.

Vigorous is really hard, and you feel like you can only continue for a short time before getting tired. You will not be able to say more than a few words without pausing for a breath. Using a 0-10 scale, vigorous-intensity physical activity is usually a 7 or 8.

**Activity Ideas**
Not sure how to get active? There are plenty of activities to choose from, both for indoors and out. Try to find a mix of exercises that work different body parts and blend aerobic and strengthening activities. Above all, make sure you choose activities you enjoy, and that are safe for you. Here are some suggestions to get you started.

**Manual Chair: *Aerobic Activities***
- Wheel for fun and endurance
- Cycle using a hand cycle or stationary bike
- Swim
- Play catch with your kids
- Follow along with an exercise video
- Play basketball

**Manual Chair: *Strengthening Activities***
- Build strength with a resistance band
- Lift weights. Don't have any? Use cans or water bottles from the kitchen
- Use cable pulleys
- Body weight exercises (wheelchair push-ups)

**Power Chair: *Aerobic Activities***
- Play bocce
- Swim with assistance
- Use an arm ergometer
- Do standing frame exercises
- Dance
- Curl

**Power Chair: *Strengthening Activities***
- Use cable pulleys
- Exercise with a resistance band
- Practice yoga, Pilates or Tai Chi for relaxation and to build balance and strength

**Benefits of Physical Activity**
Physical activity is fun, and there is more good news! Research shows that following the guidelines improves aerobic fitness and strength. Here are some benefits you can expect:

- Better endurance so that you can wheel for longer
- Easier transfers in and out of your chair
- Enhanced self-care and mobility
- Better overall health and quality of life

- More energy
- More social interaction with others

**Being active can have other benefits**
- Less pain
- Lower risk of stress
- Lower risk of depression
- Reduced cholesterol and fats in your blood, which can lower your risk of developing several chronic diseases
- Improved ability to regulate blood glucose, decreasing your risk for type II diabetes.
- Better sleep quality

**Make Your Own Action Plan**

Scientific studies have found that people are far more likely to be physically active if they make a realistic and detailed plan. Your Action Plan can be set up as a weekly calendar. Take advantage of technology to keep you on track. For instance, if you use a smart phone, program in reminders. Include in your Action Plan what activity you are going to do, where, when with whom, for how long, and at what intensity. Have fun, and be sure to choose activities you like!

Below is an example Action Plan. You can substitute activities on the chart with ones you enjoy more. So instead of wheeling, try another aerobic activity such as cycling. Instead of resistance band exercises, lift weights or soup cans. The point is to incorporate physical activity into your day for fitness and fun.

**Action Plan Example:**

| | SUN | MON | TUES | WED | THURS | FRI | SAT |
|---|---|---|---|---|---|---|---|
| Activity | frisbee/catch with kids | off | resistance band | off | go for a wheel | off | off |
| Where | park or backyard | | home | | trail | | |
| When | 2 pm | | 8 am | | 7 pm | | |
| How long | 10 min. | | 10 min. | | 10-15 min. | | |
| Intensity | moderate | | moderate | | moderate | | |

Once you are enjoying regular physical activity, gradually increase the intensity for further fitness benefits. For more information and examples of how to write an Action Plan, go to www.sciactioncanada.ca.

**How to Make Your Plan Stick**

Need help actually sticking to your Action Plan? Here are the three tactics to try so that you don't talk yourself out of doing your planned activity:

1. Use Action Cues. Cues are triggers for a planned behavior. For instance, if you are planning to go for a swim after work, place your goggles beside your computer.
2. Focus on the first stage of getting ready. If you've set your alarm clock and planned a morning activity, but you're losing motivation because of all that's involved, just focus on dressing appropriately and getting out the door... the rest will fall into place!
3. Make exercise plans with others. They will be your conscience and you will motivate each other.

**It's Easier Than You Think**

You may feel physical activity is too difficult. Here are some possible barriers and ways to overcome them.

**No Time**

- Make an action plan
- Be physically active with your family and friends
- Got down time? Make it physical activity time

**Physical Barriers**

- Physical activity may reduce your pain
- It's worth it. You'll feel energized.
- There's a way! Proper adaptation of equipment and activity can accommodate you.

**Lack of Support/Lack of Access**

- Get an exercise buddy
- Connect with your community recreation center or municipal recreation department
- Try an exercise video such as the Active Home videos available on the SCI Action Canada website

**"I Can't"**

- Start with what you know and build your skills
- Take a tour of a facility that offers an activity that interests you
- Too expensive? There are a number of community based programs that have adapted equipment available for you to use in their activities.

**Be Active Safely**

- Here are some practical and important tips to avoid injury:
- Always check with a physician before starting a physical activity program.
- Progress slowly. You are aiming for a little muscle soreness, not intense pain.
- Check your skin for pressure sores/ulcers. If this is a concern, try shifting your body weight every 10-15 minutes. Consider equipping your chair with aspecial cushion to relieve pressure.
- Stay cool. Since sweating may be inhibited below the level of injury, spray yourself regularly with a water bottle when exercising in the heat. If indoors, use a fan as well.
- Hydrate properly to avoid hypertension.
- Know the signs and symptoms of autonomic dysrelexia (AD). If you think you are experiencing AD, remain sitting up. If you deal with the suspected cause and symptoms don't go away, call a physician.

All information obtained in this section is thanks to:


Adaptive sports is an excellent way to stay active, read on to learn about the Gaylord Sports Association.

SECTION

16


# SPORTS & LEISURE

There are so many ways to stay active and engaged through the wide world of adaptive sports and leisure activities.

**Adaptive Sports**
Staying active through sports and recreation is vital for improving your physical well-being, lifting your spirits, and enhancing your overall quality of life. A spinal cord injury may change how you participate in activities, but it doesn't have to change that you participate. This chapter is an exploration of the many possibilities for staying active, engaged, and connected.

The Sports Association at Gaylord Hospital is dedicated to improving the quality of life, spirit, mind and body of persons with physical disabilities through wheelchair sports and adaptive recreation opportunities.

The Sports Association provides adaptive sports and recreation opportunities for persons with physical disabilities, such as spinal cord injuries, strokes, amputations, traumatic brain injuries, pulmonary disorders, and visual impairments. The Sports Association is the Paralympic Sport Club of Southern New England, and aims to enhance the lives of persons with various ability levels and assist athletes with disabilities in attaining the highest level of independence possible in a variety of sports and recreation pursuits. There are over a dozen sports offered that feature various ways of participating, learning and exploring the sports and activities. Examples of sports offered are:


- **Rock climbing**
- **Downhill skiing**
- **Sled hockey**
- **Tennis**
- **Paratriathlon**
- **Water skiing**
- **Yoga**
- **Archery**
- **Adaptive cycling**
- **Boccia**
- **Veteran's Fishing Tournament**
- **Golf**
- **Kayaking**
- **Wheelchair Rugby**
- **Pickleball**
- **Boxing**
- **Exercise 4 Life**

**Some ways to participate are:**

**Clinics-** hands-on experience and expert instruction in kayaking, golf, tennis, archery, waterskiing, fencing, cycling and target shooting.

**Clubs-** Clubs offer regular outings in downhill skiing, archery, water skiing and golf.

**Teams-** The Sports Association is proud to sponsor the Gaylord Sports Association Warriors Wheelchair Rugby Team, Gaylord Sports Association Wolfpack Sled Hockey Team, and the Connecticut Hornets Wheelchair Tennis team that compete throughout the region.

**Tournaments-** Tournaments in Wheelchair Rugby, Wheelchair Tennis and Golf offer athletes healthy competition and team camaraderie.




**Discovery Nights-** An evening highlighting a specific sport, its equipment and techniques in skiing, sailing, SCUBA and sled hockey.

**Day of Discovery-** An opportunity for athletes to learn over 18 adaptive sports available and how to get involved.

The Sports Association aims to enhance the lives of persons with various ability levels and assist athletes with disabilities in attaining the highest level of independence possible in a variety of sports and recreation pursuits.

**Leisure Activities You Can Enjoy:**

Gardens and houseplants need ongoing care and can provide for hours of enjoyment weekly. One can watch the results of the efforts in a living medium. It can even be done indoors.

Read: Read the paper or novel, and be sure to utilize the local library or listen to a book. If you have difficulty reading or prefer to listen you can buy books on cassette or CD or borrow one from the library. If eligible due to visual or physical disability, one may receive “Talking Book Service” free from the Library of Congress or Commission for the Blind and Visually Impaired.

Try a New Hobby: Consider needlework, woodworking, leather-craft, flower arranging, basket weaving, pottery, etc.

Collecting can be a new hobby. Collect stamps, coins, baseball cards, comic books or even coupons from the Sunday paper. It could save money as well!

Watch a movie! Have a party and run a movie marathon. Or, make a movie, or two; put together a short script, take the best shots and send them to relatives.

Try exercising. Check with your doctor first. Start out slowly, maybe just with some stretching. Look for free exercises classes on TV each morning. One can also buy or rent exercise videos, they have many geared to specific needs. One can also get some exercise by taking a stroll through the halls or outside.

Indulge in a crossword puzzle, trivia or word search. Knowledge and vocabulary will grow!!

Invite a friend, neighbor or relative over. Socializing with others keeps one in touch with the outside world and makes life more interesting. Start a social group, once a month or weekly. Meet for coffee, to play cards, to make crafts, or just gossip.

Pick a favorite recipe and give it a go. Make some cookies, a cake, or a favorite dessert. Try a box mix; you’ll be surprised with the results.

Do you have birds around the home? Some birdfeeders can be attached right to your window, you can bird watch without even leaving your room.

And while you are at it, try some photography. It's a great hobby that can be done 24 hours a day, 7 days a week, all year long.

Listen to Music. Listen to some old tunes you haven't heard in a while or keep on top of the latest hits! Listening to music can set the mood for the whole day. Or, make some music yourself! Pick up a teaching book and practice, practice.

It doesn't matter if you win or lose; it's how you play the game. To name a few: Scrabble, Trivial Pursuit, cards, Chess, Checkers, Pictionary, Backgammon, etc.

Indulge in some poetry or write a story. Writing is an excellent way to express feelings and to get things off one's chest. Keep a journal or even a pad with some simple notes! You don't have to share your writing if you don't want to.

Go Outside. Breathe the fresh air, smell the flowers, enjoy the sun or a cool fall breeze.

Surf the 'Net! Check out the internet and all it has to offer. There are thousands of educational, informative, and fun sites to visit on the "World Wide Web"! Chat with others with similar interests, play games, learn new things, correspond with friends or just browse.

Discover the artist within. Draw, paint, sculpt, or just doodle. Creating is a great way to express oneself and relieve stress.

## Community Re-Entry

Community Re-Entry is a group therapy session offered at Gaylord Hospital. The purpose of community re-entry is to provide an opportunity for exposure to potential community barriers, increase knowledge of leisure resources in the community, increase skill building through off-site therapy intervention, provide opportunity for social interaction and increase physical and/or cognitive functioning. There are specific entrance criteria for the group including but not limited to: having a discharge plan to a less structured environment (ex. Home, Traurig House) and being medically stable and be cleared by the physician to leave the hospital for 1 ½ hours for a community trip. Referrals for community re-entry are made by treating therapists during therapy meetings when the group is appropriate to run.

During your inpatient stay you will be given the opportunity to trial various adaptive sports equipment, speak one on one with a trained professional and learn about grants available to individuals with a spinal cord injury specifically for adaptive sports equipment.

For more information, please call 203-284-2732 or visit our website at www.gaylord.org

SECTION

17

# GAYLORD OUTPATIENT SERVICES

At some point in your rehabilitation, you may require outpatient services.

