

# Spinal Cord Injury

[PATIENT/FAMILY EDUCATION]



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## [WHAT IS SPINAL CORD INJURY?]

Any damage to the spinal cord is a very complex injury. Each injury is different, and injuries can affect the body in many different ways. Following is a brief summary of changes that can take place after a spinal cord injury.

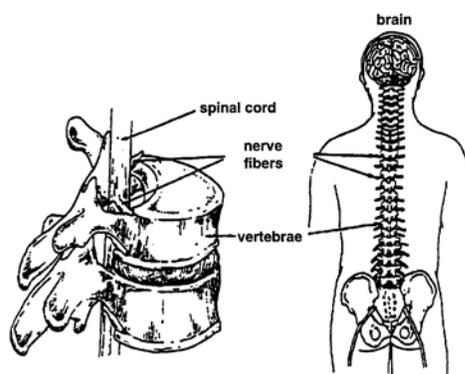
### THE NORMAL SPINAL CORD

The spinal cord is a part of your nervous system. It is the largest nerve in the body. Nerves are cordlike structures made up of nerve fibers. The spinal cord has many nerve fibers. These nerve fibers carry messages between the brain and different parts of the body. The messages may be to tell a body part to move or to bring messages of feeling or sensation (such as hot and cold) to the brain. The body also has an autonomic nervous system. It controls the involuntary activities of the body such as blood pressure, body temperature and sweating.

The spinal cord can be compared to a telephone cable. It connects the main office (the brain) to many individual offices (parts of the body) by telephone lines (nerve fibers). The spinal cord is the path that messages use to travel between the brain and other parts of the body.

Because the spinal cord is so important, it is surrounded and protected by bones called vertebrae. The vertebrae, or backbones, are stacked on top of each other and form the number one support for the body. The spinal cord runs through the middle of the vertebrae.

The spinal cord is about 18 inches long. It extends from the base of the brain, down the middle of the back to about the waist. The spinal cord is divided into four sections. The top portion is called the cervical area and it has 7 vertebrae. The next section is called the thoracic spine. The thoracic spine includes the chest area and has 12 vertebrae. The lower back section is called the lumbar area. There are 5 lumbar vertebrae. The bottom section has 5 vertebrae and is called the sacral area.



**The spinal cord runs through the stacked vertebrae that make up the vertebral column. These bones protect the spinal cord. The nerve fibers branch out from the spinal cord to other parts of the body.**

## THE SPINAL CORD AFTER AN INJURY

A spinal cord injury can occur either from an injury or from a disease to the vertebral column or spinal cord itself. In most spinal cord injuries, the backbone pinches the spinal cord. The spinal cord may become bruised or swollen. The injury may actually tear the spinal cord and/or its nerve fibers.

After a spinal cord injury, most nerves above the level of injury keep working like they always have. Below the level of injury, the spinal cord nerves can no longer send messages between the brain and the parts of the body like they did before.

The doctor examines the individual to understand what type of damage has been done to the spinal cord. An x-ray or MRI shows where the damage has occurred. The doctor may do a “pin prick” test to see what feeling the person has all over his or her body – this helps determine the level of sensation. A doctor may also ask, “what parts of the body can you move?” – this helps determine the level of motor function. These tests are important because they tell the doctor what nerves and muscles are working.

Each spinal cord injury is different. A person’s injury is described by its type and level.

## TYPE OF INJURY - COMPLETE OR INCOMPLETE

The type of spinal cord injury is classified by the doctor as complete or incomplete. The complete injury is like cutting off all telephone service to a building. No messages can be sent from the brain to the parts of the body. Sometimes the spinal cord may not be completely severed, but may be damaged so severely, that the injury is still complete. An incomplete injury is like stopping telephone service to some offices in a building, but not all of them. Some messages can get through, while others cannot. The amount and type of messages that can pass between the brain and parts of the body will depend on how many nerves are damaged.

Incomplete spinal cord injuries will differ from one person to another because different nerve fibers are damaged in each person’s spinal cord. Some people with an incomplete injury may have a lot of feeling, but little movement. Others may have some movement, and little feeling.

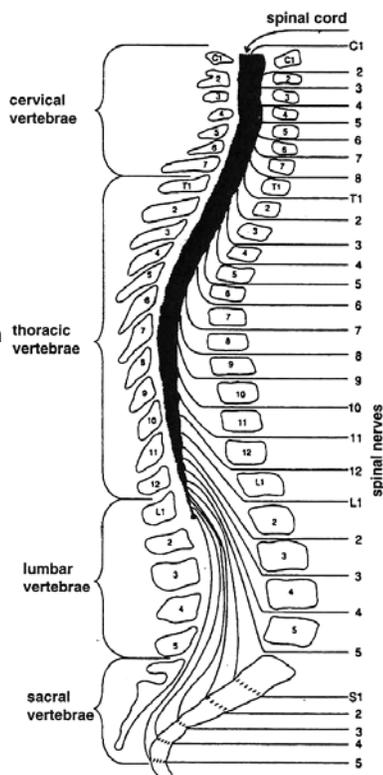
## LEVEL OF INJURY

The level of injury is determined after the doctor does several tests. The level of injury is the lowest point on the spinal cord below which there is a decrease in or absence of feeling and movement. The closer the spinal cord injury is to the brain, the more loss of

function there is. For example, an injury at the T8 level means the individual has a decrease in or loss of functioning/feeling below the eighth thoracic spinal cord segment. A person with a C5 level of injury has a decrease in or loss of functioning/feeling below the fifth cervical spinal cord segment. Someone with a T8 level of injury would have more feeling and movement than someone with a C5 level of injury.

Another way that the level of spinal cord injury can be categorized is quadriplegia (tetraplegia) and paraplegia. Quadriplegia refers to injuries of the cervical region of the spinal cord. A quadriplegic patient may be able to move parts of his/her arms if the level of injury is in the mid to lower cervical region. Paraplegia refers to injuries that occur in the thoracic, lumbar or sacral regions of the spinal cord.

**The vertebrae are numbered and named according to their location in the spinal column. The spinal nerves are numbered and indicate their corresponding vertebrae.**



## CHANGES AFTER THE INITIAL INJURY

Sometimes the spinal cord is only bruised or swollen after the initial injury. As the swelling goes down, the nerves may begin to work again. There are no tests at this time to tell how many nerves, if any, will begin to work again. The longer there is no improvement, the less likely it is that there will be improvement. If a little recovery in function does occur, there is considerably more hope. This is no guarantee how much more function will return.

Some individuals have involuntary movements, such as twitching or shaking. These movements are called spasms. Spasms are not a sign of recovery. A spasm occurs when a wrong message from the nerve causes the muscle to move. The individual often cannot control this movement.

In addition to movement and feeling, a spinal cord injury affects other bodily functions. The lungs, bowel, and bladder may not work the same as before the injury. There may also be changes in sexual function. During rehabilitation, the medical team teaches the individual with a spinal cord injury new ways to manage his or her bodily functions.

Source: Schust, Christina S. Ed., Spinal Cord Injury: Patient Education Manual. Aspen Publishers, Inc., Gaithersburg, MD 1997.

## [ANATOMY &amp; PHYSIOLOGY]

## KEY TERMS :

- **NERVES:**
  1. carry messages from the brain to the rest of the body via the **spinal cord**
  2. responsible for **movement**, **pain**, touch, **hot/cold** feeling, coordination, position sense, *balance*
  3. **different nerves** fibers carry **different messages** (i.e.- some control movement, others control feeling)
- **SPINAL CORD:**
  1. largest **nerve** in the body and carries signals to/from the brain and the body
  2. with a spinal cord injury, these **signals get blocked**, preventing the brain and body from communicating about movement, sensation, coordination, etc.
  3. contained within the **vertebral column**
- **VERTEBRAL COLUMN:**
  1. protects the spinal cord and provides attachment points for trunk muscles
  2. made up of **7 cervical**, **12 thoracic**, **5 lumbar**, **5 sacral** vertebrae

## INJURY TYPES :

- **QUADRIPLEGIA** (or tetraplegia): injuries of the cervical (neck) region, loss of full use/feeling in **all 4 extremities and trunk** (torso)
- **PARAPLEGIA:** injuries of the thoracic, lumbar or sacral segments; loss of full use/feeling in **trunk** and/or **legs** and **feet**
- **INCOMPLETE VS. COMPLETE:** **incomplete** injuries involve preservation of movement or feeling below the level of injury; **complete** injuries involve **no** preservation of movement or feeling below level of injury
- All injuries **may** involve interruption of bowel, bladder and sexual function (this will be addressed further by the nursing staff as it relates to your specific injury)

**MY INJURY:**

My injury level is

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Sensory or Motor Complete vs. Incomplete

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My sensation is impaired

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My movement is impaired

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My other impairments include:

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- \*\* Refer to the *Anatomy and Physiology* pages for more detailed information
- \*\* Use the back of this summary sheet to write down any questions you or your family members want to remember to ask your rehab team about your specific injury.



## [SPINAL CORD INJURY LEVELS OF FUNCTION]

Following is an overview of the typical neurological damage for specific lesion sites. The amount of functional deficits often varies from person to person; and in the case of incomplete injuries, which are usually specific to the individual, no generalities are valid.

**C3-4:** No movement in the upper extremities, some head and neck control. The C4 patient is able to shrug his/her shoulders. These patients can operate a power wheelchair with chin or sip-and-puff control, they are also able to operate computers with voice activated programs. Generally needs personal care attendant.

**C5:** Has use of deltoids and biceps. Can perform some simple daily activities such as grooming and feeding with special equipment. Can operate a power wheelchair with some form of joystick control. Generally needs personal care attendant.

**C6:** Has use of wrists and some chest muscle, but no hand muscle function. Can perform feeding and grooming with special equipment. Can perform dressing, bathing, and bed mobility as well as make transfers with caregiver assistance. Can operate a power or manual wheelchair. Power wheelchairs often allow for greater independence. Can sometimes drive with special hand controls.

**C7:** Can straighten arms (has triceps), but has limited use of fingers. Need fewer adaptive aids to perform ADLs. Can perform most ADL activities, bed mobility, transfers, and propel manual wheelchair independently. Can drive with special hand controls.

**C8-T1:** Performs all activities of level C7 injury, but with better finger and hand control and therefore even less adaptive equipment. Independent with bowel and bladder programs.

**T2-T6:** Has normal motor function in head, neck, shoulders, arms, hands and fingers. Has increased use of rib and chest muscles, or trunk control. Can live independently in a wheelchair accessible environment.

**T7-T12:** Has functional abdominal muscles allowing for increased trunk control, lung capacity, and an increased capability to cough.

**L1-L5:** Has additional return of motor movement in the hips and knees. Can usually ambulate using braces and other assistive devices. Care must be taken for patient's with very limited leg movement to avoid developing shoulder overuse injuries that can interfere with long term independence.

**S1-S5:** Increased ability to walk with fewer or no assistive devices. Various degrees of return of voluntary bladder, bowel and sexual functioning.

## [SPASTICITY]

### WHAT IS IT?

- An abnormal increase in muscle tension
- Often occurs with damage to the brain or spinal cord
- Legs, arms and/or trunk “draw up” or “jump” or move without you intending them to
- Often worse with **incomplete** injuries
- Can be **painful**, annoying, keep you awake at night, interfere with your ability to transfer, perform bed mobility, manage your legs or perform ADLs
- May affect your **positioning** in the wheelchair or contribute to **skin breakdown**

### HOW DO I DEAL WITH IT?

- Stretching/ range of motion exercises (see lower extremity ROM exercises in notebook)
- Medications prescribed by doctor
- Weight bearing
- Botox if prescribed by doctor
- Baclofen pumps or other surgical options if conservative treatment is ineffective

### WHAT DOES IT MEAN?

- Often, visitors or family members mistake **spasticity** for voluntary movement
- The presence of **spasticity** doesn't mean your arms or legs will be any more or less likely to regain movement or feeling than if you didn't have spasticity
- If it is interfering with your mobility or causing pain or skin breakdown either in the hospital or after you go home, speak with your doctor to discuss your options

### WHAT IF IT GETS WORSE?

- A sudden, significant increase or decrease in **spasticity** can indicate a **urinary tract infection**, a **skin sore**, or any other **noxious stimulus** (see section on complications for examples of noxious stimuli) present below your level of injury
- A significant change in spasticity can also be caused by a cyst in your spinal canal (often called a syrinx)
- For both of these options, **consult your health care provider for further information**

## WHAT IS SPASTICITY?

Spasticity is an abnormal increase in muscle tension. Normal muscle tension or tone is needed for sitting, standing, or any movement. After a spinal cord injury, nerve cells below the level of injury are unable to receive normal signals from the brain and when the body is stimulated in a certain way, abnormal reflexes or spasticity, occurs. Spasticity is often described as jerking, jumping, twitching or a “tight” feeling in the muscles. Spasticity can vary in its severity causing mild difficulty with movement or an inability to move.

## WHAT CAUSES SPASTICITY?

Spasticity can be triggered by almost anything: when you or your caregiver moves your limbs quickly, changing positions, a bladder infection (also called a UTI or urinary tract infection), skin breakdown, injuries. Or, spasticity can just happen for no reason at all other than the fact that there’s been damage to the spinal cord. Get to know your normal level of spasticity because a sudden, severe increase can indicate the presence of a new infection, skin sore, or something even more serious.

## IS SPASTICITY ALWAYS BAD?

Not always. Some amount of spasticity can assist with posture or trunk control in higher level injuries. Spasticity can also serve as a warning mechanism for new skin sores, UTIs or injuries to body parts that have no feeling. It also helps maintain muscle size and bone strength, which can help lessen the severity of osteoporosis. So, not all spasticity needs to be treated because sometimes it can actually be helpful!

## HOW CAN I KEEP SPASTICITY UNDER CONTROL?

Range of motion (or stretching) exercises keep muscles flexible and reduce spasticity. Weight-bearing activities and positioning programs can also help. The prone position (lying face down) and standing positions help inhibit flexor spasms while supine (lying face up) and side-lying help break up extensor spasms. Avoid UTIs by using clean technique with catheterization. Avoid skin sores by doing pressure reliefs and turning in bed. Medications such as baclofen (Lioresal), Zanaflex, dantrolene (Dantrium), diazepam (Valium) can be prescribed by a

doctor if spasticity is so severe that it interferes with your ability to function or interferes with sleep. If conservative treatment fails, Botox, cutting peripheral nerves, or surgical implantation of an intrathecal baclofen pump are options your doctor may discuss with you. It is important to discuss all the pros and cons of medications and surgical options with your doctor so that you can make an informed decision.

#### HOW BAD CAN IT BE IF I DON'T STRETCH AND MANAGE MY SPASMS?

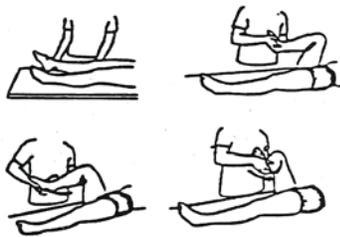
Losing Range of Motion at any joint can be really bad news. Joint contractures can cause skin breakdown, difficulty with ALL functional mobility including transfers, dressing, feeding and bathing. Contractures can impair your ability to fit correctly in a wheelchair as well as interfere with your balance and ability to walk if able. That's why it is VERY important to stretch AT LEAST once a day!