**Outpatient Medical Services**
The Outpatient Medical Services Department at Gaylord Hospital provides medical evaluations and follow-up. The Outpatient Medical Services Department is staffed with physiatrists who are skilled in the treatment of individuals with spinal cord injury. Gaylord physiatrists can prescribe specialized treatments for spasticity management. In addition, urologic care and appointments are available at Gaylord.

**Outpatient Therapy Services**
Outpatient therapy services are typically provided to you when you are living in your home environment and can attend therapy outside of your home. The Outpatient Therapy Department at Gaylord Hospital provides physical therapy, occupational therapy and speech therapy services. Gaylord's Outpatient Therapy Department is staffed with therapists who are skilled in spinal cord injury rehabilitation.

Gaylord's Outpatient Therapy Department is equipped with specialized equipment for spinal cord injury rehabilitation. These items include:

- Height adjustable padded treatment mats
- Wheelchair accessible weight lifting machines
- Standing frames
- Wheelchair accessible bikes for upper and lower extremities
- Unweighted Gait Systems
- Functional Electrical Stimulation Bicycle (Bicycle, Xcite, Bioness)
- Electrical stimulation units
- Modalities
- Computer monitored upper body exercise machine (BTE)
- Ekso

In addition to the therapy services described, Gaylord's Outpatient Therapy Department also offers the following specialty services:

- Aquatic Therapy
- Wheelchair Assessment Services Clinic
- Orthotic and Prosthetic referral options (trial and procurment of bracing available as neccessary)
- Independent fitness and aquatic programs (Exercise for Life, aquacize)

**Outpatient Psychology Services**
The Psychology Department offers short-term, evidence-based, cognitive-behavorial counseling services with a focus on helping people adjust to catastrophic injury (TBI, stroke, spinal cord injury) and related mental health concerns.

**Additional Services**
Nutrition consultations are also performed in Gaylord Outpatient Services.

SECTION

18

# RESEARCH

The future of spinal cord injury treatment is filled with hope and promise. Scientific discoveries, from stem cell research aimed at reconnecting nerves to innovative clinical trials for novel treatments, are continuously advancing our understanding and ability to promote recovery.

As part of the Spaulding New England Regional Spinal Cord Injury Center, one of only 18 Model Systems in the country, Gaylord Hospital is actively involved in conducting research to discover best practices for living a healthy, productive life after SCI. By staying connected with Gaylord through yearly follow-up visits, you ensure that you are always informed about the most current treatments and advances in care.

Now and in the future, the number of discoveries and breakthroughs in finding a cure for paralysis will only continue to increase. Stem Cell research has shown promise in helping nerves in the spinal cord to reconnect and help with improvement in strength and coordination. There are many clinical trials that are ongoing that are looking at novel treatments for spinal cord injury. Depending on what hospital you were treated at after your injury, you may have already been part of a research study looking at the optimal treatments for people with spinal cord injuries. Gaylord Hospital is a part of the Spaulding New England Regional Spinal Cord Injury Center, one of only 18 Model Systems in the United States. These centers are conducting research into recovery as well as optimal practices for living a healthy, happy, productive life after spinal cord injury. Even after you leave Gaylord Hospital, it is important to stay connected to Gaylord through at least yearly follow up visits. Your health care provider can update you on the most current treatments and best practices for living with spinal cord injury.

For more information on SCI research studies in the United States, log onto:
**www.clinicaltrials.gov**

For more information on the SCI Model Systems research, log onto:
**www.MSKTC.org**

**The Milne Institute for Healthcare Innovation**

The Milne Institute for Healthcare Innovation is the result of a generous donation from George and Carol Milne. “As a scientist and a biomedical researcher with a broad interest in outcomes, it is clear that Gaylord fills a unique niche that is not well-represented in our country – patients recovering from devastating injuries or illnesses,” said George Milne, Jr., PhD, retired Executive Vice President of Global Research and Development and President of Central Research at Pfizer, Inc.

Housed on the Gaylord campus in Wallingford, Connecticut, the Milne Institute conducts research, develops evidence-based practices, and adopts cutting-edge applied technologies. These technology

have the potential to change lives around the world, by leveraging Gaylord's expertise in the care of brain and spinal cord injuries, complex strokes, amputations, and pulmonary diseases.

The Institute provides a collaborative, multidisciplinary environment for dedicated researchers to work with Gaylord's team of clinicians while partnering with corporations and foundations to conduct and disseminate data-driven research. All research and corporate partnerships are part of the Institute including two cross-pollinating centers: The Center for Research and Innovation and The Center for Applied Technologies.

SECTION

19

# COMMUNITY RESOURCES

## Advocacy

There are several state and national options for advocacy issues. See contact information below.

### State

**Center for Medicare Advocacy**
P.O. Box 350
Willimantic, CT 06226
Phone: (860) 456-7790
Fax: (860) 456-2614
https://medicareadvocacy.org/

**State of Connecticut-Office of Healthcare Advocate (OHA)**

**Mailing address:**
Office of Healthcare Advocate (OHA)
P.O. Box 1543
Hartford, CT 06144

**Visitors address:**
153 Market Street, 7th floor
Hartford, CT 06103

**Phone:** 866-466-4446 (toll free)
**Fax:** 860-331-2499
**Email:** Healthcare.Advocate@ct.gov
**Website:** https://portal.ct.gov/oha?language=en US

**State of Connecticut Long Term Care Ombudsman Program**
55 Farmington Avenue
Hartford CT 06105-3730
**Phone:** 1-866-388-1888 or 860-424-5200
**Fax:** 860-772-1704
**Email:** ltcop@ct.gov
**Website:** https://portal.ct.gov/ltcop

**Spinal Cord Injury Association of Connecticut**
PO Box 5334
Milford, CT, 06460
(203)284-2910
**Email:** nsciact@gmail.com
**Website:** https://www.sciact.org/

### National

**Administration for Community Living (ACL)**
330 C St SW

Washington, DC 20201
(202) 401-4634
Website: https://acl.gov/

**The Americans with Disabilities Act (ADA)**
U.S. Department of Justice
Civil Rights Division
Disability Rights Section
950 Pennsylvania Avenue, NW
Washington, D.C. 20530-0001
800-514-0301
1-833-610-1264 (TTY)
Website: https://www.ada.gov/

**American Association of People with Disabilities**
1030 15th St. NW
Suite 500E
Washington, DC 20005
202-521-4316 or 1-800-840-8844
Email: info@aapd.com
Website: https://www.aapd.com/

**Christopher & Dana Reeve Foundation**
636 Morris Turnpike
Suite 3A
Short Hills, NJ 07078
1-800-225-0292 – General
1-800-539-7309 – resource specialist
Website: https://www.christopherreeve.org/

**Facing Disability.com**
312-284-2525
Email: info@facingdisability.com
Website: https://facingdisability.com/resources/advocacy

**United Spinal Association**
102 Duane Rd.
Fort Totten, NY 11359 United States
Phone: 718-803-3782
Fax: 718-228-9889
Website: https://unitedspinal.org/

## SCI Support Groups in CT

**Gaylord Hospital Wallingford CT**
Contact Kate Donohue
scisupportgroup@gaylord.org

**Mt. Sinai Rehabilitation Hospital Hartford, CT**
Contact Garrison Redd
garrison.redd@mountsinai.org
**Hospital for Special Care New Britain, CT**
Contact Sarah Barnes
(860) 827-1958 ext 5068

**Travis Roy Foundation**
**101 Huntington Ave**
**Suite 520**
**Boston, MA 02199**
**Travisroyfoundation.org**
**info@travisroyfoundation.org**

The Travis Roy Foundation was established to help spinal cord injury survivors and to fund SCI research. The foundation funds individual grants, research projects and rehabilitation institutions across North America. The individual grant funds have been used to modify vans and to purchase wheelchairs, computers, ramps, shower chairs, and other adaptive equipment to help paraplegics and quadriplegics. The application is online or can be requested in letter form.

**Oak Hill Asst. Technology**
**120 Holcomb Street**
**Hartford, CT 06112**
**(860) 242-2274 or (860) 286-3113**
**assistivetechnology.oakhillct.org**

The NEAT Marketplace (New England Assistive Technology) restores donated assistive devices and medical equipment/supplies. NEAT is a demonstration center, as well as an equipment restoration center. Restored items are available for sale at reduced rates.

**Charlie's Closet**
**310 State St Unit 200**
**Guilford, CT 06437**
**(203) 453-8359**

Charlie's Closet loans DME items for a small donation through the Guilford Interfaith Ministries, you must pick up and return items on your own.

**Easter Seals Mobility Center**
**158 State Street**
**Meriden, CT 06450**
***Additional locations in CT**
**(203) 237-1448**
**easterseals.com**

The Easter Seals Mobility Center provides thorough driving assessments to those who have an injury or impairment that may impact their ability to safely operate a motor vehicle. The Center provides a clinical assessment, an on the road assessment, as well as equipment recommendations and prescriptions.

**Educated Canines Assisting with Disabilities**
**P.O. Box 831**
**Torrington, CT 06790**
**(860) 489-6550**
**info@ecad1.org**
**ecad1.org**

Educated Canines Assisting with Disabilities helps people with various disabilities gain greater independence through the use of specially trained dogs.

## Personal Care Attendant

Between 40 and 45 percent of individuals with spinal cord injuries (SCI) need personal assistance with some daily activities. It is understandable that the majority of persons needing assistance have higher levels of injury. They may need personal care assistance with getting in or out of bed, managing bowel and bladder issues, bathing, and dressing. Some individuals may need someone to drive, shop, and clean for them too. However, there is also a growing percentage of persons with lower levels of injury needing assistance as they get older. They may need assistance with household activities as they grow older and experience increased pain or fatigue.

**Asking and Receiving**
It may not be easy at times to ask for and receive assistance. This difficulty usually stems from two notions of thought.

First, some people may not ask for help because they do not want to "burden" others, especially family members. If you feel this way following SCI, ask yourself if it would be a burden on you to help a loved one in need. Probably not. However, many people with SCI still do not ask for the help they need. We are part of a family; we are part of a society; and we all need each other. We all need help at times, and we rely on each other in many ways, and most people gladly help family and friends if needed. Children are dependent on their parents and rely on them for care, and children commonly assist their parents as they age and become increasingly dependent. It is a natural state. Likewise, we function as a society helping each other throughout life. Health care professionals help us when we are sick; teachers help educate us; and police officers and fire fighters help protect us from danger. In fact, most jobs provide some type of service for people. The reality is that there is no shame in asking for and receiving help when you need it. And you will probably make your everyday life more of a burden on you if you do not get assistance when you need it.

A person's impression of "independence" is the second problem notion of thought. Some people may refuse assistance if offered because they believe that being independent means doing things without the help from others. However, the reality is that people who refuse help are less independent than people who ask for and receive help. Independence has little to do with what you can do. Independence is having the freedom to choose what you want to do. For example, people who do not have the ability to drive can still choose to go somewhere if they have assistance. When you get assistance, you have the opportunity for independence. It is that simple.

**Finding a PCA**

There really is no "best" way to find a Personal Care Attendant (PCA). You may need to use a number of ways to find people who might be interested in the job. If you qualify for services, you might start your search by checking with your State Department of Rehabilitation Services to see if there's a local program to help you find a PCA. Another option is to advertise in your local newspaper describing your need for PCA services. A classified ad will cost money to purchase, but you can reach a lot of potential candidates who are searching for employment. If you place an ad, it is a good idea to advertise on weekends because that will reach the most people. Another option is posting flyers in community areas likely to catch the eye of persons in the field of providing personal care. For example, you might put a flyer on a hospital or nursing home bulletin board. You can also post a flyer at a local college in the schools of nursing, occupational therapy and physical therapy. Finally, people often learn of jobs through word of mouth, so let people know you are searching for a PCA.