Sources: National Spinal Cord Injury Association, <http://www.spinalcord.org>, 1-800-962-9629  
Schust, Christina S. Ed., Spinal Cord Injury: Patient Education Manual. Aspen Publishers, Inc. Gaithersburg, MD 1997.

## [LOWER EXTREMITY RANGE OF MOTION EXERCISES]

Losing flexibility in your hips, legs, and feet can present serious problems with sitting positions, mobility for transfers, and performing activities of daily living (ADL). The following range of motion (ROM) exercises help you maintain this flexibility in your lower extremities.

### HIP AND KNEE ROM



#### Hip and Knee Flexion and Extension:

##### Hip Rotation

Lift leg up, bending the hip and the knee. Bring knee up toward chest as far as possible (other leg must remain flat on the bed). Keeping the knee bent and pointing toward the person's head, roll the lower leg toward you. Roll it back toward the person as far as possible. Normally, the leg will move toward the patient farther than it will toward you. Lower the leg, lift the foot upward and straighten knee. Return to starting position.



##### Hip Abduction

With the person lying on back, support the leg under the knee and the heel. Lift leg straight up slightly and then bring leg out to the side toward you. Keep knee and toes pointing up to the ceiling.



##### Hamstring Stretch

Stabilize the opposite leg. Hold in front of the knee joint and behind the heel. Slowly stretch the limb.

Most people with paraplegia and some with tetraplegia need to obtain 100 – 120 degrees of straight leg raising. Often the heel of the person can rest on your shoulder if you have difficulty stretching the limb beyond 90 degrees.



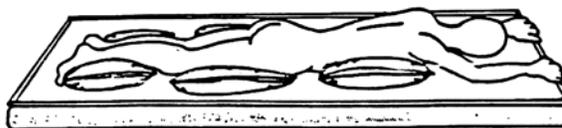
### **Ankle Stretch**

Place one hand under the heel grasping the foot with the forearm against the sole. Your other hand stabilizes above the ankle joint. Gently pull down on the heel and forward with the foot.



### **Toe Stretch**

Sometimes a person will require toe stretching with the heel cord stretching. Stretch the toes when the foot is flexed toward the body.



### **Body Stretch**

It is a good idea to lie on your stomach every day to keep hips, knees and shoulders stretched.

Note: Arms may be placed at sides.

Source: Virginia Spinal Cord Injury System, University of Virginia Medical Center and Virginia Department of Rehabilitative Services, Virginia Spinal Cord Injury Care and Teaching Manual, Fishersville, Virginia, © 1980, rev. 1985, 1988.

## [COMPLICATIONS]

Many people think being paralyzed only means that you can't move or feel your arms and/or legs. This is true but it is only part of the story. We've already learned in the Anatomy and Physiology section that your nerves and spinal cord control a lot of things from bowel, bladder and sexual function, to movement, reflexes, breathing and feeling. When you aren't able to move and feel part of your body, these parts are no longer able to send signals to your brain. So your brain is kept in the dark about a lot of things going on below your level of injury. Therefore, it is important to be aware of other sorts of clues that your body gives you when your brain isn't hearing the regular signals and things below your level of injury may be out of sorts.

**AUTONOMIC DYSREFLEXIA:** (usually in T6 or above)

- **Signs:** **HEADACHE** (from high blood pressure), flushed face, sweating, goose bumps and clammy skin, nausea, slow heartbeat, anxiety
- **What to do:** **SIT UP!** **Remove** source of irritation (full bladder, bowel, twisted clothing or "wedgie," skin sore, sexual activity)
- **CAN BE A MEDICAL EMERGENCY** if source of irritation is not located/removed and blood pressure continues to rise

**PULMONARY EMBOLISM:** (blood clot in lungs prevents adequate oxygen exchange)

- **Signs:** **Chest/shoulder/jaw pain, difficulty breathing**, fast heartbeat, pale complexion, bluish tint to lips, red streaks in coughed up secretions
- **What to do:** **CALL 911 IMMEDIATELY**, decrease activity, sit up to assist with breathing, remove tight clothing, use oxygen if available

**DEEP VEIN THROMBOSIS:** (blood clot in an arm or leg)

- **Signs:** **Swelling, warmth, redness in affected limb**, fever, pain if able to feel, spasticity
- **What to do:** **CALL DOCTOR or 911**, elevate affected arm/leg, remove TED Hose, **DO NOT** exercise/massage affected limb

**POSTURAL HYPOTENSION:** (getting dizzy when sitting/standing too quickly)

- **Signs:** Dizziness, lightheadedness, nausea, sweating, fainting, cool/clammy skin
- **What to do:** Progressive sitting, move slowly when changing positions, stay hydrated, use TED hose/ACE wraps/abdominal binder as ordered by doctor; if dizzy, lean back, elevate legs

### EDEMA: (swelling)

- **Signs:** swelling is usually in feet, ankles, hands, fingers; usually worse after sitting up all day
- **What to do:** TED hose, prop legs and feet up in wheelchair or bed, exercise, ROM

### RESPIRATORY COMPLICATIONS:

(pneumonia and decreased lung capacity)

- **Signs:** (of pneumonia): Shortness of breath, excess secretions that are yellow/greenish, fever
- **What to do:** Call doctor if secretions are yellow/green; prevent pneumonia by doing deep breathing exercises, sit in wheelchair daily, maintain turning schedule in bed, manual cough (quad cough) techniques, drink plenty of fluids

### TEMPERATURE REGULATION:

(temp. reg. may be impaired below level of injury)

- Avoiding HYPOthermia (body temp too low): dress **warmly** in cold weather and cover up to prevent exposed skin – especially wear a hat, gloves, warm socks, drink warm fluids, use blankets; **DO NOT USE electric blankets, heating pads, hot water bottles on areas with impaired sensation**
- Avoiding HYPERthermia (body gets overheated): stay out of the sun especially on hot/humid days; drink cool fluids, spray self with cool water; use fan or air conditioner; **AVOID hot tubs!**; and watch for decreased urine output which can indicate dehydration

## [AUTONOMIC DYSREFLEXIA]

Autonomic Dysreflexia or Hyperreflexia is an overreaction of the nervous system, usually occurring in injuries at T6 and above. Something below your level of injury is irritating your body (called a noxious stimulus). Normally, your body would tell your brain what the problem is and your brain would tell your body how to fix it. Now, there is a roadblock in your spinal cord so your body is unable to alert your brain. The body keeps trying and trying to alert the brain and a reflex occurs causing your blood vessels to tighten, and your blood pressure to rise. This can be a **MEDICAL EMERGENCY** because extremely high blood pressure can result in stroke, seizures, or death.

### WHAT CAUSES AUTONOMIC DYSREFLEXIA?

- Bladder: infection, overfilled, kinked or plugged catheter
- Bowel: constipation, impaction
- Skin: pressure sores, wounds, burns, cuts, bruises, twisted clothing or “wedgies,” temperature changes
- Other: sexual activity, menstruation, ingrown toenails

### WHAT ARE THE SIGNS OF AUTONOMIC DYSREFLEXIA?

- Pounding headache (caused by high blood pressure)

- Flushed face
- Red blotching of the chest
- Sweating above level of injury
- Goose bumps/ cool, clammy skin
- Nasal stuffiness
- Nausea
- Slow heart rate
- Anxious feeling

### WHAT DO I DO IF I FEEL THESE SIGNS COMING ON?

- **SIT UP** or raise the head of the bed immediately
- Look for the cause or alert your nurse, therapist or caregiver so they can look too
- Bladder: Do you need to cath? Is the Foley kinked, plugged or full?
- Bowel: Do you get constipated often? Has it been 3 or more days since your last bowel movement?
- Skin: Do you have pressure sores, burns, cuts, bruises? Is your clothing/undergarments twisted or giving you a “wedgie?” Do you have an ingrown toenail?
- **FIX IT!** Either cath, do your bowel program, adjust clothing or remove whatever offending stimulus is bothering your body! Once the stimulus is removed, you should notice relief from the above symptoms. If not, get to the **EMERGENCY ROOM** and be ready to explain dysreflexia because not all health care providers encounter SCI or dysreflexia on a regular basis.

## [PULMONARY EMBOLISM]

A pulmonary embolism is a blood clot that is in the lungs. Usually these blood clots started as DVTs (clots) in the legs that broke off, traveled to the lungs and got stuck in the arteries that supply the lungs with blood. Blood clots in the lungs prevent enough oxygen from getting into our body and oxygen is what fuels our brain, muscles, everything!

### WHAT ARE THE SIGNS OF A PULMONARY EMBOLISM?

- Shortness of breath (worse than the breathing problems your SCI may cause)
- Chest pain, also pain in jaw or shoulder (like the signs of a heart attack)
- Heavy feeling in chest
- Irritable or anxious feeling
- Fast heartbeat (pulse)
- Pale complexion, bluish tint to lips
- Red streaks in coughed-up secretions

### WHAT DO I DO IF I HAVE THE SIGNS OF A PULMONARY EMBOLISM?

- **THIS IS AN EMERGENCY! CALL 911!**
- Avoid massaging legs and avoid pressure behind legs
- Decrease activity level (your lungs aren't getting enough fuel...don't use more!)
- Sit up/lean forward or get into a position that makes breathing easier
- Remove tight clothing that may restrict breathing
- Use supplemental oxygen if available

## [DEEP VEIN THROMBOSIS (BLOOD CLOTS)]

A deep vein thrombosis (also known as DVT) is a blood clot that forms within the veins in your body. When blood sits still or flows slowly, it has more time to clot. Outside of your body, when you cut your skin, this is a good thing because it prevents large amounts of blood loss. Inside your body, this is a bad thing because clots can clog your vessels, cause a stroke, heart attack, pulmonary embolism (to be discussed more) or death.

### WHAT ARE THE RISK FACTORS FOR DVTs?

- Injury or surgery
- History of DVT or varicose veins
- Paralysis
- Decreased activity
- Hormone Therapy (birth control pills)
- Age (over 40)
- Heart disease
- Tumors
- Infection
- Pregnancy

### WHAT ARE THE SIGNS OF A BLOOD CLOT (DVT)?

- Swelling
- Warm skin when touched
- Red skin near clot area
- Pain (may not be able to feel)
- Fever
- Increased spasticity

\*\*\*Remember: often, NONE of these signs are present even if a DVT is!

### WHAT DO I DO IF I HAVE THE SIGNS OF A DVT?

- CALL DOCTOR OR GO TO THE EMERGENCY ROOM!
- Prop up affected arm/leg
- Remove TED Hose (white stockings)
- DO NOT massage or exercise affected leg/arm
- Doctor will order tests and give instructions. Always follow them!

### HOW DO I PREVENT A DVT?

- TED hose (elastic stockings, antithrombotic stockings)
- MOVE! Passively or actively, change positions frequently, walk if able, range of motion
- Drink fluids. Thick, dehydrated blood flows slowly...just like old motor oil...and is more likely to get clots
- Take medication if ordered (Heparin, Coumadin)
- Know your body. Check your skin twice a day for unusual swelling, redness, pain.

## [POSTURAL HYPOTENSION]

Postural hypotension is a feeling of dizziness or lightheadedness that occurs with fast changes in position (e.g.- sitting up or standing up too quickly). You may have felt this sensation before your injury when you stood up too quickly and some people refer to it as feeling “swimmy headed” or a “head rush.” This feeling is caused by a sudden drop in blood pressure (hypotension). After a spinal cord injury, veins and arteries can’t tighten or widen like they used to below your level of injury. Also, when the muscles in your arms/trunk/legs aren’t working, they can’t assist with circulation like they used to. Therefore, blood pressure is more likely to drop than it was before your spinal cord injury. Different people have different amounts of trouble with postural hypotension. Some peoples’ bodies adjust and dizziness isn’t a problem as much as it is in the days/months right after their injury. Some people, especially those whose injuries are higher (cervical and higher thoracic) may have trouble with postural hypotension for a longer time after their injury.

### WHAT ARE THE SIGNS OF POSTURAL HYPOTENSION?

- Dizziness
- Lightheadedness
- Nausea
- Fainting
- Sweating
- Cool, clammy skin

### HOW DO I PREVENT POSTURAL HYPOTENSION?

- Move SLOWLY (especially in the morning)
- Elevate head of bed before transferring to chair (progressive sitting)
- Wear TED hose, ACE wraps, abdominal binder if ordered by doctor

## [EDEMA]

Edema is the medical term for swelling which is simply a collection of fluid under the skin. Swelling is caused by gravity. While sitting up in a wheelchair, legs and feet dangle and gravity pulls everything down towards the earth, including blood. Blood pools in the feet and fluid moves from the blood vessels into the tissues of the feet and ankles. Thus, swelling is usually worse at the end of the day when legs and feet have been hanging down all day. Swelling is also made worse when paralyzed muscles in the feet and legs don't work to help veins push blood back to the heart. Injury or surgery can also cause damage to the valves in veins making it even easier for blood to pool in the feet and ankles.

## HOW CAN I PREVENT SWELLING OR EDEMA?

- Wear TED hose if ordered
- Prop up legs and feet throughout the day when possible
- MOVE as much as possible (exercise, propel chair, range of motion, walk if possible)
- For quadriplegia: prop hands up on pillows when sitting or massage hand towards arm
- Remember: DON'T MASSAGE FEET/LEGS...you could dislodge a blood clot that might be lurking, unnoticed and cause a pulmonary embolism or stroke!

## [RESPIRATORY COMPLICATIONS]

Respiration (breathing) may be more difficult after a spinal cord injury because many of the muscles that help with breathing no longer work. The main breathing muscle is your diaphragm and it is controlled by nerves at the C3-5 level. If your injury is at or above these levels, your breathing will be especially difficult and may even require the help of a ventilator. Muscles in the neck assist with breathing and are called “accessory muscles.” Intercostal muscles (muscles between the ribs) and the abdominal muscles (stomach muscles) help with forceful coughing, sneezing, and taking deep breaths. Quadriplegics and those with high thoracic level injuries may have difficulty coughing forcefully enough to clear their own secretions and may need a caregiver to assist with coughing (quad coughing). People with injuries at this level may also notice that it is hard to talk loudly or say long sentences without taking a breath in the middle. Your injury level will determine how many of the muscles in the neck and torso are working and able to assist with breathing/coughing.