**Interviewing a PCA**

When you get calls from people interested in the job, you should schedule an interview with each person. This is your chance to get to know the person, and it gives the person a chance to find out more information about the job. You should clearly explain the types of tasks that your PCA will need do, and you should invite questions from the candidate to make sure he/she understands your needs. Many duties are of a very personal nature, so you want to be sure candidates are comfortable doing these tasks. Describe all the duties involved such as lifting, bathing, bowel and bladder programs, housecleaning, or grocery shopping. Discuss pay. Also, tell them what education and training you will provide. You can save time by preparing a list of questions to ask each candidate. A few examples might be:

- *Do you have previous experience?*
- *Do you have physical problems that prevent you from lifting or pulling?*
- *Will you cook and do housework?*
- *Do you have a driver's license, and are you willing to drive?*
- *Do you have dependable transportation to and from work?*
- *How much money do you need to make?*
- *Do you feel comfortable assisting with more "sensitive" personal care such as bathing, bowel and bladder care?*

If you are having problems deciding on a candidate, you might make a checklist of your needs and the personal qualities that you want in a PCA.

- *Is the person dependable and on time?*
- *Is the person trustworthy and honest?*
- *Is the person able to follow instructions?*
- *Is the person someone who is friendly?*
- *Is the person someone you can be friends with?*

Based on your interviews, you can select the best candidate for you. Once you select someone, always ask for references. If a candidate does not provide references after you ask, you may want to choose another person who will provide references because you should always check all references before hiring someone who is going to come into your home. Talk with previous employers to learn about the qualities that you want in an employee. You might get the candidate's driver's license number to ask the local police to run a security check on the person. You are ready to hire the person who checks out and best fits the qualities that you desire. Initially, you might hire the person on a temporary basis. This will give both you and the PCA time to get to know each other and find out if there is a good working

relationship.

**Education and Training**
Most PCAs need education and training on general issues associated with SCI. You can find and print information sheets from reliable sources on the internet. Gives these sheets to your PCA to read.

Even if you find a PCA with a lot of experience, you also have unique needs. Although all issues are important, your bowel, bladder, skin, and respiratory care must be understood by your PCA. Communicate your bowel and bladder needs clearly. Make sure you stress the importance of daily skin care, and your PCA should know how to conduct daily skin checks and spot problems. PCAs need to know about respiratory sickness too. Flu and pneumonia can be life-threatening for most people with SCI. This fact makes it important to have PCAs understand these dangers and work to prevent spreading these conditions. Washing hands should always be done often to help prevent the spread of germs. PCAs who are sick with a cold or flu should avoid contact when possible. If contact is unavoidable, PCAs should wear a mask and wash hands more often.

For individuals on a ventilator, PCA training on all the mechanical works of a ventilator can mean life or death. There should also be an emergency plan for ventilator problems and failures.

**Partner or Spouse VS. PCA**
A spouse or partner is often the first to provide personal care following injury. Although this arrangement is initially common for couples, the partner/caregiver role can be unhealthy if it continues long following injury. They may feel it is their "duty". Some family members do not want an outsider caring for their loved one. However, it is the individual with SCI who needs to decide what help he/she needs and who will provide it.

Although a spouse or partner might provide care at times, it is generally recommended that the primary care provider be someone other than a family member. This separation of roles allows individuals with SCI to be independent of family members and avoid unnecessary conflict with loved ones. Additionally, this separation ensures that family members do not become resentful of the added responsibilities or duties in the relationship.

Unfortunately, some couples have no option other than for a partner or spouse to be the primary caregiver. In this instance, it is very important to keep the partner/ spouse role separate from the caregiver role. One way to do this is to have a routine that keeps the caregiving activities separate from those of a partner. Couples also need to have occasional time apart. Keeping the partner/ caregiver roles as distinct and separate as possible will help you to avoid confusing and blurring of the partner role with the caregiver role, which is healthier for a couple's personal relationship.

**TOP 10 Reasons PCAs Quit Their Jobs**

1. Their initial job description was incomplete or keeps changing.
2. The method and order in which they must perform their duties are illogical, inefficient and waste time.
3. Their working environment is messy, unpleasant, disorganized, etc.
4. They're not paid enough, don't get appropriate raises or don't feel their work is appreciated.

5. They feel another PCA is favored over them.
6. The employer (YOU) is either too passive or too aggressive in his/her style of interaction.
7. The employer is dishonest about the hours worked, the salary owed, or has inappropriate expectations such as monetary loans or sexual favors.
8. There are unreasonable duties–those the employer is able to perform alone, those which cannot be performed in the allotted time or those which are too tightly supervised.
9. The employer is intolerant of honest mistakes, the need for sick time, etc.
10. The employer doesn't respect PCA's personal life and expects that his or her needs should take priority over all else in the PCA's life.

Source: Home Health Aides: How to Manage the People Who Help You, by Al DeGraff, 1988, Saratoga Access Publications, P.O. Box 1427, Fort Collins, CO 80522–1427.

**Funding**
The US Department of Labor's Wage and Hour Division administers and enforces the federal minimum wage law. Please be aware of state minimum wage requirement. In cases where an employee is subject to both the state and federal minimum wage laws, the employee is entitled to the higher of the two minimum wages.

Many people cannot afford a PCA without financial assistance. You may qualify for local or state programs that can help in paying a PCA. You might contact your local Independent Living Center, State Department of Rehabilitation Services or, for veterans, the Department of Veteran's Affairs. In some cases, private insurance may pay for "skilled nursing care," which may provide some aspects of personal care. If you are getting a financial settlement for your injury, it is important to include the projected lifetime costs for a PCA.

Like most things in life, you get what you pay for when it comes to a PCA. A reliable, dependable and skilled PCA is going to cost you. You want to make the job as appealing as possible to hire and keep the best possible PCA. Utilize all of the outside services that you qualify for to pay for a PCA, and you can also pay what you can afford out of pocket. Give occasional bonuses if you can, too.

Finally, you should probably talk with an accountant about any possible issues related to the Internal Revenue Service. Before you can know how to treat payments you make for services, you must first know the business relationship that exists between you and the person performing the services. If you have an employee, you may be responsible for Federal Income Tax Withholding, Social Security and other taxes as an employer. You may also need an accountant to help you with what you can and cannot claim on your personal income tax returns.

**Working with an PCA**
A PCA is often your friend and employee. It is up to you to balance the two roles. The first step is to make clear that a PCA's role is helping you with daily activities that you cannot do for yourself, and it is you who decides what assistance is needed. There are times when you need to be assertive, and you need to also be flexible sometimes. If there is a specific way that your care needs to be done, give the PCA clear directions on what needs to be done and the proper techniques involved. However, a PCA is a person, too. Although you are in charge of your care, your PCA may have a different approach to providing the same quality care. So you need to be reasonable in listening and accepting different ideas and opinions. It is also nice to express your appreciation to your PCA for the help he/she is providing for you. Finally, it is important that you are understanding if your PCA has a "bad"

day or makes a mistake. Hopefully, you will find that you can be flexible but still keep a professional relationship.
Finally, you cannot rely on one PCA all the time. If your spouse or partner is your primary caregiver, it is very important that you find a way to give him/her personal time for rest and enjoyment. Your PCA also needs days off, and there are unexpected circumstances that require absences from work. Therefore, you need to plan ahead. Make sure you have options and the ability to call on multiple sources if needed.

**Conclusion**
Many individuals with SCI need assistance with daily activities. Although the process of finding, hiring, training, and supervising a PCA is a necessity, asking for and receiving help may be difficult for some people. But a PCA can enhance your independence and quality of life.

## Caring for Caregivers

Between 40 and 45 percent of individuals with spinal cord injuries (SCI) need personal assistance with some daily activities. The majority have tetraplegia
and often need assistance with getting in or out of bed, managing bowel and bladder issues, bathing, and dressing. The lower the level of injury, the less
assistance is needed.

**PCA Vs. Caregiver**
Most often, a parent, spouse or other close family member is the first to provide personal care following injury. Although this initial care and attention is normal, it is not generally recommended for the long-term. If at all possible, it is best to have a paid Personal Care Attendant (PCA) provide the majority of long-term care while a loved one provides occasional care.

Unfortunately, many individuals with SCI have no option other than to rely on a family member for daily assistance. Whereas a PCA is an employee, a caregiver is the term used for an unpaid family member who is primarily responsible for the care of a loved one.

There is no “typical” family following SCI. Each situation is unique, and each caregiver and the person they care for will eventually create a system
of care that works best for them.

**Adjustment to SCI**
As a caregiver, you will likely face many unique challenges. First, there is often the initial worry and concern for the condition and recovery of your loved one. There is often stress over juggling work and finances while getting your home accessible for your loved one.

At the same time, you are learning about the many issues of SCI and how to be a caregiver. You may need to learn about bowel, bladder, and respiratory care. You need to learn how to do daily skin checks and recognize signs of a pressure sore. Likewise, you may need to learn the symptoms of Autonomic Dysreflexia or ventilator care and what to do in case of an emergency. There are a number of educational materials available from reliable Internet sources, and it is to your advantage to familiarize yourself with such resources.

Long-Term caregiving for a loved one can put a strain on any relationship. There are often many

lifestyle adjustments that need to be made in providing long term care. The basis for a healthy relationship centers on open communication, learning the facts about life after injury, a willingness to adjust one's views in many areas, and paying attention to the health of both the individual with SCI as well as the caregiver.

**Managing Self-Health**

While it is important to learn how to take care of your loved one, it is even more important for you to learn how to take care of yourself. Maintaining self-health is essential for your wellness and your ability to adequately care for your loved one. After all, you cannot expect to effectively care for your loved one when you are in distress.

**Recognizing Stress**

Stress is a physical, chemical, or emotional factor that causes tension in your body or mind. Most everyone has some type of stress in their life. Stress is common because it is almost impossible to escape. Stress can quickly become a problem for people who have learned to ignore signs and symptoms of stress until it gets out of control. Continued stress puts people at higher risk for serious health problems including illness, addiction, and depression. There are several signs and symptoms of stress that you can learn to recognize when stress might be getting out of control. When you are under a lot of stress, you may experience one or more of the following:

**Mood (Emotional) Symptoms of Stress**

- Anxious
- Scared
- Irritable
- Moody

**Thought Symptoms of Stress**

- Low self-esteem
- Fear of failure
- Inability to concentrate
- Embarrassing easily
- Worrying about the future
- Preoccupation with thoughts/tasks
- Forgetfulness

**Behavioral Symptoms of Stress**

- Stuttering and other speech difficulties
- Crying for no apparent reason
- Acting impulsively
- Startling easily
- Laughing in a high pitch and nervous tone of voice
- Grinding your teeth
- Increasing smoking
- Increasing use of drugs and/or alcohol
- Being accident prone
- Losing your appetite or overeating

**Bodily Symptoms of Stress**

- Perspiration /sweaty hands
- Increased heart beat
- Trembling
- Nervous ticks

- Dryness of throat and mouth
- Tiring easily
- Sleeping problems
- Diarrhea/indegestion/vomitting
- Butterflies in stomach
- Headaches
- Premenstrual tension
- Pain in the neck and or lower back
- Weight loss or gain

Source: http://ub-counseling.buffalo.edu/stressmanagement.shtml

**Adopting a Healthy Lifestyle**
A healthy lifestyle includes a balance of things you can do to feel better emotionally and physically. Healthy behaviors reduce stress and increase our ability to cope with problem issues. A few simple acts can be a great foundation for self-health. For example:

- Get enough sleep.
- Eat regular, healthy meals and snacks.
- Participate in regular physical activities.
- Take quiet time for yourself to listen to soothing music.
- Soak in a warm bath or shower
- Read an interesting book or magazine.
- Go to the park or some other place quiet.
- Cut down or cut out use of caffeine and tobacco.
- Do not rely on food, alcohol or drugs to reduce stress.
- Balance your life with work and play.
- Spend quality time with friends and family.
- Enjoy hobbies or crafts.
- Be assertive instead of aggressive. “Assert” your feelings, opinions, or beliefs instead of becoming angry, defensive, or passive.
- Do not volunteer for something if you do not have the time or energy to do.
- Keep things organized.
- Seek out social support to share ideas, resources and coping skills.