### WHAT ARE ALL THE RESPIRATORY COMPLICATIONS?

- Decreased lung volume: fewer breathing muscles means less ability to inhale deeply with each breath and fill the lungs to their pre-injury capacity
- Congestion: shallow breathing and weak cough allows mucous to build up in the lungs
- Pneumonia: thickened mucous secretions that sit longer in lungs make a friendly environment for germs to grow. Call your doctor if you have a fever, yellow-green secretions, shortness of breath, or are unable to bring up secretions adequately

### HOW DO I PREVENT THESE COMPLICATIONS AND KEEP MY LUNGS HEALTHY?

- DON'T SMOKE! If you already do, QUIT!
- Do deep breathing exercises every day (incentive spirometer)
- Sit in wheelchair, stay active, exercise
- Turn in bed (lying in the same position allows lung secretions to collect easily)
- Cough up secretions as much as possible or have a caregiver do assisted cough
- Drink plenty of water (water helps keep mucous thinner and easier to cough up)
- Do respiratory treatments if ordered by a doctor

## [TEMPERATURE REGULATIONS]

The body regulates temperature by sweating to cool off, shivering to warm up, and by shrinking or expanding blood vessels to give off heat or keep heat in. This is why your face gets red after you exercise; your body is expanding blood vessels in your face to help give off heat and cool your body down. After a spinal cord injury, the body's ability to control temperature, or thermoregulate, may be impaired below the level of injury. The higher your injury level and the more complete an injury is, the greater the difficulty with temperature regulation. You can easily help your body regulate temperature by avoiding extreme temperatures and with a few easy solutions:

### IN COLD WEATHER :

- Wear warm clothing, hat, gloves, socks
- Use extra blankets
- Drink warm fluids
- DON'T use heating pads, electric blankets on skin you can't feel! You could burn your skin and not even know it!
- Don't set hot plates or cups on your lap without a towel! The skin on your thighs is more sensitive than the skin on your hands.

### IN HOT WEATHER :

- Stay out of the sun
- Wear hats, stay in the shade
- Spray self with cool water
- Drink cool fluids
- Use fan or air conditioner
- Avoid hot tubs
- Be careful not to put your bare feet on hot pavement
- Watch out for decreased urine output...this could signal dehydration, which can contribute to all kinds of other problems/complications!

Source: Schust, Christina S. Ed., Spinal Cord Injury: Patient Education Manual. Aspen Publishers, Inc. Gaithersburg, MD 1997

## [PAIN]

After a spinal cord injury, pain usually has some impact on your life. Sometimes you may experience pain immediately after your injury and then as your body heals the pain subsides. Musculoskeletal, neuropathic, and pain from the trauma related to your injury are common. Unfortunately, a lot of individuals with a spinal cord injury suffer with chronic pain.

### TYPES OF PAIN

#### **Musculoskeletal Pain**

Musculoskeletal pain usually occurs above the level of injury. You may experience musculoskeletal pain below your level of injury if you still have some feeling intact. Musculoskeletal pain is usually caused by overuse of your muscle and joints. This overuse can occur during everyday activities that are a part of living with a SCI such as transfers, wheelchair propulsion, and ADLs. Musculoskeletal pain is usually described as aching or throbbing. Musculoskeletal pain usually gets better with rest. There are also anti-inflammatory medications your physician may give you that help with the pain and the inflammation of the muscles.

#### **Neuropathic Pain**

Neuropathic pain can occur anywhere at or below your injury. The cause is not really understood. It is believed that neuropathic pain is related to the nerve endings at the site of the injury. It is felt that because the brain cannot receive and send messages

through the nerves, that it may think that there is pain below the level of injury when it is not. This pain is usually described as sharp, shooting or burning pain.

Neuropathic pain is very difficult to treat because each individual responds to treatment differently. Some treatments may include the use of anticonvulsants or antidepressants, which have proven to be very effective in decreasing neuropathic pain in some individuals. If one medication does not show to be effective for your pain then another one is tried. It may take several medication trials to find the one that is effective for you. If you are experiencing chronic neuropathic pain it may be best for you to be treated at a pain clinic that is familiar with treating individuals with spinal cord injuries.

Never ignore pain after a SCI. It is probably not going to go away. See your physician to help identify the type, cause and interventions that should be started to treat your pain. Unfortunately, complete pain relief may not be possible and you may want to concentrate on ways to manage your pain. Other than medications, one way to manage your pain is to stay busy with meaningful activities. If you are not busy, you are more aware of your pain. Avoid activities that cause your pain or pace those activities. Try to minimize as much stress in your life as possible. Seek psychological ways to help you manage your pain such as counseling and learning relaxation or breathing techniques.

## [OSTEOPOROSIS]

Osteoporosis or porous bone occurs due to loss of mineral to the bone, causing bone tissue to break down. This occurs normally in individuals as they age. After age 30 bone tissue is not replaced, the bone mass begins to decrease and bones become weak and thin. After a SCI a person's metabolism changes. Large amounts of calcium and other mineral are lost through the urine. The rapid loss of bone minerals continues during the first 6-16 months after a SCI, then starts to level off. Osteoporosis also occurs in individuals with SCI due to disuse. Bones begin to weaken when weight is not placed on them. Weaker bones put you at an increased risk for pain and bone fractures.

Individuals with SCI need to have a baseline Bone Density Study to identify osteoporosis or establish a person's risk level for developing osteoporosis. A (DEXA) scan is usually considered the most desirable technique for measuring bone density. This test should be repeated yearly to monitor changes in your bone density and need for treatment.

There are several treatments for osteoporosis in SCI. One treatment is exercise.

Exercises for the lower extremities that include weight bearing such as with use of a standing frame can be most effective in the fight against osteoporosis. Extra calcium in your diet along with supplements are also recommended. A new class of medications called bisphosphonates can help prevent bone loss and increase bone density. These medications may be prescribed to be taken once a week.

Protecting your bones after a SCI is important. Work out a home exercise plan with your PT and OT that will help you maintain and improve your bone density. Report any concerns to your physician immediately. Make sure you are monitored closely so that any problems can be identified early.

Sources:

- <http://images.main.uab/spinalcord/pdffiles/resrev51.pdf>
- Research Review – Osteoporosis and Spinal Cord Injury
- The Education Task Force of the Endocrine Nurses Society Brochures: Osteoporosis: Making the Right Diagnosis and Osteoporosis: A Silent Disease

## [SKIN CARE]

### MAJOR PROBLEM AREAS:

- Heels
- Sacrum (tailbone)
- Ischials (sit bones)
- Hip bones
- ANY OTHER BONY PROMINENCES you cannot feel like knees, shoulder blades, elbows, spine, pelvis, back of head
- PROTECT these areas with pillows in bed or proper positioning in wheelchair

### SKIN CHECKS

- Should be done twice a day (first thing in morning, last thing before bedtime)
- Check all trouble areas for redness that doesn't disappear within 20-30 minutes
- If the wound does not improve within 2 weeks, follow up with your doctor because something new might need to be prescribed. Don't wait for the wound to get worse!

### PRESSURE RELIEFS

- Every 30 minutes in wheelchair for 1-3 minutes

### TURNING IN BED

- Every 2 hours

After a spinal cord injury, sensation (feeling) below the level of injury may be impaired or completely absent, which makes the skin more likely to get pressure sores. A pressure sore, also called **pressure ulcer, decubitus ulcer or bed sore**, is an area of skin or other tissue that is dead or dying because of a lack of blood flow to the area. Before your spinal cord injury, your legs would tingle or “fall asleep” which was your body’s way of telling you that you needed to change position because circulation was being cut off. After a spinal cord injury, if sensation is absent, your body will not tell you that circulation is impaired or that it is time to change positions by tingling or “falling asleep”. Therefore, you have to tell your body when to change positions to prevent skin breakdown. Other types of injuries like cuts, burns (even sunburns), frostbite, or abrasions can be a problem too if they go unnoticed, get infected or get worse before they’re treated. Spasticity can also contribute to skin sores by causing excessive shearing, especially at the heels. Buttocks are also at risk of shearing during transfers or from sliding in the wheelchair. Pressure sores and other skin problems can have life-threatening consequences if left unchecked including infection that can spread to vital organs, autonomic dysreflexia, amputations, and prolonged bedrest.

## WHAT ARE THE “STAGES” OF PRESSURE SORES?

Pressure sores are categorized by stages 1-4 with a stage 1 sore being the least severe and a stage 4 sore being the most severe.

### STAGE 1:

- **Signs:** The top two layers of skin (epidermal and dermal layers) are affected. The skin is not broken. Redness or discoloration doesn’t turn white when touched and redness does not disappear within 20-30 minutes when pressure is removed.
- **Treatment:** Keep pressure off the area, keep area clean with mild soap and water (don’t rub!), make sure to eat healthy and stay hydrated, evaluate equipment/clothing/transfers/turning schedule to find the source of the pressure, watch ulcer to make sure it heals.

### Stage 1 Examples:



Picture #1 shows a left heel sore on a T10 Para, 2 months after his injury occurred.

Picture #2 shows a right heel sore, near the Achilles Tendon on a C7 quad. This sore was actually caused by excessive spasticity that caused the patient's heels to dig down into his Prafo boots and was irritated by his shoes.

Picture #3 shows the heels of a deconditioned patient who is lying on his left side. There is a small spot of redness on the outside edge of the top heel. The bottom heel sore has dead tissue (called eschar) in it. Until this dead tissue is cleaned out, the stage of the sore cannot accurately be determined.

#### STAGE 2 :

- **Signs:** Topmost layer of skin (epidermis) is slightly broken. Drainage may be present.
- **Treatment:** Follow steps for Stage 1 sores and follow additional instructions given by health care provider which may include some form of dressing to absorb drainage and keep the sore clean. Watch for signs of infection and consult your healthcare provider if you notice any.

#### Stage 2 Examples:



Pictures #1 and #2 show a stage 2 sore on the top of the foot of a C6 incomplete quad, 2 months post injury. This patient had a pre-existing bone spur on the top of her foot that got excessive pressure and shearing from her shoes and Prafo boots. Be aware of your own unique bony abnormalities that may cause pressure in areas not typical for other people.

### STAGE 3 :

- **Signs:** Damage extends through skin layers and into fat tissue and possibly muscle tissue. This wound is deeper than a stage 2.
- **Treatment:** These wounds require special treatment in addition to all the above-mentioned steps and you should always consult your healthcare provider for instruction. This care may include special cleaning agents, debriding agents, irrigations, wound packing or an antibiotic.

### Stage 3 Examples:



This picture shows a stage 3 sacral sore on T8 para. In this picture, the patient is positioned lying on his right side with his head towards the right side of the page and his feet towards the left side of the page. The yellow area is dead tissue and the large red area surrounding the sores shows that this skin is not in optimal health either. The darkened area between the two obvious sores is further breakdown that is referred to as “tunneling”. If the deadened surface tissue were to be removed, the true wound would appear much larger and deeper.

#### STAGE 4 :

- **Signs:** The damage extends down to the bone and joint structures. Often there is more extensive damage than can be seen on the surface and significant dead tissue and drainage are present.
- **Treatment:** Immediately consult your healthcare provider. Surgery is often the only option for wounds this severe and after surgery, prolonged bedrest is required for the surgical site to fully heal.

#### Stage 4 Examples:



Picture #1 shows a Stage 4 sacral sore on a C5 quad. The patient is lying on his right side and his head would be towards the right side of the page, his feet would be towards the left side. This wound has a significant amount of dead tissue on the surface. If it were to be cleaned out, it would probably look more like Picture #2 which has been debrided (cleaned out) by a surgeon.

The patient in Picture #2 is a T10 para who is also lying on his right side. This patient eventually had to have his sacral wound surgically closed by a plastic surgeon because it was so deep it would not heal on its own.

Picture #3 shows this patient's sacrum 4 days after surgery. Healthy, good tissue from the lateral buttock area has been moved over top of the pressure sore. This new skin will heal after 6-8 weeks of bedrest in a special air flotation bed. While on bedrest, the patient is not allowed to sit in the wheelchair, transfer to the bedside commode, and is only allowed limited range of motion at the hips to allow for proper healing. Even after this surgery, the new skin is not as tough and strong as the original skin had the original skin remained healthy and intact.

## HOW DO I PREVENT PRESSURE SORES?

Pressure sores can have very serious consequences, but 95 percent of pressure sores are preventable if you follow several simple rules without fail:

Do pressure reliefs every 30 minutes in your wheelchair and maintain for 1-3 minutes. Pressure reliefs can be done by tilting back in a power wheelchair (this moves pressure from the buttocks onto the back), leaning forward or to one side then the other in a wheelchair (this relieves pressure off one buttock at a time), pushing on your wheels or armrests to lift your body up (this takes a lot of arm strength and removes pressure off your whole bottom at once). Your therapists will help you decide which method is the best.

Do skin checks TWICE a day. Once in the morning to look for pressure areas that may have arisen at night and once right before bed to check for pressure areas that may have arisen from sitting all day. Look for areas of redness or other discolorations that don't disappear within 20-30 minutes. Check all bony prominences, skin folds (genitals, buttocks, breasts, etc), anywhere you wear a brace. We all have different skin tones so get to know what is normal for you! Don't forget to check your feet, between your toes and toenails...don't ever expose your feet to snow, ice, hot pavement/sand, the rough bottom of a pool, or hot/cold water that you haven't tested with a part of

your body that has normal sensation.

Wiggle! The more you move and shift your weight the better your circulation will be.

Turn regularly in bed every 2 hours. Make sure all bony prominences are padded and wear Prafo boots in bed if ordered by a doctor to protect your heels.

Use proper equipment. Make sure your cushion isn't over or under-inflated or make sure it isn't getting worn out. Make sure your mattress provides proper support at night and use pillows to help pad bony areas such as knees, ankles and hips. Make sure your haven't outgrown your wheelchair; weight gain, contractures or spasticity can alter how you sit in your wheelchair and lead to new areas of pressure or friction.

Keep skin clean and dry. Clean skin immediately after a bowel or bladder accident. Change clothes if they become wet; wet skin is weaker and breaks down more quickly. Use lotion instead of powder and also make sure skin isn't overly dry and cracked.

Eat healthy and drink enough water! Protein, vitamins and minerals provide the building blocks of our cells and you need good nutrition and enough fluids for your skin to stay healthy and to heal itself if you do have any skin sores. Remember, in those hot summer months, you may need to drink more to stay adequately hydrated.

**DON'T SMOKE!** If you do smoke, STOP! Smoking impedes blood flow and decreases

oxygen to the skin making it more likely to breakdown and less likely to heal once broken down. Also avoid other drugs and excessive alcohol consumption.

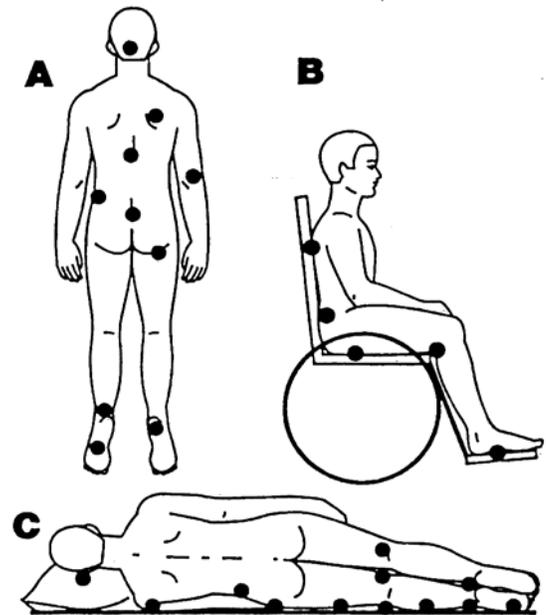
### HOW DO I DO A PROPER SKIN CHECK?