**Getting Help**
Getting help is essential to finding time for yourself. Help can come in various forms such as other family members helping with household chores. It may be an understanding boss that allows you to work from home or adjust your work schedule to be able to maintain your job while still providing care.

Caregiving is not a one-person job. You need time away for a healthy lifestyle, and there are going to be times when you are sick or need to get to get away for other reasons. The best thing that you can do is have a list of people that you can call when you need someone. You might also have one or two people on your list who can be a backup care provider on short notice in case of sickness or crisis.

**Learning to Solve Problems**
Although avoiding problems might ease stress in the short-run, most problems do not simply fade away. In fact, you can usually expect stress to continue until you resolve your problem issue.

Research suggests that having effective problem solving skills is also essential for the health of both

the caregiver and care recipient. You can use problem solving skills in almost all aspects of your life. As you set out to resolve problems, it is important to set your priorities. What needs to be done first? What can be left until later? Work on what needs to be done first.
There are 5 basic steps for effective problem solving.

**STEP 1** - Identify the problem: you must know the problem in order to solve it. You might make a list of your problems and rank them in order of importance. You need to make sure that you break large problems into smaller parts, and select the most troublesome problem to resolve first. Remember to work on one issue at a time and get all of the facts before moving onto step 2.

**STEP 2** - Brainstorm for possible solutions: thinking about the problem you most need to resolve, make a list of as many possible solutions to your problem as you can. Be free thinking, and do not judge your ideas at this time. If you have problems thinking of possible solutions, ask your family and/or friends for their thoughts on how they might solve the problem. If you need more information, you might search on the Internet or at your local library.

**STEP 3** - Select the best solution: from your list of possible solutions, choose the solution that you think will best solve your problem. Again, you can ask for opinions on which solution might work best. Once you make your choice, put your list in a safe place to keep for a later date if needed.

**STEP 4** - Try your solution: the only way to know if the solution works is to try it out. Take notes on your progress and any problems that you experience.

**STEP 5** - Evaluate your tried solution: if your solution works, give yourself a big pat on the back for a job well done. If you are not satisfied with the results of your solution, review your notes. It may be that there were unforeseen obstacles that need to be corrected. Make adjustments if needed. Try another possible solution from your list, or you can do more brainstorming for other ideas and edit your solution list based on new information.

**Learning to Relax**
Relaxation techniques are additional self-care skills you can learn. You first need to prepare yourself before you can relax. You can dim the lights and quiet all distractions by turning off the television, radio and phones. You can sit back in a comfortable chair.

**Self-Guided Imagery**

- Close your eyes. Focus on your breathing and take slow, deep breaths.
- Imagine that you are in a peaceful setting such as relaxing on a beach, meadow, or mountain top.
- Focus on the peaceful setting that you are imagining and pay close attention to all the details. Notice the sounds (any birds, wind rustling the leaves, waves crashing on the shore?). Pay attention to what you feel (warm sun on your skin, hot sand on your feet, cool grass beneath you). Attend to any smells and tastes you may imagine having. Spend some time focusing on all the sensations you are experiencing while imagining your peaceful place.
- After a few minutes return your attention on your breathing. Notice how you are breathing deeply in and out and focus on what is going on around you (the pressure of the seat against your legs, the ticking of a clock, etc.).
- Ask yourself how relaxed you are at the moment using a scale from 0 - 10 with zero indicating not relaxed at all and 10 reflecting the most relaxed you have ever been.

**Abdominal Breathing**

- Slow your breathing down by taking slow, deep breaths.
- You know you are breathing abdominally by placing your hand on your abdomen and seeing that your hand moves up and down.
- This is the type of slow, deep breathing that we do while we are sleeping.
- Slowing the rate of your breathing can slow your heart rate and give you a peaceful sense of relaxation.
- This takes practice, so keep trying if you are unable to do it the first few times.

**Progressive Muscle Relaxation**

- Beginning with your toes, slowly work your way up through the muscles in your body by tensing and then relaxing your muscles. After your toes, slowly tense and relax your feet, then your calves, thighs, abdomen, arms, hands, fingers, neck, and finally, your face.
- Take as long as you need to tense and then relax all the muscles in your body.

**Partner or Spouse Caregiving**

For couples, it is very important to keep the partner/ spouse role separate from the caregiver role. One way to do this is to have a routine that keeps the caregiving activities separate from those of a partner. Another way is to have a specific area or room devoted to intimacy - where no caregiving tasks are performed. Keeping the two roles as distinct and separate as possible will help you to avoid confusing and blurring the roles in your mind. When you and your partner are feeling romantic, you will be better able to see yourself as a romantic partner and not as a caregiver.

Couples need to also work to maintain equality within their relationship. Both partners need to make significant and meaningful contributions with every day issues such as parenting, various household chores or money management. This equality will help caregivers not to become resentful of being "overwhelmed" with daily responsibilities or duties.

**Problem Issues**

Most couples face obstacles early after injury. For most adults, pre-injury life is routine, familiar, and comfortable. People usually have established views of what they consider "normal," and they generally have defined notions of their relationship. In most cases, pre- and post-injury routines are very different for caregivers and their spouses or partners. Like many other aspects of life post-injury, changes in views and established routines are usually necessary in adapting to life after injury. Again, each family is different, so every family will not necessarily experience the same problem issues. As a caregiver, however, you will likely experience many of the same issues as others. Research has shown that caregivers generally report problem issues with:

1. The negative attitude of the person with SCI
2. Personal feelings of guilt
3. Lack of appreciation for being a caregiver
4. Not enough time for personal activities
5. Having to say "no" to the person with SCI
6. Feeling overwhelmed

Individuals with SCI expressed problem issues with:

1. Wanting to walk
2. Sexual function
3. Pain
4. Bowel and bladder function
5. Lack of money
6. Not being able to do simple tasks
7. Being anxious

Although the two groups are affected by the same injury, those reported problem issues tend to be self-oriented. Therefore, the key to a healthy relationship centers on open communication, learning the facts about life after injury, and a willingness to adjust one's views in many areas.

It is essential to talk about problem issues and openly discuss how these issues are affecting your relationship. In time, hopefully, the two of you can reach a mutual understanding of how, together, you can overcome the situation, resolve problem issues if possible and strengthen the relationship.

**Resolving Conflict**
You cannot avoid conflict because it is a necessary and healthy element in all relationships. People are simply different. Disagreements are going to occur because everyone has a unique point of view that often results in differing opinions.

If a problem is important to one member of the family, it is important to all. But conflicts with loved ones can be especially stressful for everyone involved. This is why it helps to learn how to resolve conflict to reduce or relieve stress.

**STEP 1** - Ground Rules: when two people disagree about an issue, the first emotional reaction is often anger. It is nearly impossible for people to resolve issues when they are angry. Therefore, it is important for everyone to let emotions calm before making an effort to resolve conflicts.

The purpose of conflict resolution is not to have one winner. It is to reach a solution in which all sides agree. When you think of resolving issues this way, people are likely to respond with a willingness to succeed. If the conflict is a question of fact, it is everyone's responsibility to know the facts.

**Basic Conflict Resolution Guidelines**
- Keep things in perspective.
- Focus on resolving one issue at a time.
- Be clear and direct when discussing issues.
- One person talks at a time.
- Allow each person to respond.
- Don't use physical contact, intimidation, or threats to get your way.
- Don't use the "Silent Treatment" and expect others to know what you think or feel.
- Don't dig up old issues that are not important to the issue at hand.
- Don't use emotional blackmail by saying "if you really love me, you would..."
- Don't over exaggerate or use words like "always" and "never."

**STEP 2** - State the Problem: you cannot resolve issues unless everyone knows exactly what the issue is. You are more likely to have success in resolving the problem if you are respectful when stating the

issue. For example, state the problem in the form of a self-expression, not a personal attack.

**Examples of Request**
- "I feel like my work is not appreciated."
- "I feel overwhelmed because I am getting no time for myself."
- "I feel guilty when I take time for myself."

**Example of Attacking Statement**
- "You make me mad when you do not give me a break."

If the problem is about behavior, make it a positive request about behavior, not a demand.

**Examples of Request**
- "I would like you to take a more active role in helping with the children."
- "I prefer that we do (something) this way."

**Examples of Demand Statement**
- "You have to start acting like a father."
- "You are going to do (something) my way."

**STEP 3** - Listen and Understand: listening is the hardest yet most important part of conflict resolution. Listening requires a open mind to hear what is said. When two people are in an emotional argument, who is really listening? Sometimes people talk over each other hoping the loudest voice wins Many people who are not talking are thinking about what they are going to say instead of listening Resolving issues requires a willingness to listen to what is said.

It is tough being a good listener. If you find it difficult, you might try to "repeat" in your head what is being said as another person talks. That way, you stay focused on hearing what is said. There may be times when you hear what is said but do not really understand the other persons meaning.

When someone talks to you, it is natural to imply your own reasoning to what is being said. However, people often mean to express themselves differently than you might think. If you are not clear about another person's meaning, you can easily repeat what they said and ask for more information. If you are open minded, listen and understand; it is easier to suggest possible solutions that both parties can agree.

**STEP 4** - Problem Solve for Resolutions: Following the 5 problem solving steps on page 3, conflict resolution is often similar to solving other problems. You want to work together because your goal is to resolve the issue in a manner that is acceptable to all those involved. Work together to pick one or more solutions from your list that everyone agrees offers a realistic chance for success. If you try a solution that does not work for everyone, work together to modify your solution or choose other possible solutions from your list.

**STEP 5** - Resolution: the issue is finally resolved when the solution works for everyone.

However, there may be issues that cannot be resolved. If the conflict is a matter of opinion, recognize that it is impossible to control the thoughts of anyone else. You may not change another person's mind even with your best efforts and intentions. Likewise, you cannot change other people's behaviors.

When there is no mutual resolution, you have to resolve the issue for yourself. You might agree to disagree on matters of opinion, or “let go” of a matter that you simply have no control over. These concepts may be hard to do at times, but they can be the best thing that you can do for your overall health.

**Conclusion**
As a caregiver, you can expect to experience ups and downs. You may feel overwhelmed or stressed at times with all of the added responsibilities you have. You might feel under appreciated for all your hard work and devotion.

Caregiving takes hard work and devotion, and providing care for a loved one is an expression of affection and commitment. After all, you are choosing to be primarily responsible for the care of someone you love. Therefore, it is important to take care of your health to best be able to give your loved one the care he or she needs.

However, it is equally important that you make a commitment to take care of yourself because it is best for you, too. You need care and attention as much as
anyone else. Although it takes hard work and devotion, you can find balance in your life if you make that commitment. Do not forget that.

**Family Caregiver Alliance**
https://www.caregiver.org/hospital-discharge-planning-guide-families-and-caregivers
The Family Caregiver Alliance addresses the needs of family and friends providing long-term care for loved ones at home. It provides support, information, and tools to manage the complex demands of caregiving. These include online support and resources, navigators to help locate support services by state, and the National Center on Caregiving which unites research, policy, and practice to develop cost-effective programs for caregivers. Click the link to find out more about how FCA could help you or your family.

## Mental Health and Substance Abuse

Substance Abuse & Mental Health Services Administration (SAMHSA)
Samhsa.gov.

Substance Abuse & Mental Health Services Administration U.S. Department of Health and Human Services is a searchable directory of mental health, substance abuse, and support services treatment facilities.

**Department of Mental Health and Addiction Services (DMHAS)**
**410 Capitol Avenue**
**Hartford, CT 06134**
**1-800-446-7348**

The Department of Mental Health and Addiction Services (DMHAS) promotes and administers comprehensive, recovery- orientated services in the areas of mental health, abuse prevention and treatment throughout CT.  DMHAS services adults over the age of 18 with psychiatric or substance abuse disorders, or both, who lack the financial means to afford services on their own. DMHAS provides a wide range of treatment including inpatient hospitalization, outpatient clinical services, 24

hour emergency care, day treatment, psychosocial and vocational rehabilitation, outreach services for persons with mental illness who are homeless, and comprehensive, community based mental health and support services.

DMHAS provides a variety of treatment services to persons with substance abuse disorders, including ambulatory care, residential detoxification, long-term care, methadone or chemical maintenance, outpatient, partial hospitalization, and aftercare. Services for HIV-infected include counseling, testing, support and coping therapies, alternative therapies and co management. The department also provides prevention services, designed to promote health and wellness of individuals and communities.

**UCONN Mental Health Service**
**Storrs, CT 06269**
**(860) 486-4705**
**Adult Outpatient Clinic**
**(860) 679-6700**

**Stonington Institute**
**North Stonington, CT**
**800-832-1022**

**American Foundation for Suicide Prevention**
**www.afsp.org**

Mission: Save Lives and Bring Hope to Those Affected by Suicide. Established in 1987, the American Foundation for Suicide Prevention (AFSP) is a voluntary health organization that gives those affected by suicide a nationwide community empowered by research, education and advocacy to take action against this leading cause of death.

**National Suicide Prevention Lifeline**
**preventsuicidect.org**

The National Suicide Prevention Lifeline is a 24-hour, toll-free, confidential suicide prevention hotline available to anyone in suicidal crisis or emotional distress. Your call is routed to the nearest crisis center in the national network of more than 150 crisis centers. For assistance, call 1-800-273-TALK (8255) The Crisis Text Line www.crisistextline.org: Text to 741741

**National Center for PTSD**
**https://www.ptsd.va.gov**

A national resource for trauma survivors, which includes information about PTSD, resources such as the PTSD Coach Online, and videos from other survivors and professionals.

## Employment

**Office of Disability Employment Policy**
**www.dol.gov/odep**

The Office of Disability Employment Policy (ODEP) is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities.

**Office of Personal Management, Individuals with Disabilities**
**https://www.opm.gov/about-us/careers-at-opm/individuals-with-disabilities/**

The Federal Government is actively recruiting and hiring persons with disabilities. We offer a variety of exciting jobs, competitive salaries, excellent benefits, and opportunities for career advancement.

**Rehabilitation Services Administration**
**https://rsa.ed.gov**

Our mission — to provide leadership and resources to assist state and other agencies in providing vocational rehabilitation (VR) and other services to individuals with disabilities to maximize their employment, independence and integration into the community and the competitive labor market.

**https://www.disability.gov/resource/employment-networks-connecticut/**

**Aging and Disability Services**
**55 Farmington Ave.**
**12th Floor**
**Hartford, CT 06105**
**Phone: (860) 424-5055**

## Connecticut Bureau of Rehabilitation Services Offices

**CENTRAL OFFICE**
Connecticut Bureau of Rehabilitation Services
55 Farmington Ave., 12th Floor
Hartford, CT 06105
Toll-free: 1-800-537-2549
Voice: (860) 424-5055
TDD/TTY: (860) 424-4839
Fax: (860) 424-4850
Email: www.brs.state.ct.us

**NORTHERN REGION**

**Greater Hartford**
184 Windso Ave.
Windsor, CT 06095
Tel: (860) 602-4000

**East Hartford**
893 Main Street
East Hartford, CT 06108
Tel: (959) 200-4400

**Manchester**
699 East Middle Turnpike
Manchester, CT 06040
Tel: (860) 647-5960

**Danielson**
562 Westcott Road
Danielson, CT 06239
Tel: (860) 455-1617

**New Britain**
30 Christian Lane
New Britain, CT 06051
Tel: (860) 612-3569

**SOUTHERN REGION**

**New Haven**
370 James Street, Suite 306
New Haven, CT 06513
Tel: (203) 974-3000

**Willimantic**
1320 Main Street
Willimantic, CT 06226
Tel: (860) 455-1606

**Middletown**
442 Smith Street
Middletown, CT 06457
Tel: (860) 740-1080

**Uncasville**
601 Norwich New London Turnpike
Suite 1
Uncasville, CT 06382
Tel: (860) 848-5950

**WESTERN REGION**

**Bridgeport**
1057 Broad Street
Bridgeport, CT 06604
Tel: (203) 683-0500

**Waterbury**
249 Thomaston Ave.
Waterbury, CT 06702
Tel: (203) 578-4550

**Torrington**
30 Peck Road, Bldg. #1, Unit 1102
Torrington, CT 06790
Tel: (860) 294-0013

**Stamford**
1642 Bedford Street
Stamford, CT 06905
Tel: (203) 653-1939

**Danbury**
342 Main Street
Danbury, CT 06810
Tel: (203) 702-0152

The goal of the Vocational Rehabilitation (VR) Program is to assist individuals with significant physical and mental disabilities to prepare for, obtain and maintain employment. Through the provision of individualized services, persons with disabilities who are eligible for vocational rehabilitation are supported in planning for and achieving their job goals. To be eligible for the VR program, an individual must have a physical or mental condition which poses a substantial barrier to employment, and must require VR services in order to prepare for, find and succeed in employment.

**The Independent Living Program**

The Bureau's Independent Living (IL) program provides comprehensive independent living services, through contracts with Connecticut's five community-based independent living centers (ILCs). These centers promote empowerment and self-reliance for persons with disabilities. There are four core services provided by an independent living center:

**Peer Support**
Peer counselors at ILCs provide support to consumers by drawing on their own life experience with disabilities and negotiating the system.

**Information and Referral**
ILCs assist the individual in identifying and accessing services and supports, benefits, assistive technology, housing, personal assistance services, or any other resources to enhance independent living.

**Individual and Systems Advocacy**
ILCs assist consumers to secure the supports and services needed to maximize their independence. Advocacy on a systems level challenges the barriers that can stigmatize and exclude people with disabilities from full community participation.

**Independent Living Skills Training**
ILCs provide training in activities of daily living and the skills needed to make community living as full and rich as possible. Examples of skill training areas are: management and recruitment of personal attendants, financial management, utilizing community resources, locating housing, consumer rights and responsibilities.

In response to the "Olmstead Decision" (Olmstead vs. L.C., June 22, 1999), which prohibits states from institutionalizing persons with disabilities who with proper supports can live in the community, BRS is working in partnership with representatives of state agencies, independent living centers and advocates for persons with disabilities, to find innovative ways to restructure services and expand independent living opportunities for persons who are at risk of, or who are, institutionalized.

Olmstead and Connecticut's response to it represent a profound and positive shift in disability policy. Independent living centers are fundamentally different from other providers that serve people with disabilities. The traditional approach to assisting people with disabilities originated from a medical perspective that thinks of these people as requiring curing or fixing. Using this approach, a medical professional controls the service and the desired outcome is to achieve maximum physical or mental functioning.

The independent living model of service provision believes that the problem lies with society, not the

individual. A disability is viewed as a condition, often times permanent, that affects or restricts an individual's ability perform certain tasks. With this approach, the person with the disability controls the service instead of the professional; the desired outcome of service is to achieve complete control over daily living whenever and wherever possible.

Independent living centers offer services designed to empower persons with disabilities to maintain an independent life, no matter what their living situation. The guiding principle is integration of the person with a disability to the fullest degree possible into the community of choice.

**Independent Living Centers are:**

**Consumer-Controlled**
Directed, managed and staffed to a substantial degree by qualified persons with severe disabilities.

**Community-Based**
Located within the community in which the consumers of its services reside.

**Community Responsive**
Designed to address the disability-related needs of the community, by identifying service gaps and barriers which limit the independence of people with disabilities in that community.

**Cross-Disability**
Provide a single point of access to services for all people regardless of the nature or type of disability.

**Non-Residential**
Support self-sufficiency and independent living for the individual in their chosen community and setting.

**CACIL**
To contact the website for the Connecticut Association of Center for Independent Living(CACIL), please go to www.cacil.net

**Disability Resource Center**
80 Ferry Boulevard, Suite 210
Stratford, CT 06615
(203) 378-6977 (V)

**Center for Disability Rights**
369 Highland St
West Haven, CT 06516
(203) 934-7077 (V)
cdr-ct.org

**Independence Unlimited**
151 New Park Avenue #65
Hartford, CT 06106
(860) 523-5021 (V/TDD)
e-mail: contactus@independenceunlimited.org
**Disabilities Network of Eastern Connecticut**

19 Ohio Avenue
Norwich, CT 06360
(860) 823-1898 (V/TDD)
web site: www.dnec.org
e-mail: dnec@dnec.org

**Independence Northwest**
Independence Northwest, Inc.
1183 New Haven Road, Suite 200
Naugatuck, CT 06770
203-729-3299 (V)
203-729-1282 (TDD)
Email: info@independencenorthwest.org

**Ability Beyond**
**4 Berkshire Blvd.**
**Bethel, Connecticut 06801**
**1-888-832-8247**
**info@abilitybeyonddisability.org**

Ability Beyond's mission is to enable individuals whose independent living skills are impaired by disability, illness or injury, to achieve and maintain self-reliance, fulfillment and comfort at home, at work and in the community, by providing the best comprehensive home, health and rehabilitation services.

## Financial Assistance

**Medicare**
**Centers for Medicare & Medicaid Services**
**7500 Security Boulevard, Baltimore MD 21244-1850**
**1-800-MEDICARE (1-800-633-4227)**
**www.socialsecurity.gov**

Medicare provides hospital insurance, medical insurance and prescription drug coverage. Hospital insurance, sometimes called Part A, covers inpatient hospital care and certain follow-up care. Medical insurance, sometimes called Part B, pays for physicians' services and some other services not covered by hospital insurance. Prescription drug coverage, sometimes called Part D, helps pay for medications doctors prescribe for treatment. Medical insurance and prescription drug coverage are optional, and you must pay monthly premiums. People who are 65 or older are automatically eligible for Medicare. Those that are determined to be disabled by the SSA are eligible after 2 years as long as certain other criteria are met. Starting January 1, 2014, Medicare recipients must get a Medicare Part D Plan. For help with this process you may call Agency on Aging and they will connect you with a counselor that can help.

**Social Security Disability**
**Social Security Administration**
**Office of Public Inquiries**
**Windsor Park Building**
**6401 Security Blvd.**

**Baltimore, MD 21235**
**1-800-772-1213**
**www.socialsecurity.gov**

The Social Security Administration is responsible for two major programs that provide benefits based on disability: Social Security Disability Insurance (SSDI), which is based on prior work under Social Security, and Supplemental Security Income (SSI). Under SSI, payments are made on the basis of financial need. Social Security Disability Insurance (SSDI) is financed with Social Security taxes paid by workers, employers, and self-employed persons. To be eligible for a Social Security benefit, the worker must earn sufficient credits based on taxable work to be "insured" for Social Security purposes. Disability benefits are payable to blind or disabled workers, widow(er)s, or adults disabled since childhood, who are otherwise eligible. The amount of the monthly disability benefit is based on the Social Security earnings record of the insured worker. Supplemental Security Income (SSI) are payable to adults or children who are disabled or blind, have limited income and resources, meet the living arrangement requirements, and are otherwise eligible. The monthly payment varies up to the maximum federal benefit rate, which may be supplemented by the State or decreased by countable income and resources.