As mentioned above, skin checks should always be done twice a day; first thing in the morning and last thing before bedtime. A long-handled mirror can be used to visualize hard-to-see areas or a caregiver can assist with this task.

Common areas of skin breakdown are shown to the right. These areas, in addition to any skin folds, or areas under/around a brace should always be checked carefully.

If any of these areas are red or discolored and the redness/discoloration does not disappear within 20-30 minutes, follow the previously-mentioned instructions for how to care for the various stages of pressure sores and consult your health care provider if the sore looks infected, is foul-smelling, or gets bigger/deeper. Remember, if you have bone spurs that are unique to you, you may have additional areas to be concerned about!

Source: Schust, Christina S. Ed., Spinal Cord Injury: Patient Education Manual. Aspen Publishers, Inc. Gaithersburg, MD 1997



**Pressure Points.** Dots show pressure points when lying on back (A), when sitting (B), and when lying on side (C).



**It is not enough to take a quick look at the parts of your skin you can see easily. You will need to use a long-handled mirror to see areas that are not easy to see (back, tailbone, heels, groin, buttocks, etc.), or ask someone to check those areas for you.**

## [SCI FACTS AND FIGURES]

- Approximately 11,000 new spinal cord injuries (SCI) occur in the U.S. each year
- Motor vehicle accidents are the leading cause of SCI and account for 37% of all SCIs; violence = 28%; falls = 21%; sport/recreational activities = 6%
- Males account for 82% of all SCIs
- Since 1988, 45% of SCIs are complete, 55% are incomplete
- Half of all SCI cases have other associated injuries
- Each year, approximately 1/3 to 1/2 of all people with a SCI are readmitted to the hospital due to secondary complications
- The most common cause of death for people with SCI is respiratory ailments

These statistics are summarized from the National Spinal Cord Injury Statistical Center in Birmingham, Alabama.

## [VOCATIONAL REHABILITATION]

What Is It? Vocational Rehabilitation (VR) is a state-funded program that helps individuals with disabilities return to work. The following county offices may be contacted to initiate referral:

CUMBERLAND	1200 Fairmont Ct. Fayetteville, NC 28304 (910) 486-1101	ORANGE	248 Smith Level Rd Carrboro, NC 27510 (919) 969-7350
DURHAM	4312 Western Park Place Durham, NC 27705 (919) 560-6810	SAMPSON	215 W. Main St. Clinton, NC 27832 (910) 592-2988
EDGECOMB	201 St. Andrews Street Tarboro, NC 27886 (252) 977-2112	WAKE	436 N. Harrington St. Raleigh, NC 27603 (919) 733-7807
FRANKLIN	10 Medical Court Henderson, NC 27536 (252) 492-3141	WAYNE	1206 L. Box 288 N. Berkley Boulevard Goldsboro, NC 27533 (919) 778-3795
HALIFAX	16683 Hwy 125 Halifax, NC 27839 (252) 445-2027	WILSON	306 W. Nash Street Wilson, NC 27893 (252) 237-7161
HARNETT	214 W. Edgerton Street Dunn, NC 28334 (910) 892-7040		
JOHNSTON	101 N. Fourth Street Smithfield, NC 27577 (919) 934-0525		
NASH	1224 S. Old Carriage Rd. Rocky Mount, NC 27804 (252) 937-4551		

## [SPINAL CORD INJURY BOOK LIST]

Callahan, John. *Don't Worry. He Won't Get Far on Foot.* Vintage Books, New York. 1990

Eareckson, Joni and Estes, Steve. *A Step Further.* Zondervan Publishing House, Grand Rapids, MI. 1978.

Eareckson, Joni. *Joni.* Zondervan Publishing House, Grand Rapids, MI. 1976.

\* Joni Eareckson Tada has written numerous books on spiritual, physical and emotional healing of those affected by disability.

Ellison, Brooke and Jean. *Miracles Happen: One Mother, One Daughter, One Journey.* Hyperion Books, New York. 2001.

Helms, Tom. *Against All Odds.* Thomas Y. Cromwell Publishers, New York. 1978.

Reeve, Christopher. *Still Me.* Ballantine Books, New York. 1998.

Reeve, Christopher. *Nothing Is Impossible: Reflections on a New Life.* Ballantine Books, New York. 2002.

Stepanek, Mattie, J.T. *Journey Through Heartsongs.* VSP Books/Hyperion, New York. 2001.

\* Mattie Stepanek has written numerous books on living with disability.

## [SPINAL CORD INJURY WEBSITES]

- <http://www.ncscia.org> - North Carolina Chapter of the National Spinal Cord Injury Association
- <http://www.spinalcord.org> - National Spinal Cord Injury Association
- <http://www.pmr.vcu.edu> - Dept. of Physical Medicine and Rehabilitation Medical College of VA
- <http://www.cureparalysis.org> - Cure Paralysis Now – especially for researchers and clinicians
- <http://www.spinalvictory.org> - National Paralysis Foundation
- <http://www.apacure.org> - Christopher Reeve Paralysis Foundation
- <http://www.ncddr.org> - National Center for the dissemination of Disability Research
- <http://www.spinalcord.uab.edu> - Spinal Cord Injury Information Network
- <http://www.pva.org> - Paralyzed Veterans of America
- <http://www.va.gov> - Department of Veterans Affairs
- <http://www.newmobility.com> - New Mobility
- <http://www.nwba.org> - National Wheelchair Basketball Association
- <http://www.naric.com/naric> - National Rehabilitation Information Center
- <http://neurosurgery.mgh.harvard.edu> - SCI, Stroke and Paralysis Resources Guide
- <http://sciwire.com> - CareCure Community Website

\*\* please note that there is no guarantee that the information on any of these websites is accurate or reliable. All medical information should be confirmed by your physician or healthcare professional. Government agencies, hospitals, major corporations and universities will likely have the most reliable information.

## [INDEPENDENT LIVING]

The path to independence leads to many places!

North Carolinians want to participate in family and local activities to the best of their abilities. For Tar Heels with severe disabilities, the NC Independent Living Rehabilitation Program can be the path to better managing their own lives and assuming more responsibility in their families, homes and communities.

### HOW DOES INDEPENDENT LIVING HELP?

The Independent Living Rehabilitation Program assists eligible individuals with severe disabilities obtain services that:

- Provide an alternative to institutionalization, where possible.
- Improve functioning in one's family, home, and/or community.
- Help prepare a person for a Vocational Rehabilitation Program.

### WHO IS ELIGIBLE?

A person may be eligible for independent livings services if all of the following apply:

- The person has a severe disability.
- The disabling condition severely limits the ability to live independently.
- Services will significantly improve a person's ability to live independently.

A person's financial resources must be considered to determine if the agency can

pay for many services. Some services are available to eligible individuals without regard to economic need.

### WHAT SERVICES ARE AVAILABLE?

The Independent Living Rehabilitation Program will help eligible individuals develop objectives and identify services that will result in a plan of action.

These services may include, but are not limited to:

- Guidance and counseling
- Rehabilitation engineering
- Attendant care and attendant management training
- Home and vehicle modification
- Housing information and placement assistance
- Independent living skills training
- Certain equipment purchases
- Assistance with recreational activities

Services may be provided directly, purchased, or coordinated through other community resources. If the Independent Living Rehabilitation Program is unable to meet a person's needs, that individual may be referred to other agencies for services as appropriate.

**THE PATH ALSO LEADS  
TO FUN!**

The Independent Living Rehabilitation Program, in conjunction with the NC Travel and Tourism Division, produces a vacation and travel guide for persons with disabilities called ACCESS North Carolina. The guide's objective is to find vacation spots that are the most accommodating by rating all tourist attractions based on the accessibility of an individual who uses a wheelchair.

Special notations within the guide indicate attractions that provide outreach to persons with visual, hearing or development disabilities.

For more information, contact the NC Independent Living Rehabilitation Program, 805 Ruggles Drive, Raleigh, NC 27603, (919) 733-5407, or one of the offices listed below.

**Albemarle** – (704) 985-1172  
Centre Pointe Plaza, Suite 17, 28001  
Counties: Union, Stanly, Montgomery,  
Rowan, Richmond, Anson and Cabarrus

**Asheville** – (704) 298-9137  
599 Tunnel Road, 28805  
Counties: Buncombe, Henderson,  
McDowell, Madison, Polk, Rutherford and  
Transylvania

**Boone** – (704) 265-5419  
190 Southgate Drive, 28607  
PO Box 1309  
Counties: Alleghany, Ash, Avery, Mitchell,  
Watauga, Wilkes and Yancey

**Charlotte** – (704) 342-6003  
401 S. Independence Boulevard, Suite 660,  
28204  
Counties: Gaston and Mecklenburg

**Durham** – (919) 560-6815  
3414 N. Duke Street, Suite 100, Fairfield II  
PO Box 15670, 27704  
Counties: Chatham, Durham, Lee, Orange,  
Person and Granville

**Elizabeth City** – (919) 338-0175  
305B S. Road Street 27909  
Counties: Camden, Chowan, Currituck,  
Dare, Gates, Pasquotank, Tyrrell and  
Washington

**Fayetteville** – (910) 486-1717  
711B Executive Place, Suite 200, 28305  
Counties: Bladen, Cumberland, Harnett,  
Hoke, Robeson, Sampson, Moore and  
Scotland

**Greensboro** – (910) 852-4523  
3401A W. Wendover Avenue, 27407  
Counties: Alamance, Caswell, Guilford,  
Randolph and Rockingham

## [INDEPENDENT LIVING]

**Greenville** – (919) 830-3471  
PO Box 2427; 101 Foxhaven Drive, 27836  
Counties: Beaufort, Greene, Hyde, Lenoir,  
Pitt and Wayne

**Hickory** – (704) 294-0338  
1050 Zion Church Road, 28602  
Counties: Alexander, Burke, Caldwell,  
Catawba, Cleveland, Iredell and Lincoln

**New Bern** – (919) 514-4806  
2203 Neuse Boulevard, 28561  
Counties: Carteret, Craven, Jones, Onslow  
and Pamlico

**Raleigh** – (919) 715-0543  
436 N. Harrington Street, 27603  
Counties: Franklin, Johnston, Vance, Wake  
and Warren

**Rocky Mount** – (919) 446-0867  
Station Square, suite 163, 27804  
Counties: Bertie, Edgecombe, Halifax,  
Hertford, Martin, Nash, Northhampton and  
Wilson

**Sylva** – (704) 586-3455  
122 Sylva Plaza, PO Box 756, 28779  
Counties: Cherokee, Clay, Graham,  
Haywood, Jackson, Macon and Swain

**Wilmington** – (910) 251-5810  
1506 Market Street, Suite B, 28401  
Counties: Brunswick, Columbus, Duplin,  
New Hanover and Pender

**Winston Salem** – (910) 761-2433  
1510B Martin Street, Suite 201, 27103  
Counties: Davidson, Davie, Forsyth, Stokes,  
Surry and Yadkin

## [HOME AND/OR RAMP MODIFICATION RESOURCES]

Amigo Mobility Center  
782-5110

Can assist in several areas  
Has 2 inch hinges for doors, great for  
widening bathrooms

City of Raleigh Community Services  
Department  
831-6100

Property must be located in city of Raleigh  
Must meet financial eligibility requirements

Doug Svehaug  
345-7382  
Project Coordinator

IMAGINE  
779-3487

(Increased Mobility and Greater  
Independence)  
Adopt a Ramp: Recruits teams of 4-8 people  
from corporations to donate funds and labor  
to build a modular wheelchair ramp. Ramps  
are built on site, but are made in modules so  
they can be disassembled and given to  
someone else if no longer needed.

Independent Living (Raleigh office)  
715-0543

Must meet financial eligibility requirements

O'Neal Construction  
270-1120

Ask for Ken O'Neal

Paul Kwiatkowski  
496-7029

Resources for Seniors  
872-7933

Housing and Home Improvement

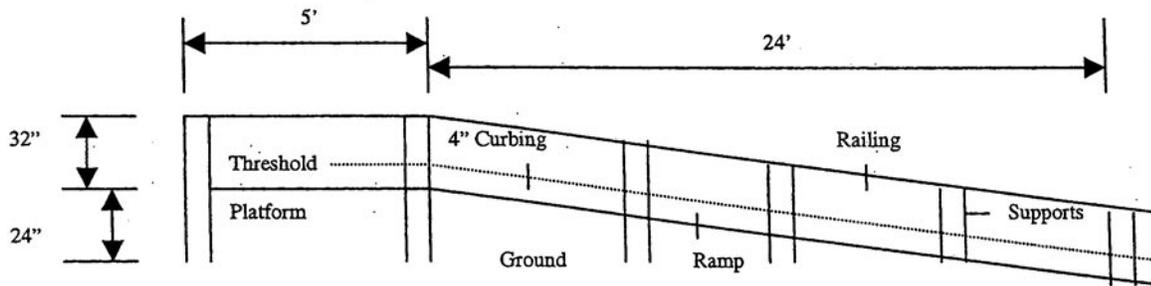
Van Products  
863-1304  
Ramp rental

Larry Ward  
669-3885 mobile

[www.servicemagic.com](http://www.servicemagic.com)  
click on area code to find  
builders/contractors in your area

*WakeMed does not endorse or recommend any of  
the above agencies/individuals*

## [RAMPING GUIDELINES]



1. For every inch of rise, there should be 1 foot of ramp. The rise is determined by measuring the height of the steps, including the door threshold (i.e., when total rise is 24 inches, ramp length should be 24 feet).
2. Pressure-treated lumber, marine plywood, or concrete should be used for exterior ramp construction. The ramp/platform should have a nonslip surface (e.g., gritty paper adhesive, nonskid paint, or, if surface is concrete, a broom finish). Ramp footings should be excavated to below the frost line.
3. Door thresholds should have a maximum height of one-half inch.
4. A platform (5 feet by 5 feet) that is level with the door threshold should be constructed immediately outside the doorway with an 18-inch space (minimum) opposite the door swing for wheelchair approach.
5. Ramp surfaces are recommended to be 42 inches wide (minimum) and to extend from level platforms.
6. Bilateral railings should be present and at a maximum height of 32 inches. The ideal width of the railing grip is 1.5 inches. Railings should not extend 1 inch beyond the end of the ramp. Ends of railings should be turned down to avoid dangerous projections.
7. A four-inch-high curbing should border the perimeter of the ramp and platform surfaces to prevent wheelchairs from deviating from the path of the ramp.
8. At the ramp bottom, six feet of straight clearance is recommended.
9. Level platforms (5 feet by 5 feet) are required for safety and resting in ramps longer than 30 feet and wherever the ramp surface turns.
10. Overhead coverings for ramped surfaces are suggested.

## [SEXUAL FUNCTION FOR WOMEN WITH SPINAL CORD INJURY]

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 activities 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.

### ADJUSTMENT AFTER SPINAL CORD INJURY

Body image is an important adjustment issue for women with spinal cord injury (SCI) because their feelings can influence their desire to engage in sexual activity. It is natural for women who are newly injured to take time to become more comfortable with their bodies, and a woman who is comfortable with her body before her injury will likely adjust well to her new condition. When a woman sees herself as desirable, it is easy to believe that others also find her attractive. On the other hand, a woman with a negative opinion of her looks before her

injury will likely find it difficult to see herself as sexually attractive after injury. Thus, she will be more likely to have a difficult time with sexual adjustment and will likely avoid sexual activity.

One of the main keys to adjustment issues is learning to manage impairment related issues of everyday life. Sexuality is a natural part of life, so healthy adjustment begins with knowing the facts about the impact of SCI on sexual issues. No matter the level of injury, it is normal for women to have doubts, concerns and questions. 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; and
- can become pregnant and have children.

Women who accept these facts as true may have questions about relationship issues.

Simply put, women who put themselves in a position to meet new people have a greater opportunity to establish a relationship. Then, it does not matter whether a woman is asked on a date or asks someone on a date; the answer will be either "yes" or "no." Women who are in a relationship may wonder whether or not they can maintain the relationship. In reality, it is almost impossible to assure the success of any

relationship. Lasting relationships depend on a number of factors such as personal likes and dislikes, common interests, communication, and long-term compatibility. Considering that about half of all marriages end in divorce, it is obvious that relationships are not easy whether a woman has SCI or not.

Anytime women with SCI are in a relationship, it is very important for them to remember that their partners also need to understand the facts about sexuality. When a partner understands the issues, sexual adjustment becomes easier for everyone. Plus, women and their partners can talk about issues and work together to solve problems, which is also a great way to build physical and emotional intimacy.

While women and their partners work together to solve problems, it is important to remember that sexual adjustment takes time. There may be many concerns about sexual activity along with unexpected problems or setbacks. The thing to remember is that couples can work together and solve problems if they focus on common interests.

## SEXUAL FUNCTION

For women, normal sexual response brings about lubrication of the vagina, clitoral swelling, and an increase in heart rate, respiratory rate, and blood pressure. This response typically occurs as a mental (psychogenic) and/or physical (reflex)

response to something sexually stimulating or arousing. A mental response occurs with sexually stimulating thoughts, and activities such as touching and kissing are physically stimulating.

Although women with SCI can engage in sexual activity, the impact of impairment on normal sexual response depends on the degree of injury and its location on the spinal cord. Most women with SCI will likely retain their physical response to physical stimulation but not retain their physical response to mental stimulation. However, it appears that women who have light touch and pinprick sensation from the waist (T-11) to the thigh (L-2) have a greater likelihood of sexual response to mental stimulation.

The most significant impact of impairment on sexual response seems to be an inability of some women to produce vaginal lubrication. The purpose for this lubrication is to allow easier vaginal penetration, so a lack of lubrication can result in problems such as vaginal tearing or pain during intercourse. An artificial water-based lubricant can be used by women who can no longer naturally produce lubrication. Oil-based lubricants should never be used.

Most women with SCI will also experience some, or all, loss of vaginal sensation and muscle control. With a loss of sensation, the physical feelings associated with sexual activities are different from women without SCI. The loss of muscle control results in an

inability to tighten vaginal muscles, which means there may be less friction during sexual intercourse. Women may try out different sexual positions to help improve vaginal friction. If a lack of friction continues to be a problem, women should talk to their doctor about treatment options.

## SEXUAL AROUSAL

Sexual arousal is the process of stimulating excitement and readiness for sexual activity. Although there are individual preferences as to what is considered arousing, some women with SCI may find it difficult to identify physically stimulating areas. Plus, some women may require lengthier foreplay to stimulate physical arousal when compared to women without SCI.

Women with SCI can help identify areas of physical stimulation through sexual exploration with or without a partner. They can experiment with touch or use a vibrator to try to find stimulating areas. It may also help to know what other women find physically arousing. The following list ranks areas of physical arousal reported by women with spinal cord injury.

### Areas of Sexual Arousal

- Mouth and lips
- Neck and shoulder
- Stomach
- Clitoris
- Thigh
- Feet

- Ears
- Breast
- Buttocks

## ORGASM

An orgasm is the intense physical pleasure at the height of sexual arousal. Because orgasms generally vary in type and intensity among all women, it is difficult to determine whether or not a spinal cord injury actually impacts a woman's ability to achieve orgasm. The evidence shows that about 54 percent of women with SCI engaging in sexual activity reported experiencing orgasm. Moreover, the feelings associated with orgasm, which usually includes vaginal contractions followed by a feeling of relaxation, seem to be similar for women with and without SCI. Some women, including women with SCI, have reported having orgasms after breast and upper body stimulation.

## FERTILITY

Fertility is an issue for women with SCI who are of child-bearing age. It is normal for most women to experience a brief pause in their menstrual cycle after a traumatic injury. This pause may last for as much as six months before the menstrual cycle resumes. However, the ability of women to have children is not usually affected once their period resumes. Women whose period does not resume should talk to a doctor about possible treatment options.

## PREGNANCY AND CHILDBIRTH

After any trauma or stress, it is common for you not to have a menstrual cycle. If your menstrual cycle does not resume in four to six months you will need to see your GYN physician. Once your menstrual cycle resumes you can get pregnant. Women with spinal cord injuries have babies all the time. Pregnancy will present you with more challenges and complications. Some of the complications you may experience are more spasticity, having to alter your bowel and bladder programs due to constipation or incontinence, and having more difficulty with transfers due to the weight gain. During childbirth you may experience some complications such as autonomic dysreflexia, increased spasticity, and increased blood pressure. Additionally, you will need to discuss specific issues related to labor and delivery with your doctor. Some of these issues would include a discussion of whether your pregnancy is considered high risk, whether or not you will be able to push during delivery, the possible need for a C-section, and different analgesia needs. Parenting will also present new challenges. Internet sites provide a lot of resources including adaptive baby and childcare equipment. Before you become pregnant you should research risks, challenges and complications, so you can make an informed decision about what is best for you and your family. The most important thing you should do if you are considering pregnancy

is to find an Obstetrician who is educated about SCI or is willing to learn.

## SAFE SEX

The risk of sexually transmitted disease (STD) is the same both before and after spinal cord injury. STDs include diseases such as gonorrhea, syphilis, herpes, and the HIV virus. These STDs can cause other medical problems, such as infertility, urinary tract infections, genital warts and AIDS.

Everyone needs to take precautions to protect against STDs. The safest, most effective way to prevent sexually transmitted diseases is to use a condom. The condom must be used correctly to be most effective in preventing both STDs and pregnancy. Even if your partner is using another form of birth control, a condom still needs to be used to protect against STDs. It is important to note that even condoms do not protect well against some STDs (for example HPV and herpes) but condoms are a better alternative than no protection at all. To ensure that both partners are disease free, each person can be tested by a health care professional.

## AREAS OF CONCERN

Women who are sexually active after injury generally report participating in similar activities such as they did before injury. However, 87 percent of women with spinal cord injury report participating in sexual activity before injury compared to 67 percent participating after injury. Although the likelihood of participating in intercourse after injury increases with time after injury, many women with SCI are sexually inactive.

For women who are hesitant to engage in sexual activities, it is important to understand the source of hesitation. It is natural for women who are newly injured to take time to become more comfortable with their bodies, but women who have prolonged feelings of discomfort will need to identify problems and work to solve them.

The list below ranks the 10 common areas of concern for women with spinal cord injury. No matter what the concern, women and their partners should learn about potential problems and prepare to manage issues. Once issues are managed, couples will probably become more at ease with sexual activities.

### Areas of Concern about Sexual Activity

- 1 Urinary Accidents
- 2 Bowel Accidents
- 3 Not satisfying a partner
- 4 Feeling sexually unattractive
- 5 Others viewing me as sexually unattractive
- 6 Not getting enough personal satisfaction

- 7 Preparation too much trouble
- 8 Hurting self
- 9 Loss of interest
- 10 Not liking methods for satisfaction

**Bladder management** is a concern for most women with SCI engaging in sexual activities. There are a number of ways to reduce the chance of urinary accidents. 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, women are much less likely to have an accident. They might also reduce the chance for accidents by emptying the bowels and avoiding meals prior to engaging in 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. These concerns are usually the result of a lack of education on available methods for gaining satisfaction. Again, some women may find self-exploration helpful. This not only can help identify sensual areas of the body, but self-exploration can also help build confidence in a woman's ability give and receive pleasure.

**Sexual exploration** can also help couples enhance their physical pleasure. The goal is to find sexual activity that is interesting, enjoyable and mutually pleasurable. As couples work together, it may help to try different methods to give and receive 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. Then, it might be helpful to start sexual exploration with simple acts of hugging, kissing and touching. As women and their partners express comfort with furthering exploration, they might progress to sexual stimulation, oral sex, vaginal and anal intercourse, or other means of physical intimacy.

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 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.

## OTHER POTENTIAL PROBLEMS

**Autonomic Dysreflexia (AD)** is a life-threatening condition for women with level 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. Women who experience multiple signs of AD during sexual activity should stop immediately. If symptoms continue after stopping, it is crucial to contact a doctor immediately for advice on treatment.

**Verbal and physical abuse** is an unfortunate reality in some relationships. The chances of getting into an abusive relationship are greater for women who have low self-esteem. 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.

**Sexual Dysfunction** in women is gaining interest in the medical community, and it can be a concern for women with SCI. Much of their difficulties are related to 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** might impact sexuality in many ways. For example, many women have a decline in sexual interest. Some women have a decrease in vaginal lubrication after menopause. Although it is natural to experience some changes in sexuality over time, there is no reason why women cannot continue to enjoy an active sex life late into life.

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 a great 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.

## C O N C L U S I O N

Sexuality does not have to change after spinal cord injury. Woman with SCI can still express sexuality both physically and emotionally. However, it is important for women to learn about how impairment can impact their mind and body. When potential problems are prevented or managed, women can feel comfortable in exploring, expressing, and enjoying all aspects of sexuality no matter their level of impairment.

## [SEXUAL FUNCTION FOR MEN WITH SPINAL CORD INJURY]

A spinal cord injury (SCI) affects a man's sexuality both physically and psychologically. The type and level of injury both can play a role on the impact that the injury has on a man's sexuality. After injury, men may face changes in relationships, sexual activity, and their ability to biologically father children. Men can also experience emotional changes that can affect sexuality. All of these issues involve both the man with SCI and his partner. Therefore, it is very important to understand and confront these issues as a part of the overall adjustment to life after injury.

### PHYSICAL CHANGES

Men normally have two types of erections.

- **Psychogenic erection** results from sexual thoughts or seeing or hearing something stimulating or arousing. The brain sends these messages through the nerves of the spinal cord that exit at the T10-L2 levels. The messages are then relayed to the penis, resulting in an erection. For men with spinal cord injury, the ability to have a psychogenic erection depends on the level and extent of injury. Generally, men with an incomplete injury at a low level are more likely to have psychogenic erections than men with high level, incomplete injury. Men with complete injuries are less likely to experience psychogenic erections.
- **Reflex erection** happens when there is 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 sexual or stimulating thoughts. The nerves that control a man's ability to have a reflex erection are located in the sacral segments (S2-S4) of the spinal cord. Most men with spinal cord injury are able to have a reflex erection with physical stimulation if the S2-S4 pathway is not damaged.

Many men with SCI are capable of having an erection. However, the erection may not be hard enough or last long enough for sexual activity. This condition is called Erectile Dysfunction (ED). There are various treatments and products available for treating ED but men with SCI may have special concerns or problems with their use. It is important to see a doctor or urologist for accurate information on the various treatments and products as they relate to men with SCI.

Because each spinal cord injury is different, each man's physical response is different. Men with SCI need to rely on their own observations and experiences to fully understand the changes in their sexual functioning.

### SEXUAL AIDES AND OPTIONS FOR MEN WITH SCI

**Viagra®** is the most recent breakthrough in treating ED. It is a pill taken by mouth. The Food and Drug Administration (FDA) approved Viagra in 1998 for use in the

treatment of ED. Research studies show that Viagra, taken as required (not more than once daily), significantly improves the quality of erections and satisfaction with sex life in men with ED due to spinal cord injury between T6 and L5. Men who have low or high blood pressure or vascular disease should not take Viagra. Some medications cannot be taken with Viagra so all medications should be reviewed with the doctor.

Viagra and other similar medications new to the market such as Levitra and Cialis, are now being prescribed to males with all levels of SCI injury. Men with a T6 or higher injury level are at risk for experiencing autonomic dysreflexia with the use of these medications. Men who already experience severe signs of autonomic dysreflexia should not use these medications. Also, men who have high or low blood pressure or vascular disease should not take these medications. Certain medications are contraindicated with the use of these drugs for ED. Men should never use these drugs in combination with any other medical treatment for ED, such as injection therapy. Make sure you consult with a urologist familiar with SCI before you consider any ED treatment.

**Penile injection therapy** is another treatment option. It 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. If not used correctly, the result

could be a prolonged erection, called priapism. When priapism occurs, the blood fails to drain from the penis. This can damage the penile tissue and be extremely painful. Other risks from the injection are bruising, scarring or infection of the penis. 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 spinal cord injury. Therefore, he must have assistance in getting the injection.

**Medicated Urethral System Erection (MUSE)**, or transurethral therapy, is a relatively new treatment option. A medicated pellet is placed into the urethra (tube through the penis) 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. Reported side effects include a risk of infection, a burning sensation and decreased blood pressure and fainting.

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 penis. 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. There are

several models of vacuum pumps available. A battery-operated model is an option for those with limited hand function. Other models require 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 surgical procedure involves inserting an implant directly into the penis to obtain an erection. Three types of implants are available: semi-rigid or malleable rods, fully inflatable devices, and self-contained unit implants. There are risks of mechanical breakdown and the danger that the implant could push out through the skin. Men with SCI usually do not have good sensation in the genital area, so there may be no signs of pain to indicate that the implant is breaking through the skin. All surgical implants also carry a high risk of infection. If an infection develops, the prosthesis may need to be removed. Penile implants are the most expensive option and some health insurance plans do not cover the costs.

Talk to a doctor before any treatment. Men with spinal cord injury who are experiencing ED should have a thorough physical exam by a urologist familiar with SCI before using any medications or assistive devices. Level of injury, possible side-effects, and other medical conditions need to be considered when deciding which treatment option is best. With all treatments, men with SCI must be watchful for signs of Autonomic

Dysreflexia (AD), a life-threatening condition. Signs of AD include flushing in the face, headaches, nasal congestion and/or changes in vision.

## F E R T I L I T Y

Men with SCI also experience a change in their ability to biologically father a child. The major factor interfering with a man's fertility is primarily due to an inability to ejaculate as a result of damage to the spinal cord. In fact, 90 percent of men with SCI are not able to ejaculate during intercourse; this is called anejaculation. Another problem men with SCI may experience is retrograde ejaculation. This occurs when semen does not leave the urethra but travels back up the tube and is deposited in the bladder.

One myth is that the number of sperm that a man produces decreases the longer the time after injury. There is no evidence that this occurs and should not be a concern for men who want to biologically father a child. However, the motility (movement) of the sperm is of concern. The average motility rate among men with SCI is considerably lower than for the average man without SCI. Recent research shows the average motility rate of sperm in semen samples from men with SCI is 20 percent compared to 70 percent in able-bodied men.