Your Care Management Department can provide you with some assistance in this process or you can file for either program online.

**Department of Social Services**
**25 Sigourney St.**
**Hartford, CT 06106-5033**
**1-800-842-1508**
**www.ct.gov/dss**

The Department of Social Services provides a broad range of services to the elderly, disabled, families, and individuals who need assistance in maintaining or achieving their full potential for self-direction, self-reliance and independent living. DSS administers over 90 authorized state programs.

**Medicaid**
**Department of Social Services**
**25 Sigourney St.**
**Hartford, CT 06106-5033**
**1-800-842-1508**
**www.ct.gov/dss**

The Medicaid program provides for preventive and long term medical care for income eligible aged, blind or disabled individuals, and families with children. Payment is made directly to health care providers, by the department, for services delivered to eligible individuals. Eligibility is determined on an individual basis. An application must be filed with DSS and medical and financial need must be determined.

**Husky Health of Connecticut**
**11 Fairfield Blvd. Suite 1, Wallingford, CT 06492**
**Telephone: 800-440-5071**

This company manages all Title 19 or Medicaid products for all ages. The programs provide medical

coverage assistance to low income persons. Applications and approval is still done through the state DSS or Department of Social Services. All services included in the CT Medicaid program are covered, including homecare and skilled nursing facilities. Gaylord has a benefits Liason who can assist you with the application process. Your care manager can make a referral to Joan Hogan if that will be helpful to you.

**Medicaid for the Employed Disabled**
**Department of Social Services**
**25 Sigourney St.**
**Hartford, CT 06106-5033**
**1-800-842-1508**
**www.ct.gov/dss**

The program allows people with a disability to engage in employment without risking eligibility for needed medical services through the Medicaid program. The program also allows certain individuals to keep other necessary services needed to remain employed. In general an eligible person with a disabling condition who is employed, can qualify for Medicaid without the use of spend-down while earning income in excess of traditional income limits.

**Aquired Brain Injury (ABI) Waiver**
**Department of Social Services**
**25 Sigourney St.**
**Hartford, CT 06106-5033**
**1-800-842-1508**
**www.ct.gov/dss**

This program is designed to provide a range of non-medical, home and community based services to maintain adults who have an acquired brain injury (not a developmental or degenerative disorder), in the community. Adults must be age 18-64 to apply, must be able to participate in the development of a service plan in partnership with a Department social worker, or have a Conservator to do so, must meet all technical, procedural and financial requirements of the Medicaid program, or the Medicaid for Employed Disabled program. An adult deemed eligible for the ABI Waiver, is eligible for all Medicaid covered services. Application is made by contacting the Department's regional offices, and returning a completed ABI Waiver Request Form.

**Personal Care Assistant (PCA) Waiver**
**Department of Social Services**
**25 Sigourney St.**
**Hartford, CT 06106-5033**
**1-800-842-1508**
**www.ct.gov/dss**

A Medicaid Waiver program that provides personal care assistance services included in a care plan to maintain adults with chronic, severe, and permanent disabilities, in the community. Without these services, the adult would otherwise require institutionalization. The care plan is developed by a Department social worker in partnership with the adult. Adults must be age 18-64 to apply, must have significant need for hands on assistance with at least two activities of daily living (eating, bathing, dressing, transferring, toileting), must lack family and community supports to meet the need, and must meet financial requirements of the Medicaid program, or the Medicaid for Employed

Disabled program. Eligible adults must be able to direct their own care and supervise private household employees, or have a Conservator to do so. An adult deemed eligible for the PCA Waiver, is eligible for all Medicaid covered services. Application is made by contacting the Department's regional offices, and returning a completed PCA Waiver Request Form.

**'Money Follows the Person'**
**Department of Social Services**
**25 Sigourney St.**
**Hartford, CT 06106-5033**
**1-800-842-1508**
**www.ct.gov/dss**
**1-888 992 8637**

'Money Follows the Person' is a program to assist people living in nursing homes or applying to them from an acute care hospital or rehab center. This program is designed to assist people by helping to give them the opportunities to live in their own homes or in other community settings. An application can be done online at CTMFP.com/application with the assistance of your healthcare professional. This program works along with other state programs including waiver programs. The process can be lengthy, one to two year wait list.

**Alternate Care Unit - Connecticut Home Care Program for Elders (CHCPE)**
**Department of Social Services**
**25 Sigourney St.**
**Hartford, CT 06106-5033**
**1-800-445-5394 (toll-free) or 860-424-4904**
**www.ct.gov/dss**

To be eligible, applicants must be 65 years of age or older, be a CT resident, be at risk of nursing home placement and meet the program's financial eligibility criteria. To be at risk of nursing home placement means that the applicant needs assistance with critical needs such as bathing, dressing, eating/meals, taking medications, using the toilet. The CHCPE helps eligible clients continue living at home instead of going to a nursing home. Each applicant's needs are reviewed to determine if the applicant may remain at home with the help of home care services.

## Housing

You and your family members can call the Housing Authority or the Department of Human Services in the town(s) in which you wish to live. You will need to ask to be placed on the wait list and complete an application for handicapped accessible housing. Please specify what you are looking for ie: wheelchair accessible housing, elevator access building, wider doorways if your wheelchair requires that etc. If you need assistance with obtaining phone numbers your care manager can assist you. Gaylord is not responsible for finding housing after discharge but is happy to assist with providing you with any known resource available.

**Nursing Home Placement**
Should you be unable to return home following your Gaylord stay secondary to physical impairments or medical issues, you may need to consider nursing home (also known as SNF or Skilled Nursing Facility) placement. Nursing homes provide their residents with continued rehabilitative care including nursing and therapies, assist with personal care, protective supervision, meals, and recreational

activities. Residents usually have physical or mental impairments that keep them from living independently. Unlike some other facilities, nursing homes employ medical personnel to provide health care to residents. Some facilities provide sub-acute care, which is medically more sophisticated than traditional nursing home care. These facilities can usually provide this care at a lower cost than hospitals, therefore you may need to consider this option at the recommendation of your team or your insurance provider as your condition indicates. The Care Management Department will assist you in the nursing home placement process.

## Transportation Services

**Public Transportation**

Federal law requires that providers of mass transit services who receive federal financial assistance must certify that they provide people with disabilities full and equal access to the same services and accommodations as persons without disabilities. One of those services is public transportation. The U.S. Department of Transportation's Urban Mass Transportation Administration (UMTA), the funding source, allows local areas to select one of a few acceptable options to meet that requirement. These options are:

1. **The operators to ensure that at least 50% of the fixed route buses running during service hours are lift equipped.**
2. **The operator to establish a Paratransit or special system which is known as "door-to-door" or "dial a ride", on a demand responsive basis.**
3. **The operator may establish service that is a combination of the other two options listed (1 and 2). Whenever a special service is employed, that service as a whole, must meet certain criteria of comparability with the service available to able-bodied persons.**

Anyone who would like to use the ADA Paratransit service must be certified ADA Paratransit eligible. Information and/or an application can be obtained by contacting your local ADA Paratransit office.

**CTRides.com** provides a resource directory to local bus service and public transportation services by regional district.

**Greater Bridgeport Transit Authority**
www.gogbt.com
203-333-3031
203-579-7777 – Paratransit

**Estuary Transit District (Central Shoreline)**
860-388-1611

**Greater Hartford Transit District**
www.hartfordtransit.org
860-247-5329
860-724-5340

**Greater New Haven Transit District**
203-288-6282

203-288-6643 – Paratransit

**Rides+Interfaith Volunteer Care Givers of Greater New Haven**
carenewhaven.org/ridesplus
*For seniors 60 and over, membership
Administration@CareNewHaven.org
Phone: (475) 257-6538

**My Ride of the Greater New Haven Transit District**
840 Sherman Ave.
Hamden, CT 06514
(203) 288-6282

My Ride offers transportation for disabled or elderly persons living in the South Central CT area.

**Greater Waterbury Transit District (Northeast Transportation Paratransit Division of CT Transit)**
www.northeastbus.com/paratransit-service/
203-756-5550

**Housatonic Area Regional Transit (HART)**
www.hartransit.com/
203-748-2034
203-748-2511 – Paratransit

**Rivervalley Transit District**
860-346-0212
860-347-3313 – Paratransit

**Milford Transit District**
203-874-4507

**Northeastern Connecticut Transit District**
860-774-3902

**Northwestern Connecticut Transit District**
860-489-2535

**Norwalk Transit District**
www.norwalktransit.com
203-852-0000

**Southeast Area Transit District (SEAT)**
860-886-2631

**Valley Transit District**
www.valleytransit.org
203-735-6824
203-735-6408

**Windham Region Transit District**
www.wrtd.org
860-456-2223
860-456-1462 – Paratransit

If your transit provider discriminates against you, ask your operator for a copy of the UMTA certification. Check the UMTA certification with the State Office of Protection and Advocacy for Person with Disabilities – 1-800-842-7303.

## Additional Services Available

Many cities and towns, as well as some non-profit agencies operate special services for persons who are elderly or disabled. Most non-profit agencies limit the use of their special services to medical or shopping trips for which modest fees are charged. To obtain information on service availability in your area, visit your town or city hall or contact the local regional planning agency listed below. Or call your local senior center.

**Central Connecticut Transportation Services:**

**BRISTOL**
Human Resource Agency of New Britian (HRA) Dial-A-Ride (860) 589-6968
Monday through Friday, 9:00am to 1:15pm. Return trip can be anytime before 3pm.
(Contact – Nancy Shannon or Barbara Parsons, (860) 826-2282
*Bristol resident, social security or proof of SSD

**BERLIN**
Senior Center Transportation – 860-828-7006
24-hour notice required. They will go to New Britain for medical trips, therapy, hair, post office, grocery, food share, Walmart, Job Lot, Khols, and the bank. Resident of Berlin, age 60+ (Contact – Tina Doyle) Servicing the following towns: New Britian, Cromwell, Rocky Hill, Farmington, Southington

**ENFIELD**
Dial-A-Ride – 860-272-3645 – Senior citizens over 60. Physically disabled.
Annual one time cost of $120. 8:00am to 4:00pm. Call for further details.

ITN North Central CT Service – 860-521-3600
itncentral.org

**NEW BRITAIN**
The Senior Center Dial-A-Ride – 860-826-3555
Monday through Friday, 8:30am to 3:15pm. Rides are provided for seniors age 62+ and persons with disabilities age 55+. Medical/Dental, weekly grocery shopping, trips to Senior Center, personal appointments. Cost $1.50 each way. Membership $10, Lifetime membership for residents, non-residents $20 a year.
Newsletter: https://www.newbritainct.gov/services/community/senior/defaulthtm

**PLAINVILLE**
The Senior Center – 860-589-6968
Provides rides for members in conjunction with Bristol Community Organization

**PLYMOUTH**
Dial-A-Ride – 860-283-0060
Available to elderly and disabled persons around Plymouth and surrounding towns. Disabled persons continue to receive top priority as well as those in need of medical care. Service available Monday through Thursday 11:00am to 4:00pm, Friday 9:00am to 1:00pm and Sunday 8:00am to 11:00am for church services. Service is free although donations are accepted.