Options are available to assist men with spinal cord injury improve their ability to father children. Men who are interested in

fathering a child should get medical advice and treatment options from a fertility specialist experienced in issues of spinal cord injury. The fertility specialist needs to be aware of methods that can improve sperm quality in men with SCI, as well as complications that can occur, such as autonomic dysreflexia.

**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 spinal cord injured men. It is important to consult a physician before using a vibrator. One danger of using a vibrator is it could cause swollen or inflamed skin. If the male does not have feeling, the vibrator must be used very carefully to avoid any bruising, bleeding or ulceration.

**Rectal Probe Electroejaculation (RPE)** is an option if PVS is not successful. RPE is when 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. Once sperm are collected they can be used in artificial insemination.

## EMOTIONAL CHANGES

Men with SCI can experience many emotional changes that can influence sexual functioning. Men are often concerned with maintaining their ability to perform sexually as well as how their injury might affect their relationship with a partner. Men who do not have a partner at the time of injury may also be concerned with how to meet and attract a partner.

A man can continue both a romantic and an intimate relationship with a partner after a spinal cord injury. However, good communication with his partner is essential. Many men with spinal cord injury become angry, depressed, and/or uncertain about relationships after the injury. It is important for both partners to understand the physical changes that occur after injury, but it is equally important to talk about how each person feels about the issues. Without good communication, these emotions can be inappropriately directed at each other, which can result in more negative feelings. The couple can talk about, explore and experiment with different ways to be romantic and intimate. Together, they can then discover what is sexually stimulating and fulfilling for both of them.

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 their needs and feelings.

## S A F E S E X

The risk of sexually transmitted disease (STD) is the same both before and after spinal cord injury. STDs include diseases such as gonorrhea, syphilis, herpes, and the HIV virus. These STDs can cause other medical problems, such as infertility, urinary tract infections, genital warts, and AIDS.

Everyone needs to take precautions to protect against STDs. The safest, most effective way to prevent sexually transmitted diseases is to use a condom. The condom must be used correctly to be most effective in preventing both STDs and pregnancy. Even if your partner is using another form of birth control, a condom still needs to be used to protect against STDs. It is important to note that even condoms do not protect well against some STDs (for example HPV and herpes) but condoms are a better alternative than no protection at all. To ensure that both partners are disease free, each person can be tested by a health care professional.

## A R E A S O F C O N C E R N

For men who are hesitant to engage in sexual activities, it is important to understand the source of hesitation. It is natural for men who are newly injured to

take time to become more comfortable with their bodies, but men who have prolonged feelings of discomfort will need to identify problems and work to solve them.

The list below ranks the 10 common areas of concern for men with spinal cord injury. No matter what the concern, men and their partners should learn about potential problems and prepare to manage issues. Once issues are managed, couples will probably become more at ease with sexual activities.

### **Areas of Concern about Sexual Activity**

- 1 Urinary Accidents
- 2 Bowel Accidents
- 3 Not satisfying a partner
- 4 Feeling sexually unattractive
- 5 Others viewing me as sexually unattractive
- 6 Not getting enough personal satisfaction
- 7 Preparation too much trouble
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- 9 Loss of interest
- 10 Not liking methods for satisfaction

**Bladder management** is a concern for most men with SCI engaging in sexual activities. There are a number of ways to reduce the chance of urinary accidents. First, men 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. Men who use intermittent catheterization for bladder management can empty their bladder before engaging in sexual activity.

**Bowel management** is another concern for men with SCI. The best way to avoid accidents is to establish a consistent bowel management program. Once a routine is established, men are much less likely to have an accident. They might also reduce the chance for accidents by emptying the bowels and avoiding meals prior to engaging in sexual activity.

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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 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.

#### OTHER POTENTIAL PROBLEMS

**Autonomic Dysreflexia (AD)** is a life-threatening condition for men with level T-6 injury and above. Although sexual activity normally results in a rise in blood pressure, which is one sign of AD, men 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. Men who experience multiple signs of AD during sexual activity should stop immediately. If symptoms continue after stopping, it is crucial to contact a doctor immediately for advice on treatment.

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**Aging** might impact sexuality in many ways. For example, many men have a decline in sexual interest. Although it is natural to experience some changes in sexuality over time, there is no reason why men cannot continue to enjoy an active sex life late into life.

#### CONCLUSION

This information cannot address in detail all the issues related to sexuality. Please talk to your doctor, nurse or case manager if you have questions. For additional resources, see the following list.

## [SEXUAL FUNCTION RESOURCES]

### BOOKS

*Guide and Resource Directory to Male Fertility following Spinal Cord Injury/Dysfunction.*  
(2000) Miami Project to Cure Paralysis.  
305-243-7108 or Email:  
mfp@miamiproject.med.miami.edu.

*Male Reproductive Function after Spinal Cord Injury. Fact Sheet #10.* (1996)  
National Spinal Cord Injury Association, 8701 Georgia Ave, Suite 500, Silver Springs, MD 20910. \$2 or FREE with NSCLA association membership.

*Reproductive Issue for Persons with Physical Disabilities.*(1995)  
Florence Haseltine, Sandra S Cole, & David Gray. Paul H Brooks Publishing Co. Cost: \$34.

*Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide.*  
(1997) Marca Sipski, MD and Craig Alexander, MD., Aspen Publishers. Cost \$57. ISBN: 0834208865.

*Sexuality after Spinal Cord Injury: Answers to your questions.* (1996)  
Stanley H Ducharme, PhD and Kathleen M Gill, PhD. Brookes Publishing Co.  
Cost: \$22. ISBN: 1557662657.

*Spinal Network: The Total Wheelchair Resource Book.*  
(1998, 3rd Ed)  
Barry Corbet Chapter 7, Sex, Relationships and Parenting. Cost: \$49.95+s/h.

### VIDEOS

*The Treatment of Erectile Dysfunction Following Spinal Cord Injury.* (1995)  
Produced by SCI Video, 706 Sunnybrook Dr, Edmond, OK 73034.  
405-330-8657 Cost: \$30.

*Sexuality Reborn.* (1993).  
Producers: Craig Alexander, MD and Marca Sipski, MD.  
Kessler Institute for Rehabilitation. Cost: \$39.95+s/h

## ONLINE FACT SHEETS

- The Facts about MUSE® (alprostadil) urethral suppository.  
[/www.vivus.com/frames/products/facts.shtm](http://www.vivus.com/frames/products/facts.shtm)].
- Fertility and Parenting.  
SCI Forum, Dec, 1998. [Available: <http://depts.washington.edu/rehab/sci/forum-fertility1298.shtml>] NW Regional SCI System.
- Fertility and Parenting Options. (1997)  
Sexual Health Network. [Available: <http://www.sexualhealth.com/content/fertilit.htm>]
- Let's Talk about It. (July, 1998)  
Andrea M Crensky, RN, MSN  
[www.pn-magazine.com/pn/xxxxxxx/9807spou/default](http://www.pn-magazine.com/pn/xxxxxxx/9807spou/default)
- Possible Effects of SCI on Sexual Function. (1997)  
Sexual Health Network [Available: <http://www.sexualhealth.com/Disability/sci.htm>]
- Research Review: Viagra and SCI. (1999)  
UAB-RRTC on Secondary Conditions of Spinal Cord Injury, Birmingham, AL  
<http://main.uab.edu/show.asp?durki=21614>]
- Sexuality and SCI: Update on Having Kids.(1999)  
S. Ducharme, PhD. Paraplegia News.  
<http://www.pva.org/pn/articles/kids.htm>]
- Sexuality and SCI: Viagra Frenzy. (August, 1998)  
S. Ducharme, PhD. Paraplegia News.  
<http://www.pva.org/pn/xxxxxxx/9808sex/default.htm>
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## [BOWEL CARE AND MANAGEMENT]

### HOW THE BODY WORKS

The food you eat and drink provides your body with many nutrients. These nutrients give you energy and help you stay healthy. As food moves through your body it breaks down so the nutrients can enter your body. This process is called digestion. After the food is digested, the leftover waste products move into the large intestine. Here water is removed, leaving stool or fecal matter. The stool moves into the last part of the large intestine, called the colon or bowel. The last part of the bowel, where the stool waits to be released, is called the rectum.

As the bowel fills with stool it stretches. This triggers messages to the body. One message starts muscles to move the stool down through the bowel. Another message lets you know it is time to go to the bathroom and controls the muscle at the opening of the rectum (anus). This muscle allows you to control when the waste (stool) leaves the body. This is often called a bowel movement or BM.

After a spinal cord injury, the message sent by the nerves located in your bowel are not able to reach your brain like before your injury. This means you will not get the message that tells you the bowel is full and it is time to go to the bathroom. Another change is you may not be able to move the muscle at the opening of the rectum (anus) that controls when you have a bowel movement.

### HOW WILL YOU HAVE A BOWEL MOVEMENT AFTER A SPINAL CORD INJURY?

You will need to train your bowels to have a bowel movement at the time you want. Your bowel program outlines the steps you need to take in order to have a BM. You and your doctor will decide which bowel program is best for you, based on the kind of spinal cord injury that you have.

### HOW DOES YOUR LEVEL OF SPINAL CORD INJURY AFFECT YOUR BOWEL PROGRAM?

If you have a spinal cord injury above the T12 level, your program will differ from someone who has an injury below T12.

With an injury above T12 you do not receive the message telling you the bowel is full. The muscle that controls the opening and closing of the anus stays tight. When the bowel gets full it will empty by reflex (or automatically). Your doctor and nurse call this bowel problem a reflex bowel.

With an injury below T12 the messages do not get to the spinal cord. That means your reflexes do not work normally and the anal muscles stays relaxed. Your nurse and doctor call this a flaccid bowel.

## WHAT ARE THE DIFFERENT TYPES OF BOWEL PROGRAMS?

Individuals with a spinal cord injury above T-12 follow a bowel program that usually includes taking a daily stool softeners/laxative combination and using a suppository with digital stimulation (using a finger to stimulate a bowel movement).

Stool softeners are medicines like ducolox, pericolace or senokot. You want the stool to remain soft so it is easier to empty the bowel.

A suppository is medicine shaped like a bullet that you put in your rectum. The ingredients in the suppository help trigger the muscles and nerves in the bowel so you have a BM. It helps you have a bowel movement at the right time and avoid accidents. At first, it is likely that you will use Ducolax suppositories.

You will learn, by trial and error, what medicines you need to make your bowel program work for you. Some people do not need to use both suppositories and stool softeners. Your body will let you know what you need.

The bowel program for an individual with an injury below T-12 includes digital stimulation and manual removal (disimpaction) of the stool. Your bowel program may need adjusting, depending on what and how much you eat. You may need to do your bowel program both after

breakfast and dinner to avoid accidents (unplanned BM's).

## WHAT YOU NEED TO DO TO HELP MAKE YOUR BOWEL PROGRAM WORK FOR YOU?

For the best results with any bowel program you should try to:

- Do your bowel program at the same time every day. You want to teach your bowels when to have a BM. You can train your bowels by following a regular schedule.
- Transfer to a toilet or bedside commode. It helps to sit up during your bowel program. Remember, gravity helps move the stool down into the rectum.
- Do not use a bedpan. A bedpan may damage your skin.
- If you cannot sit up on a toilet or commode, lay on your left side. The bowel ends on the left side of your body. This makes it easier to complete the BM.
- Do your bowel program about 30 minutes after a meal or a high fiber snack. If you are not able to do your bowel program right after your meal, do it as close to your regular time as possible. Eating some high fiber food (such as fruits, popcorn, cereal, bran muffins) and drinking a warm liquid (such as hot tea, warm prune juice, or coffee) before using a suppository, will help you have a BM. The new food going into your digestive system starts the intestine to move the stool out of your body.

- Take time to complete your program in private. If you share a bath, find a time when you can relax and not be rushed.
- Keep the stool well formed. If your stool is either too hard or too soft, it will be difficult to empty your bowel. You may need to adjust your stool softeners or diet. Some medicines, like antibiotics, may cause you to have softer or loose stools.
- If you take stool softeners or laxatives by mouth, make sure you are taking them at the opposite time you perform your bowel program. For example if you perform your bowel program in the morning after breakfast, then you should take those medications at night before you go to bed. If you perform your bowel program in the evening after dinner then you should take those medications in the morning. Most stool softeners and laxatives take 8-10 hrs to work fully.
- If you are having constipation, clean out your bowel completely before making changes to your bowel program. This may mean taking MOM, Magnesium Citrate and or an enema. All these things are available over the counter.
- Give your body at least three days to adjust to a change in your bowel program before you make any more changes.

Digital Stimulation is used to help completely empty the bowel. It is performed by inserting a finger or a dilstick into the rectum and moving it around in circles. This movement signals the nerves in the rectum like a full bowel normally would. This causes

the muscles to contract and move the stool down into the rectum so it can be emptied. If you are not using digital stimulation in your bowel program and are still having bowel accidents your bowel may not be completely emptying during your bowel program and digital stimulation may be the answer. You should perform digital stimulation during your bowel program for about 30 seconds at a time every few minutes over a 20-minute period.

#### STEPS TO FOLLOW IN YOUR BOWEL PROGRAM

**REMEMBER:** The lining of the rectum is delicate. Be gentle when placing the suppository, removing stool, or doing digital stimulation during your bowel program.

#### How to do digital stimulation.

- Wash your hands.
- Put on gloves.
- Insert a lubricated gloved finger into the rectum. (coat the gloved finger with a lubricant such as, K-Y jelly).
- Move the finger gently in a circular motion for several minutes.
- If little or no results, try again. If that fails, you may use a suppository

#### How to give yourself a suppository

- Wash your hands.
- Put on gloves.
- Insert lubricated gloved finger into the rectum. (coat the gloved finger with K-Y

jelly to lubricate)

- Remove any stool that is in the rectum. (If you put the suppository in stool it will not work)
- Take off the wrapper and coat the suppository with a lubricant (KY jelly).
- Insert suppository into the rectum as high as you can and place it against the wall of the intestine (bowel).
- If after waiting 30 - 45 minutes you have had little or no results, you may need to do digital stimulation. Do this until the rectum is empty.

\* Note: If you have a bowel accident during the day, still use the suppository after your meal in the evening. This will help keep your body on schedule for regular bowel movements.

#### **How to do manual disimpaction. (remove by hand)**

- Wash your hands.
- Put on gloves
- Insert lubricated gloved finger into the rectum.
- Remove stool that is in the rectum with your finger.
- Continue to remove the stool until you cannot feel or reach any stool in the bowel.
- Wait a few minutes and check your rectum again to make sure you emptied your rectum of stool.