**SOUTHINGTON**
The Employment Development Center (EDC) – 860-620-5166
Provides "Access Shuttle Service" for elderly and disabled residents. Service available Monday through Friday, 8:00am to 4:30pm

**REGIONAL PLANNING AGENCIES**

**Capitol Regional Council of Governments**
241 Main Street, Hartford, CT, 06106
860-522-2217

**Northeast Transportation/Greater Waterbury Transit District**
P.O. Box 4670, Waterbury, CT, 06704
203-756-5550

**Southwestern CT Regional Planning Agency**
888 Washington Boulevard, 3rd Floor, Stamford, CT, 06901
203-316-5190

**Valley Regional Planning Agency Council of Governments/Valley Transit**
41 Main Street, Derby, CT, 06418
203-735-6824

**Windham Regional Transit District**
968 Main Street, Willimantic, CT, 06226
860-456-2223

## Private Transportation

Private livery services operate in some parts of the state. Many are available for long distance as well as local trips. A list of these services is in the Yellow Pages of your telephone directory under Wheelchair and Invalid Transportation. Call for fee schedules. Or check on line for local services. You may also try your local ambulance company as some have a full range of transport, car, w/c van, ambulance even limo services.

## SCI Organizations and Information

- National Spinal Cord Injury Statistical Center (NSCISC) (www.nscisc.uab.edu)
- SCI Information Network (University of Alabama) (spinalcord.uab.edu)
- Christopher and Dana Reeve Foundation (christopherreeve.org)

- United Spinal Association (unitedspinal.org)
- Paralyzed Veterans of America (PVA) (not just for veterans) (pva.org)
- Arkansas Spinal Cord Commission (spinalcord.ar.gov)

Spinal Cord Injury Guide - Best sites chosen by you for you (sciguide.org)

## SCI Cure and Recovery Information

- CareCure Community (sci.rutgers.edu)
- Miami Project to Cure Paralysis (miamiproject.miami.edu)
- Reeve-Irvine Research Center (reeve.uci.edu)
- Spinal Cord Society (SCSUS.com)
- International Center for Spinal Cord Injury at Kennedy Krieger Institute (spinalcordrecovery.org)
- Institute of Medicine: Spinal Cord Injury - Strategies in Search for a Cure (iom.edu)
- International Campaign for Cures for Spinal Cord Injury Paralysis(icord.org) - information about clinical trials in SCI and downloadable guidelines for persons considering participation in experimental treatments or SCI.

## SCI and Disability Publications

- Disability World (disabilityworld.org) —Web-zine of international disabilitynews and views, in Spanish and English.
- New Mobility (newmobility.com) - "The disability lifestyle magazine"
- Paralinks (paralinks.net) - Electronic magazine for people with SCI
- Paraplegia News (pvamagazines.com) —published by Paralyzed Veterans ofAmerica.
- Pushin' On (spinalcord.uab.edu) (newsletter of the SCI Information Network)
- Ragged Edge (raggededgemagazine.com) —Disability Rag's Online Magazine
- Sports 'n Spokes (pvamagazines.com/sns/) —wheelchair sports magazine published by Paralyzed Veterans of America.
- SCI Update (sci.washington.edu/info/newsletters) —the newsletter of the Northwest Regional Spinal Cord Injury System

## Medical Complications of SCI

- Staying Healthy After a Spinal Cord Injury (sci.washington.edu/infopamphlets) -patient education pamphlet series about bladder and bowel management, skin care, pressure ulcers, pain and depression.
- Medical complications information from the SCI Information Network (spinalcord.uab.edu)
- American Syringomyelia Alliance Project (asap.org)
- American Pain Society (ampainsoc.org)
- American Chronic Pain Association (www.theacpa.org)

Since 1980, the ACPA has offered peer support and education in pain management skills to people with pain, family and friends, and health care professionals. The information and tools on this site can help you to better understand your pain and work more effectively with your health care team toward a higher quality of life.
New England Spinal Cord Injury Toolkit (gaylord.org/SCI Toolkit)

## SCI Research

- National Institute of Neurological Disorders and Strokes (ninds.nih.gov) research on neurological disorders and diseases.
- Modely Systems Knowledge Translations Center (MSKTC.org)

## SCI Research Sites

http://www.miamiproject.miami.edu/Page.aspx?pid=464
http://www.spinalcord.uab.edu/show.asp?durki=21777
Clinical trials registry of all clinical trialsarouone the world (clinical trials.gov)
http://www.wpi.edu/research/index.html
http://www.invivotechnology.com/cms/section/technologies.html
http://discoverysedge.mayo.edu/spinal_cord_injury/index.cfm
http://spinal-research.org/Research.asp
http://www.geron.com/patients/diseaseinformation/spinalcordinjury.aspx
http://www.dvbiosciences.com/media.php
http://www.namiscc.org/newsletters/December01/SCI-stem-cell-research.htm
http://www.christopherreeve.org/site/c.ddJFKRNoFiG/b.4343879/k.D323/Research.htm
http://sci.washington.edu/info/forums/forum_videos.asp
http://scimodelsystems.org/social
http://scope-sci.org/index_files/exp_treatments_for_sci.pdf
http://sci.washington.edu/info/forums/reports/intrathecal_baclofen.asp
http://backtoyourlife.com/
http://sci.washington.edu/info/pamphlets
http://sci.washington.edu/info/pamphlets/index.asp#skincare
http://sci.washington.edu/info/forums/forum_videos.asp.
http://sci.washington.edu/info/forums/reports/nutrition.asp
http://scope-sci.org/index_files/exp_treatments_for_sci.pdf

**SCI Sites written and maintained by individuals with SCI**

SCI Guide from SCI orgs and info
- Spinal Cord Injury Resources (makoa.org/sci.htm) (Jim Lubin)
- Vent Users Support Page (makoa.org/vent/index.html) (Jim Lubin)
- The Spinal Cord Injury Zone (thescizone.com)
- Spinal Cord Injury Resource Center (spinalinjury.net)
- SCI Information Pages (sci-info-pages.com)

Listservs for individuals with SCI

- SCI Mailing List: There is an Internet mailing list on the topic of spinal cord injury, called SCIPIN-L List. To join it, send a message to listserv@health.state.ny.us with only the words “subscribe SCIPIN-L” in the body of the message. (After you join, send all messages to the list to scipin-l@health.state.ny.us, NOT to the address above.)
- Quadriplegic (Tetraplegic) Discussion Group: This Internet mailing list, called QUAD-LIST, is a forum for quadriplegics (tetraplegics) to communicate with one another. To subscribe to the list, follow the instructions found on Jim Lubin’s QUAD-LIST web page (makoa.org/quadlist.htm)

- Vent Users Mailing List: This Internet mailing list is a forum where ventilator users can communicate with one another. To join, fill out the online form at the website of list owner Jim Lubin.

International SCI Sites
- Spinal Injuries Association (spinal.co.uk) (United Kingdom)
- Spinal Cord Research Centre (scrc.umanitoba.ca) (University of Manitoba, Winnipeg, Manitoba, Canada)

Disability Web sites
-Americans with Disabilities Act (www.ADA.gov)
The ADA website provides information and technical assistance regarding the Americans with Disabilities Act.
1-800-514-0301 (voice)
1-800-514-0383 (TTY)
- Mobilewomen.org (carecure.rutgers.edu/mobilewomen/mobilecover.php) - online magazine for women in wheelchairs.
- Proyecto Vision (proyectovision.net) - a bilingual Web site for Latinos with disabilities.
- The Disability Resources Monthly (DRM) WebWatcher SCI Information (disabilityresources.org/SCI.html)
- Through the Looking Glass (lookingglass.org/index.php) - for families in which a child or parent has a disability.
- WheelchairNet (wheelchairnet.org) - all about wheelchairs.


## Emergency Preparedness

It is key to have a plan before an emergency takes place. Many agencies share helpful information to guide you in making a plan. For websites with detailed information and guides for emergency preparedness, see the resource section below.

When making your plan, think about the needs of the people in your home. Create a contact list to be shared with other family members, caregivers, and neighbors. You will also need contact information for important offices and people such as doctors, hospital, utility company, pharmacy, etc.

Let first responders know there is a person with disabilities in the house. In addition, inform your utility company if you have a power w/c or respiratory equipment requiring power. The utility company will often prioritize your needs during times of power outages.

**Make an emergency kit with:**

- **all contact information**
- **an up to date medication list and if possible a 1-2 week supply of medications**
- **over-the-counter medications**
- **Personal health items such as gloves, catheter or ostomy supplies**
- **any backup medical devices or assistive technology needs**
- **bottled water**
- **flashlights and extra batteries**

- first aid kit
- masks
- tool kit for w/c repair
- cell phone charger

Practice your plan with your family and friends. Just like fire drills, emergency drills are the best way to see if all your needs will be meet before it counts.

If an emergency evacuation takes place, you will be able to provide first responders your information, needs, and where you hope to stay. If you or someone in your home has a wheelchair, it's important to know the size and weight of it in case it needs to be transported. You might want a collapsible transport wheelchair for backup. If oxygen is needed, back up tanks and portable concentrators also need to be planned for.

Protecting yourself and your family in an emergency takes planning. By having contact lists, your emergency kit, and a plan can make it much less scary. Know how to get the help you need. Be sure to practice and be prepared.

**Resources:**
**Helpful websites containing resource information/guides for emergency preparedness:**

https://www.christopherreeve.org/wp-content/uploads/2023/05/Emergency-Prep-Booklet-4-2023-online-A.pdf
https://unitedspinal.org/ready-to-roll/
https://www.veteranshealthlibrary.va.gov/rehab/SpinalCordInjury/142,41201_VA
https://www.ready.gov/people-disabilities
https://www.redcross.org/get-help/how-to-prepare-for-emergencies/inclusive-preparedness-resources.html?srsltid=AfmBOopADr8ZvZasqcM0tCD7gSr0XX2aMn1e1NngoN6gFkUX7Ro2adIb
https://www.cdc.gov/disability-emergency-preparedness/people-with-disabilities/index.html
https://www.dhs.gov/prepare-my-family-disaster

**Link to website for a printable medication card:**
https://portal.ct.gov/dph/facility-licensing--investigations/health-care-quality/wallet-medication-card

**Local Resources/Contact Information:**
American Red Cross of Connecticut: https://www.redcross.org/local/connecticut.html?srsltid=AfmBOoqKwams_4vnxk3w7wPC4Uv1XnDfOkv9ZU5N21kG_ZWkAoCaZjn9

**Bridgeport Office:**
158 Brooklawn Avenue
Bridgeport, CT 06604
(877) 287-3327

**Darien Office:**
39 Leroy Avenue
Darien, CT 06820
(877) 287-3327

**Farmington Office – Regional Headquarters**
209 Farmington Avenue
Farmington, CT 06032
(877) 287-3327

**Milford Office:**
1 Plymouth Place
Milford, CT 06460
(877) 287-3327

**Southbury Office:**
385 Main St South Suite 214
Southbury, CT 06488
(877) 287-3327

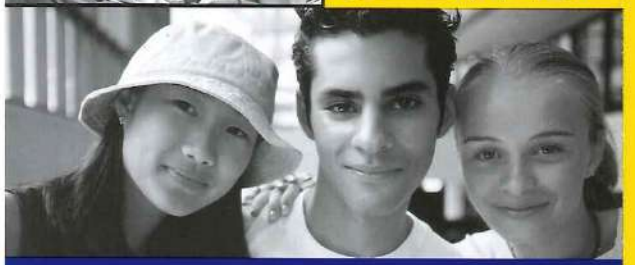
**Montville Office:**
1031 Rte 32
Uncasville, CT 06382
(877) 287-3327

**Neighboring Town Points of Contact for Non-Emergency Situations:**

- Wallingford Police Dispatch: 203-294-2800
- Cheshire Police Dispatch: 203-271-5500
- Meriden Police Dispatch: 203-238-1911
- North Haven Police Dispatch: 203-239-1618

***Note:** If a true medical or other type of emergency exists, Dial -911 for immediate assistance. Be sure to give your name and location and describe as best you can any medical symptoms related to you

2-1-1



# Help *Starts* Here.

UNITED WAY

## *Call 2-1-1 for your connection to:*

- *Alzheimer's resources*
- *basic needs –food, clothing, shelter*
- *child care services*
- *child health care*
- *consumer help*
- *counseling*
- *crisis intervention*
- *disability services*
- *drug & alcohol programs*
- *emergency shelter*
- *energy assistance*
- *financial assistance*
- *health care*
- *HIV/AIDS testing*
- *housing*
- *legal assistance*
- *parenting programs*
- *pre-natal care*
- *senior services*
- *suicide prevention*
- *transportation*
- *veterans' services*
- *volunteering*
- ***and much more...***

2-1-1

# Help *Starts* Here.

### 2-1-1

Who do you call when someone you love is battling an addiction? Or when your electricity is shut off and you can't pay the bills? What if you or someone you know is facing a crisis, where do you get help?