## **HOW TO HANDLE PROBLEMS WITH YOUR BOWEL PROGRAM**

### **CONSTIPATION**

#### **Signs:**

- Hard, loose, or watery stools
- Irregular bowel movements
- No bowel movement in several days
- Swollen or hard stomach
- Lack of appetite
- Nausea, throwing up
- Autonomic dysreflexia

#### **Causes:**

- Not drinking enough fluids
- Not following a scheduled bowel program
- Not eating a diet with plenty of fiber
- Not getting enough activity
- Not taking stool softener
- Some medications: Narcotics, iron, and certain anti-acids

#### **Solutions:**

- Eat a balanced diet that includes plenty of foods high in fiber.
- Drink at least 8-9 (8 oz) glasses of water/liquid a day.
- Stay on a scheduled bowel program.
- Keep active.
- Take a stool softener (Surfak, Colace, Castor Oil).
- Take a laxative (Dulcolax, Senekot)
- Add a dose of a bulk former (Metamucil, Fibercon).

## **IMPACTION (stool stuck in the rectum)**

### **Signs:**

- Same as for constipation

### **Causes:**

- Same as for constipation

### **Solutions:**

- Gently remove stool from rectum with a lubricated, gloved finger. If this does not help, use an enema.
- If you become more uncomfortable, call your doctor.

## **DIARRHEA (loose or liquid stools)**

### **Signs:**

- Many, loose and watery stools.

### **Causes:**

- Eating foods that are spicy, high in fat, or contain caffeine (coffee, tea, chocolate, or cola drinks)
- Over use of stool softeners/laxatives
- Medications that irritate the stomach or intestines.
- Antibiotics may cause soft or loose stools.
- Medical problems, like the flu.
- Emotional problems, stress.
- Poor diet.

### **Solutions:**

- Check to see which foods disagree with you.
- Stop taking any laxatives until the diarrhea stops.
- Stop using stool softeners. After diarrhea is over, adjust your dose until your stool is proper hardness.
- Drink plenty of liquids to prevent dehydration.

*\*\*\* If the diarrhea lasts longer than 24 hours, call your doctor.*

*\*\*\* Often what appears to be diarrhea (loose, liquid stools) is actually severe constipation*

## **AUTONOMIC DYSREFLEXIA**

Autonomic Dysreflexia is a response to a painful stimulant. This pain can be caused by hemorrhoids, rough digital stimulation, or a full bowel. If you have an AD attack during your bowel program, try the following:

- Keep on a regularly scheduled bowel program with adequate emptying. You may have to increase the frequency of your bowel program.
- Get in a comfortable position during bowel program.
- Use anesthetic ointment on the anal area 5-10 minutes before digital stimulation.

## **HOW TO PREVENT BOWEL ACCIDENTS**

The best way to prevent bowel accidents from happening is to follow a schedule for your program. You want to teach your bowels when to have a BM. You can train your bowels by following a schedule. If you are on a regular schedule and know you are emptying well, but still have accidents, keep track of what you eat and drink. Foods are often the cause.

## HOW TO HAVE A SUCCESSFUL BOWEL PROGRAM

To avoid problems with your bowel program, remember what you can do to help your S-E-L-F!\*\*

**Schedule:** Plan a time every day or every other day to do your bowel program. It works best if it is after eating a meal. Keep the same schedule every day. Plan ahead for special occasions that may interrupt your normal schedule to avoid problems.

**Exercise:** The more active you are, the easier it is for the food you eat to travel through your digestive system. Get out of bed and exercise some every day.

**Liquids:** An important part of your diet is liquids. Drink at least 8 - 9(8oz) glasses of liquid each day. This will keep your BM from getting too hard, preventing constipation.

**Food:** Eat a variety of foods every day, especially foods with fiber. Fiber (roughage) is found in fresh fruits and vegetables and whole grain breads and cereals. Roughage helps control your bowels and prevents constipation. Try to limit spicy foods, greasy foods, and “junk” foods. Eat foods like fruits and vegetables, such as apples, beans, carrots, okra, potatoes, greens, and green salads.

Remember, if a specific food gave you diarrhea or constipation before your injury, it still can - and probably still will.

Sources: SILS [Spinal Injury Learning Series] Norris, Noble, and Strickland: Learning Systems, Jackson, Mississippi, 1978

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## [BLADDER CARE AND MANAGEMENT]

The body's urinary system is made up of five parts:

1. The kidneys make urine by filtering the blood. They are located in the middle part of the back.
2. The ureters are tubes between the kidneys and the bladder.
3. The bladder is a muscular sac that holds urine until it is ready to be released.
4. The sphincter muscles are the muscles at the bottom of the bladder that open and close to allow the urine to pass through the urethra.
5. The urethra is the tube from the bladder to the outside of the body.

The urinary system has three major functions.

1. It makes urine in the kidneys;
2. stores urine in the bladder; and
3. removes urine from the body through the urethra.

Urine is made when the kidneys filter out waste products and water from the blood. The urine moves from the kidneys through tubes, called ureters, to the bladder. The bladder temporarily stores the urine. Normal voiding, or urinating, occurs when:

- the bladder muscles contract
- the sphincter muscles (small muscles that act like a valve), relax
- Urine flows from the bladder through the urethra (tube from the bladder to the outside of the body) and out of the body.

When the process is finished, the bladder is empty.

## THE URINARY SYSTEM AFTER A SPINAL CORD INJURY

After a spinal cord injury, the kidneys continue to make urine, and urine can continue to flow through the ureters. These parts work because they work without the brain telling them to act.

The bladder muscles and sphincter muscles are voluntary (controlled by the brain). Messages from the brain tell the bladder and sphincter muscles to empty the bladder. These messages are normally sent through nerves near the end of the spinal cord. However, those messages cannot travel through the spinal cord after an injury. So, individuals with spinal cord injury may not feel the "urge" to urinate when their bladder is full. They may not have voluntary (conscious) control of their bladder and sphincter muscles.

The bladder is usually affected in one of two ways after injury:

- Spastic (Reflex) bladder means your bladder fills with urine and a reflex automatically makes the bladder empty. Individuals with spastic bladder do not know when, or if, the bladder will empty.
- Flaccid (Non-reflex) bladder means the reflexes (automatic contractions) of the bladder muscles are slow or missing. If you do not feel when the bladder is full, it can become over-filled (distended), or stretched. The urine can back up through

the ureters into the kidneys. Stretching also affects the muscles of the bladder.

Sphincter muscles may also be affected after injury:

- Dyssynergia is when the sphincter muscles do not relax when the bladder muscles contract. The urine cannot flow through the urethra. This can result in the bladder not emptying completely or urine backing up into the kidneys. This backup is called “reflux” and reflux can result in reflux nephropathy which may eventually require the patient to be on hemodialysis. Therefore, it is extremely important to follow up with your urologist regularly.

## WHAT KINDS OF BLADDER MANAGEMENT PROGRAMS ARE THERE?

There are 3 main types of bladder management programs:

1. Intermittent catheterization programs have you put a catheter (tube) into your bladder on a schedule.
2. Indwelling catheters (Foleys) are catheters (tubes) that are left in the bladder and attached to a bag which collects the urine.
3. Condom catheters (for men only) are “condoms” which are worn and attached to a bag to catch the urine.

For any bladder management program you use, you need to:

- Follow a regular schedule
- Empty your bladder completely.

## URINARY TRACT INFECTION

Individuals with spinal cord injury are at a high risk for urinary tract infection (UTI). In fact UTIs are the number one medical concern of people with spinal cord injuries.

**Bacteria cause UTIs.** Bacteria (“germs”) are microscopic single-celled life forms that live in the body and can cause infection.

It is normal for individuals with spinal cord injury to have bacteria in their bladder. Bacteria from the skin and urethra get into the bladder with all forms of bladder management. Also, many individuals with spinal cord injury are not able to completely empty their bladder. Bacteria are likely to grow in urine that stays in the bladder.

## DO YOU HAVE A UTI?

Some of the symptoms of a urinary tract infection (UTI) are:

- Fever
- Chills
- Nausea
- Headache
- Increased spasms
- Autonomic dysreflexia (AD).

Depending on your level of injury, you may also feel:

- Burning while urinating
- Pelvic pain or discomfort
- Abdominal pain or discomfort
- Lower back pain or discomfort

You may experience one symptom or more if you have a UTI.

There is a good chance that you have a UTI if you begin to show signs or symptoms of illness. However, you may also have another health problem. Call your doctor immediately for advice on treatment if you have any symptom of illness.

### **Know the warning signs of infection**

There are often early signs of a urinary tract infection before symptoms of illness occur.

You may have one or more of the following:

- Sediment (gritty particles) or mucus in the urine
- Cloudy urine
- Bad smelling urine (foul odor)
- Blood in the urine (pink or red urine)

When these signs appear, take these steps to help prevent illness:

- Drink more water
- Stop drinking beverages with sugar, caffeine, and alcohol
- Catheterize more often

## **TREATMENT OF URINARY TRACT INFECTION**

Even with a regular bladder management program and proper prevention methods, you are still at risk for urinary tract infection. Treatment for a UTI almost always includes an antibiotic medication prescribed by a doctor. Antibiotics kill bacteria.

## **PREVENTING URINARY TRACT INFECTION**

Individuals with spinal cord injury can help to prevent UTIs. Keeping the urinary system “clean” is very important. You can do this in a number of ways.

### **Keep your skin clean**

- Clean skin is an important step in preventing infection.
- Always wash your hands before and after catheterization.
- Wash the area around the genitals with soap and water every day.
- Change your clothes and wash the area immediately after you have any urine or bowel accidents.

### **Use proper techniques**

It is important to follow proper steps when emptying the bladder. It is also important to completely empty your bladder. This helps prevent bacteria from being left in the body long enough to multiply.

- Drink plenty of fluids
- Make water your “Beverage of Choice!”
- Drinking the proper amount of fluids helps to “wash out” bacteria and other waste materials from the bladder. This can help prevent UTI and other problems of the urinary system. The amount of fluid you need to drink each day depends on your bladder management program. For intermittent catheterization it is recommended that you drink between 8 to 10 (8oz) glasses of liquid per day, which is about 2 quarts. It is also a good idea to

drink your fluids primarily between breakfast and dinner. Water is the best beverage choice. Drink all other beverages in moderation. Limit drinks with sugar, caffeine and alcohol.

### **Empty your bladder on a regular schedule.**

If you drink the recommended amounts of fluid and use intermittent catheterization for your bladder management, you should empty your bladder at least every 5 or 6 hours while you are awake. We suggest that you empty your bladder when it contains 300 – 400 ml of urine.

It is very important that you empty your bladder when needed. Remember, you may not feel the “urge” to urinate.

When the bladder becomes full and is not emptied:

- Urine that remains in the bladder too long allows bacteria to grow
- Bladder muscles stretch. This can damage the bladder muscles.
- The urine can back up into your kidneys. This is called reflux and it can cause infection and other health problems.

### **Have a regular urologic check-up**

It is important to have a complete medical check-up at least once a year. This exam should include a urologic exam (an exam of the urinary system) to see that your urinary system is healthy.

After your spinal cord injury you should establish a urologist who can continue to follow you. Initially you will need to have a

Urodynamic Study. This study will tell your urologist how much urine your bladder can hold and how much urine in your bladder will cause the bladder to reflex. Your urologist may also do a renal ultrasound to evaluate the function of your kidneys. They will use this as a baseline and repeat the test every couple of years.

## **CLEANING AND STORING URINARY CATHETERS**

### **Red Rubber Catheters**

- These catheters may be used once in the hospital and then saved for use at home.
- After using the catheter while in the hospital, wash it with warm soapy water, rinse under warm running water, lay it on a clean towel to dry and then place it in a plastic bag. Do not use the catheter any more while you are still in the hospital.
- After you return home, the red rubber catheters should be placed in a pan of water on the stove and boiled for 20 minutes, then placed on a clean towel to dry and then stored in a plastic bag.
- These catheters should be cleaned as instructed above after each use. You can continue to use these catheters until you note signs of wear such as discoloration or cracking.

### **Long or Short Clear Catheters**

- These catheters can be used once while in the hospital and then saved for home use.
- After using the catheter wash it in warm soapy water, rinse under warm running

water, lay it on a clean towel to dry and place it in a plastic bag.

- After you get home, the catheters should be cleaned again in hot, not boiling, soapy water, rinsed well under hot running water and placed on a clean towel to dry. Then place in a plastic bag for storage.
- These catheters should be cleaned as instructed above after each use. You can continue to use these catheters until you note signs of wear such as discoloration or cracking.

## [ADJUSTING TO DISABILITY IS A JOURNEY]

by Phil Punzarino

If you recently experienced a significant physical disability, then you are about to embark on a journey that has been well traveled. In the early stages of disability, the majority of your thoughts and energy are dedicated to survival. Where will I live? How will I get around? Who will help me get showered and dressed? Who will prepare my meals? Will I have enough money? These and many more questions will leave you feeling very alone and isolated. What you have to remember, however, is that you are not alone! This road has been traveled by millions of people before you. These people are your peers and they can help show you the way. Being open minded and willing to accept their guidance is critical. I am confident that if you listen and accept the knowledge of you peers you will be on your way to becoming truly independent. Maybe not in a physical sense, but on an emotional level, you will direct your life. You will be in charge. Only then can you live with dignity. But, it's up to you!

At first, the onset of a disability is much like being a newborn. There are lots of new things, unknowns, and much learning required to survive. For an infant, survival is dependent on a great deal of assistance from mom and dad. Reality to a newborn is based on dependency and feelings of helplessness. The early stage of disability is much like the experience of the newborn. Remember the time when you were left in the crib longer than you could tolerate? Mom wasn't far away, but it seemed like an eternity before she came to your rescue. You wanted to get out, but you couldn't. You wanted your independence, but the railings were too high. The more you fought, the more frustrated you got.

Having a disability is a lot like this experience. There are railings seemingly everywhere. The railings are the barriers. You will need to learn to eliminate them, or at least mangle and adapt to them. Only then can you become as independent as your abilities and talents will allow. Importantly though, you have a choice in this process. You can be passive or active. I strongly suggest you choose the latter approach. Taking an active role or "taking charge" in choosing your destiny will reward you with the riches of self-esteem and the respect of others. But it does not happen overnight! It takes time and persistence. Just like the newborn, a person with a disability must grow and mature. Sometimes you must re-learn to do something that only months before you took totally for granted, like signing your name. You may have to adapt to a new and different body. But most importantly, you just need to gain experience in you new environment before you can effectively live within in.

Now you may be thinking, that may be true for some people, but I'm different. And it's true, you are. Each individual's experience with disability is unique. Some are born with a disability. Some acquire a disability during childhood. Some are injured as teenagers. Some experience an illness at middle age during their prime working years. Some become disabled in the midst of retirement. But I guarantee you there are others that have traveled on your road. I suggest you embrace them, as they will make your journey a much more pleasant one.

*Reprinted, and distributed, by permission from The Bridge (July 2001), a free publication of Arizona Bridge to Independent Living.*

## [PLAYING WITH THREE STRINGS]

We have seen Yitzhak Perlman  
Who walks the stage with braces on both legs,  
On two crutches.

He takes his seat, unhinges the clasps of his legs,  
Tucking one leg back, extending the other,  
Laying down his crutches, placing the violin under his chin.