### Dial 2-1-1 for community services.

2-1-1 can help you find the answers. Whether you need help – or want to give help – 2-1-1 is the free and confidential way to locate hundreds of services available in your community.

2-1-1 is open 24 hours a day and multilingual call specialists are available.

### Personal, professional answers.

When you dial 2-1-1 from anywhere in Connecticut, you speak with a call specialist who makes it easier for you to:

- *find information*
- *discover options*
- *deal with a crisis*

2-1-1 is certified by the American Association of Suicidology for crisis intervention and accredited by the Alliance of Information and Referral Systems.

### Helping people is right at your fingertips.

- *volunteer opportunities*
- *donating food, clothing, toys, furniture, books and more*
- *mentoring*

### Visit us on the Internet at

www.211ct.org

United Way

2-1-1 is a partnership of Connecticut United Ways and the State of Connecticut

***Free • Confidential • 24 hours a day • Every day • Multilingual/TTY***

NSCISC
National Spinal Cord Injury Statistical Center
Spinal Cord Injury Model System

# Traumatic Spinal Cord Injury Facts and Figures at a Glance

2025 SCI Data Sheet

The Spinal Cord Injury Model Systems was created in 1970 as a prospective longitudinal multicenter study on demographics and the use of services by people with traumatic spinal cord injury (tSCI) in the United States.

This data sheet is a quick reference on demographic and condition status for 37,866 people with tSCI collected through 2024 by 31 federally funded SCI Model Systems and 4 Form II (follow-up) centers and entered into the National SCI Database. This data sheet does not include the 16,175 people who were added to the SCI Database registry due to not fully qualifying for follow-up.

National SCI Statistical Center
515 Spain Rehabilitation Center
1717 6th Avenue South
Birmingham, AL 35233-7330

For Statistics: 205-934-3342
TDD: 205-934-4642
FAX: 205-934-2709
E-mail: NSCISC@uab.edu
Website: uab.edu/NSCISC

## Incidence

The 2024 population size in the United States was estimated to be about 341 million people. The most recent estimate of the annual incidence of traumatic spinal cord injury (tSCI) is approximately 54 cases per one million people in the United States, which equals about 18,421 new tSCI cases each year. New tSCI cases do not include those who die at the location of the incident that caused the tSCI.

- **Data Source:** Jain NB, Ayers GD, Peterson EN, et al. Traumatic spinal cord injury in the United States, 1993-2012. JAMA. 2015;313(22):2236-2243.

## Prevalence

The estimated number of people with tSCI living in the United States is approximately 308,620 persons, with a range from 259,374 to 393,913 persons.

- **Data Source:** Lasfargues JE, Custis D, Morrone F, Carswell J, Nguyen T. A model for estimating spinal cord injury prevalence in the United States. Paraplegia. 1995;33(2):62-68.

## Age at Injury

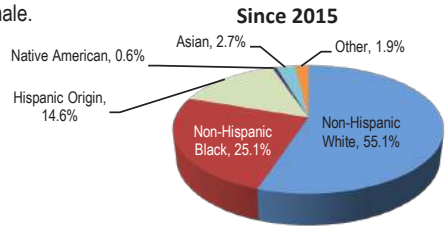
The average age at injury has increased from 29 years during the 1970s to 44 years since 2015.

## Sex

About 78% of new tSCI cases since 2015 are male.

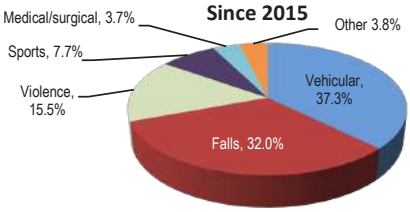
## Race/Ethnicity

About 25% of recent injuries have occurred among the Black – Not Hispanic or Latino population. Yet, about 12% of the U.S. population is Black – Not Hispanic or Latino.




## Cause

Vehicle crashes and falls account for almost 70% of recent injuries. Acts of violence (mostly gunshot wounds) and sports/recreation injuries account for about 23%.



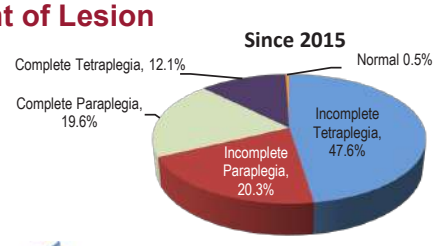

## Lengths of Stay

The average lengths of stay in the hospital acute care unit have declined from about 30 days in the 1970s to about 19 days since 2015. The average rehabilitation lengths of stay have also declined from about 110 days in the 1970s to about 37 days since 2015.

- **Note:** Lengths of stay have been shown on this data sheet in averages since 2024. Lengths of stay in previous years were shown in median.

## Neurological Level and Extent of Lesion

Recently, incomplete tetraplegia is the most frequent neurological category. The frequency of incomplete and complete paraplegia is almost the same. Less than 1% of persons experienced complete neurological recovery by the time of hospital discharge.




SCIMS
Spinal Cord Injury Model System
Since 1970

MSKTC.org
SCI · TBI · BURN
Model Systems Knowledge Translation Center

## Education

Since 2015, 24% of persons with tSCI have a college degree at the time of their injury, compared with 44% of people who survived 40 years of injury.

| Education (%) | At Injury | Year 1 | Year 10 | Year 20 | Year 30 | Year 40 |
|---|---|---|---|---|---|---|
| **High School Only** | 52.3 | 52.8 | 49.1 | 45.8 | 41.7 | 35.6 |
| **College or Higher** | 23.6 | 25.8 | 29.0 | 28.8 | 34.3 | 44.2 |

## Employment Status

Since 2015, 18% of persons with tSCI are employed at year 1 post-injury. The employment rate increases over time before peaking at 30 years post injury.

| Status (%) | At Injury | Year 1 | Year 10 | Year 20 | Year 30 | Year 40 |
|---|---|---|---|---|---|---|
| **Employed** | 65.0 | 17.8 | 25.6 | 29.0 | 30.3 | 27.0 |
| **Student** | 6.7 | 5.4 | 2.4 | 0.7 | 0.3 | 0.1 |

## Marital Status

Since 2015, the percentage of people who are married is relatively consistent up to year 30 post-injury, with single/never married status slowly decreasing and divorce status slowly increasing.

| Status (%) | At Injury | Year 1 | Year 10 | Year 20 | Year 30 | Year 40 |
|---|---|---|---|---|---|---|
| **Single** | 44.7 | 43.5 | 38.2 | 36.1 | 34.3 | 24.8 |
| **Married** | 36.9 | 36.3 | 34.1 | 35.1 | 35.1 | 44.1 |
| **Divorced** | 8.8 | 10.3 | 18.4 | 19.8 | 22.4 | 21.7 |

## Re-Hospitalization

Since 2015, about 29% of persons with tSCI are re-hospitalized at least once during any given year following injury. About 18 days is the average length of stay when re-hospitalized. Diseases of the genitourinary system are the leading cause of re-hospitalization, followed by disease of the skin. Respiratory, digestive, circulatory, and musculoskeletal diseases are also common causes.

## Historical Lifetime Costs

The average yearly expenses (health care costs and living expenses) and the estimated lifetime costs that are directly attributable to tSCI vary greatly based on education, neurological impairment, and pre-injury employment history. The below estimates do not include any indirect costs such as losses in wages, fringe benefits, and productivity (indirect costs averaged $95,309 per year in 2024 dollars).

| Severity of Injury | Average Yearly Expenses (in 2024 dollars) | | Estimated Lifetime Costs by Age at Injury (discounted at 2%) | |
|---|---|---|---|---|
| | First Year | Each Subsequent Year | 25 years old | 50 years old |
| **High Tetraplegia (C1–C4)** AIS ABC | $1,410,163 | $244,879 | $6,256,937 | $3,438,706 |
| **Low Tetraplegia (C5–C8)** AIS ABC | $1,018,966 | $150,222 | $4,571,708 | $2,812,009 |
| **Paraplegia** AIS ABC | $687,262 | $91,042 | $3,059,615 | $2,007,933 |
| **Motor Functional at Any Level** AIS D | $460,224 | $55,900 | $2,090,344 | $1,475,423 |

**Data Source**: Economic Impact of SCI published in the journal Topics in Spinal Cord Injury Rehabilitation, Volume 16, Number 4, in 2011.
American Spinal Injury Association Impairment Scale (AIS) is used to grade the severity of a person's neurological impairment following tSCI.

## Historical Life Expectancy

Since the 1970s, life expectancies have increased steadily for people with tSCI during their first year of injury. However, life expectancies after their first year have not changed since the early 1980s and remain substantially below the life expectancies of the general population. An individualized Life Expectancy Calculator is available at uab.edu/nscisc/life-expectancy-calculator.

| Age at Injury | No tSCI | Life Expectancy (years) for Post-Injury by Severity of Injury and Age at Injury | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | For Persons Surviving the First 24 Hours | | | | | For Persons Surviving at Least 1 Year Post-Injury | | | | |
| | | High Tetraplegia (C1–C4) AIS ABC | Low Tetraplegia (C5–C8) AIS ABC | Paraplegia AIS ABC | Motor Functional AIS D (Any Level) | Ventilator Dependent (Any Level) | High Tetraplegia (C1–C4) AIS ABC | Low Tetraplegia (C5–C8) AIS ABC | Paraplegia AIS ABC | Motor Functional AIS D (Any Level) | Ventilator Dependent (Any Level) |
| 20 | 57.1 | 28.0 | 34.9 | 40.3 | 48.4 | 8.2 | 28.7 | 35.5 | 40.7 | 48.7 | 14.2 |
| 40 | 38.8 | 17.5 | 21.6 | 26.4 | 32.1 | 6.7 | 18.2 | 22.1 | 26.7 | 32.3 | 10.5 |
| 60 | 22.1 | 10.0 | 11.6 | 14.5 | 17.8 | 3.3 | 10.9 | 12.0 | 14.8 | 18.0 | 7.0 |

## Historical Causes of Death

During the first year of injury, the three leading causes of death among people with tSCI were respiratory diseases (mostly pneumonia and influenza), other heart diseases (often unexplained heart attacks that usually do not represent a true underlying cause of death), and infective and parasitic diseases (mostly septicemia secondary to urinary or pressure injury infections). Among people surviving the first year after injury, respiratory diseases were the leading cause of death (19.6%), followed by infective and parasitic diseases (13.1%), cancer (12.1%), hypertensive and ischemic heart diseases (11.0%), and other heart diseases (7.2%).

- **Data Source:** National Spinal Cord Injury Statistical Center. 2024 Annual Statistical Report for the Spinal Cord Injury Model Systems. University of Alabama at Birmingham: Birmingham, Alabama.

 Publication content was developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90SIMS0016 and 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). Content does not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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# NOTES

# NOTES


SPORTS
ASSOCIATION
SPORTS
ASSOCIATION

Gaylord
Specialty Healthcare

**gaylord.org**

Scan to learn more
about Gaylord

7/2026