On one occasion one of his violin strings broke.  
The audience grew silent but the violinist did not leave the stage.  
He signaled the maestro, and the orchestra began its part.  
The violinist played with power and intensity on only three strings.

With three strings, he modulated, changed and  
Recomposed the piece in his head  
He retuned the strings to get different sounds,  
Turned them upward and downward.

The audience screamed delight,  
Applauded their appreciation.  
Asked later how he had accomplished this feat.  
The violinist answered  
It is my task to make music with what remains.

A legacy mightier than a concert.  
Make music with what remains.  
Complete the song left for us to sing,  
Transcend the loss,  
Play it out with heart, soul, and might  
With all remaining strength within us.

## [EMOTIONAL ADJUSTMENT]

Recovering from a spinal cord injury involves the whole person – body, mind, and spirit. Recovery is emotional as well as physical.

Take a few minutes to realize how you have been feeling since you learned about the spinal cord injury. Your feelings may have a broad range, or it may seem that you have felt numb or empty inside. Depression, anger, fear, sadness, anxiety, hopelessness, overwhelming tiredness, confusion, powerlessness, and resentment are only a few of the feelings that can come along with having a new spinal cord injury. You may also experience a sense of relief, hope or confidence that you are succeeding in dealing with a difficult life situation. You may have mood swings from high to low with a stop anywhere in-between. By the way, your family and close friends are probably experiencing many of the same feelings. As you go through this recovery together, you may feel closer or you may find that there are more arguments and stress between you. Stress tends to bring out both the best and the worst in all of us.

Give yourself a break here, stop and take a look at what you have been through. Of course this has been emotional! So much has changed over a short period of time. Spinal cord injury can mean loss of movement/mobility, bodily functions, income, job, independence, self-esteem and control. Loss triggers change, which in turn means having to cope with and adjust to changes.

## WHAT CAN YOU DO TO HANDLE ALL OF THIS?

Here are a few suggestions that have helped others through tough times and may get you thinking about your own situation.

**ATTITUDE.** Develop a win/win attitude. Every time you say “I can’t” you give yourself that message and pretty soon you’ll be convinced that you can’t before you even give it a try. Believe in yourself and trust your rehabilitation team’s belief in you. Develop a sense that there is always something for you to gain in a situation, exercise, or challenge. Substitute phrases like “that’s worth a try” or “I don’t see why not.” Anyway you want to say it is fine, as long as you give yourself a positive message!

**TAKE ONE DAY AT A TIME.** Thinking of having pain or numerous limitations for the rest of your life would be very overwhelming. In fact, dealing with any situation forever would be hard to take. So break it down to small, manageable segments – a few minutes of therapy? Sure.

**TAKE ADVANTAGE OF YOUR RESOURCES.** Some resources are family, friends, staff and support groups. Talk to someone who has been there. Another person who has had the same experience would be ideal, and your nurse or case manager may help introduce you to the right people.

**TALK ABOUT IT.** Discussing your feelings doesn't change the situation, but it will help to lighten your burden. When a sorrow is shared it becomes half and when joy is shared it doubles. Talking things out with someone who cares makes it much easier to keep going. We all need a kind ear and a word of understanding.

**BE GOOD TO YOURSELF.** Do something good for yourself each day. For example, take a long, relaxing shower at the end of the day, dress up in your favorite outfit, spend time reading, listen to music, or watch an enjoyable TV show. Also make sure you rest at night and eat a healthy diet.

**EASY DOES IT.** Set your goals so that they can be achieved in the time you have.

**DEVELOP A SENSE OF HUMOR.** Everyone has a sense of humor, but when we are under stress we sometimes forget to take advantage of one of our greatest and most healing powers. So share a funny story or a joke. Get involved with recreation programs, play games, and have fun just for the fun of it.

**RELAX.** As crazy as it may seem, relaxing can be hard to do. There are simple exercises and relaxation techniques that can be done. Practice relaxing every day.

**PRACTICE.** With time and practice, your new skills will become more natural, your confidence will increase, and you will begin to feel more like yourself again.

**WORK ON ACCEPTING LIFE ON ITS TERMS.** Change is change. Don't attach judgment to it. When we experience a change, quite often we tend to say it's "bad" or "good" when in fact it's just different. So avoid attaching judgments and look for what you need in each change you experience. Look for opportunities for growth.

Each person has his or her own way of dealing with the events that happen day to day. After a spinal cord injury, this does not change. There are changes in your life that you will have to deal with, changes that can cause stress. Being in the hospital, the changes caused by your spinal cord injury, learning new ways to do things, and worrying about what it will be like after you go home, can all cause stress. Stress is a normal reaction to ALL change, good and bad. Stress can cause many feelings that include:

- Anger at the injury, its cause, what you may have done or may not have done to cause the spinal cord injury
- Frustration when things are hard to do or do not happen the way you want
- Depression when things seem very bad, as if they will never be better
- Fear about what the future will be like
- Helplessness when others are doing things for you

Having these feelings is **NORMAL**. If you have any of these feelings, it is because of what has happened to you, not because something is wrong with your mind. You may not have all these feelings, or they may

be very strong. These feelings often come and go. Most people find ways to deal with these feelings, but it takes time. There will be good days and bad days. It is when these feelings begin to supercede all aspects of your thoughts and hinder your functioning and ability to participate that concern arises.

Source: Schust, Christina S. Ed., Spinal Cord Injury: Patient Education Manual. Aspen Publishers, Inc., Gaithersburg, MD 1997.

## [FATIGUE]

Many people with a spinal cord injury can be deeply affected by chronic fatigue. It not only hinders their physical abilities, but also affects their mental health. Chronic fatigue may make people with a spinal cord injury too weak to perform their activities of daily living. It can also keep them confined at home because they have no energy to get out in the world. As their daily life becomes more difficult, they may feel depressed, bored, hopeless, and helpless. These feelings will add to their exhaustion and begin a cycle of fatigue and depression that is hard to break.

Often the best treatment for easing chronic fatigue comes when people make changes in their daily routine and lifestyle.

**CHANGE OR REDUCE THE DAY'S TASKS.** Limit what is done during the day and focus on how to complete those tasks.

**GET HELP FROM OTHER PEOPLE.** Ask for help from family, friends and caregivers when it is needed. When you reach out for help, you give friends and family a chance to feel positive and useful.

**GET HELP FROM ASSISTIVE TECHNOLOGY.** Many adaptive tools or devices can help reduce the effort it takes to get things done.

**GET HELP FROM MUSCLE CONDITIONING.** Talk to your physical therapist about things that can be done to help improve muscle condition.

**SELF-HELP.** Get enough rest, learn relaxation or meditation techniques and add light exercise to daily routine.

**REST.** Frequent, short rest periods work better than long rest breaks to refresh the body.

**RELAXATION.** Meditation, deep breathing, guided mental imagery, yoga. Holistic healing helps the body by using the person's whole self – mind and body – to improve health.

**EXERCISE.** Helps to tone muscles, boost energy by increased oxygen levels in the body, and can reduce muscle spasticity. Doctors and therapists can provide instruction on the level of activity that is appropriate and safe.

**MEDICATIONS.** While medications won't cure fatigue, they can make a person feel more energetic. Doctors can sometimes prescribe mood-altering medications to fight chronic fatigue.

Source: Schust, Christina S. Ed., Spinal Cord Injury: Patient Education Manual. Aspen Publishers, Inc., Gaithersburg, MD 1997.

## [ALCOHOL]

Alcohol, a drug, is a central nervous system depressant. It is the mood-altering ingredient in wine, beer and liquor. Alcohol is absorbed into the blood stream and transmitted to virtually all parts of the body. Several factors influence the effects of alcohol, including the amount of alcohol consumed; the rate at which it is consumed; the presence of food in the stomach during consumption; and the individuals' weight, mood and previous experiences with the drug.

With moderate drinking, a person may experience flushing; dizziness; dulling of senses; and impairment of coordination, reflexes, memory, and judgment. Taken in larger quantities, alcohol may produce staggering, slurred speech, double vision, dulling of senses, sudden mood changes and unconsciousness. Taken in larger quantities over a long period of time, death may occur due to depression of the parts of the brain that control breathing and heart rate. Over long periods of time, alcohol can cause damage to the liver, heart, and pancreas. It may lead to malnutrition, stomach irritation, lowered resistance to disease, and irreversible brain or nervous system damage.

Increased tolerance to alcohol may lead to physical dependence. At that point, alcohol becomes part of a person's normal physical functioning. Physical dependence is characterized by the presence of withdrawal symptoms when use is discontinued suddenly.

## ALCOHOLISM

- Progressive: gets worse over time
- Fatal: leads to death
- Chronic: lasts for longer than 6 months
- Inability to control drinking: unable to limit the amount of alcohol consumed and/or the frequency of drinking occasions
- Preoccupation with drinking: spending a lot of time thinking about drinking and its outcomes
- Negative consequences: problems such as poor physical health, poor judgment, emotional difficulty, and unwanted behavior created as a result of drinking
- Denial: inability to be aware of problems resulting from drinking alcohol

## WHAT CAN I DO ABOUT MY DRINKING?

Until recently, many people believed that the troubled drinker had to "hit bottom" – be totally defeated by alcoholism – before he or she could be treated successfully. This is a myth. Alcoholism can usually be arrested at any point: in fact, the earlier help is sought, the better the chances for recovery. But whether your drinking problem is in its early stages or you are severely addicted to alcohol, you can find the kind of help you need. The most important criterion for successful treatment is a real commitment to overcoming your dependency of alcohol.

Nevertheless, it is often difficult to make the decision to seek help. Most of us have grown up with the notion that an alcoholic person

is somehow “weak” or “immoral”. Although these false stereotypes are fading, many people still think there is something shameful about acknowledging a drinking problem. In dealing with these feelings, it is important to recognize that you are suffering from an illness.

A good start toward getting help is to talk to someone you trust about your problem with alcohol. The person you confide in can be anyone with whom you feel comfortable and secure: a family member, a friend, coworker, a member of the clergy, or a counselor. Once you have acknowledged your drinking problem, you have already taken an important step toward recovery. Your next step is to find out what kind of help is available in your area and begin a program of treatment that best meets your needs.

## HELP IN THE COMMUNITY

There are numerous local resources that can either provide you with information about treatment resources or direct you to actual treatment services. These resources include: physicians (including psychiatrists), information and referral programs (in the yellow pages under “alcoholism”), private treatment facilities (in the yellow pages under “alcoholism”), hospitals (in the yellow pages under “alcoholism”), local health/mental health departments, local human services/social services departments, family service centers (often run through United Way), clergy/spiritual counselors, as

well as your employer through confidential Employee Assistance Programs (EAPs).

If you have difficulty finding a local resource that is satisfactory, you may wish to contact one of the following state and national resources for further information:

- National Council of Alcoholism and Drug Dependence (NCADD) – 212-269-7797
- Alcoholics Anonymous (AA) – 212-870-3400
- Al-Anon and Alateen – for spouses/relatives/friends of alcoholics – 888-425-2666
- Federal Substance Abuse + Mental Health Services Administration (SAMHSA) – 1-800-729-6686

## [RESEARCH: WHERE ARE WE WITH FIXING SPINAL CORD INJURIES?]

### **Why don't the nerves in the spinal cord regrow like other nerves can?**

A couple reasons actually....

**First:** They're LAZY! The nerves in the central nervous system (CNS) simply don't "try" very hard to regenerate like the nerves in your arms and legs do. In other words, when you suffer a nerve injury in your arm or leg, the injured nerve turns on genes that are necessary for the regrowth process, while the "lazy" CNS nerves do not.

**Second:** The CNS is an unfriendly place! After an injury, substances that are unfriendly to nerve growth are released from the damaged nerves. And if that wasn't bad enough, the scar that is formed after a SCI releases its own substances that are hostile to nerve growth.

So does this mean there's no hope for a future treatment or cure?

**OF COURSE NOT!**

OK, then where are we on the research front?

Well, it's a complex topic so let's break it down by goals and areas of research focus. And remember, research is always going on and many studies are not published yet. So, this information is by no means 100 percent complete.

### **First: What are the GOALS?**

A functional improvement...greater use of muscles, better sensation, improved bowel or

bladder function, an improvement in bed mobility, transfers, walking or wheelchair propulsion, or ADLS.

In some quadriplegic patients, gaining 1-2 spinal levels of function can make a HUGE difference in function. It can be the difference between feeding yourself independently versus having a caregiver feed you; between using a hoist lift for transfers and having someone assist you with slideboard transfers or transferring independently.

So, research is focusing on functional improvements rather than a complete and total cure. This means that we need to figure out how to make the nerves in the spinal cord grow about 2-3 centimeters!

However, the nerves we WANT to grow are the nerves that carry information about movement or feeling. We DON'T want to grow a bunch of nerves that carry PAIN information so researchers need to figure out how to avoid avenues that will regrow pain nerves.

### **Second: How does one BEGIN to figure out how to repair the spinal cord?**

There are four major areas of research:

- Decrease the laziness of the injured nerves
- Make the spinal cord less hostile to regrowth or learn how to build a bridge over the damaged area.
- Eliminate the hostile, unfriendly substances released by the damaged spinal cord nerves.

- Eliminate the hostile, unfriendly substances released by the scar that forms after injury.

**We understand the goals and the basics now...what about the details of published studies?**

Again, this is a complicated topic with lots of long, scientific words. If you have any specific questions, or this all sounds like we're speaking another language, ask one of your healthcare providers for further explanation.

**Decreasing laziness:** neurotrophins have been found to increase growth on nerves in the spinal cord, especially when combined with treatments that make the spinal cord less hostile

**Building a bridge across the damaged area of the spinal cord:**

- Peripheral Nerve or Schwann Cell Grafts: not so successful. The new nerves grew into the graft but then found the graft environment SO friendly, they refused to grow back out into the spinal cord and complete the bridge! Stubborn grafts!
- Olfactory Ensheathing Cell Grafts (OECs): The olfactory nerve (allows us to smell things) is the one nerve in the CNS that regenerates. These grafts have been highly successful. The new nerves followed the bridge that the graft made and grew over the damaged area of the

spinal cord.

- Embryonic Spinal Cord Tissue Grafts: when babies grow inside their mothers, the spinal cord nerves grow and become the adult spinal cord. Once this process is finished, these nerves lose their ability to regenerate. Implanted embryonic spinal cord tissue, given with neurotrophins (see "decreasing laziness"), has been successful. Of course, embryonic tissue and stem cell research has been a major cause of moral and political debate in this country. Many foreign countries are performing this research with less political debating.

**Eliminate the hostile substances released by the damaged spinal cord nerves:**

- IN-1 is an antibody that blocks the unfriendly substances produced by damaged spinal cord nerves. As an unexpected bonus, it also causes sprouting of nearby, healthy nerves, which can help take over the actions of the damaged ones.
- Procord: this study puts specially treated macrophages in the damaged area of the spinal cord. Macrophages are cells that act like little trash collectors at the site of an injury, cleaning up all the damaged cells and refereeing the immune response. Unlike the rest of the body, macrophages don't rush to the scene in the spinal cord so, in this study, researchers took it upon themselves to

put extra macrophages in the spinal cord with success and regrowth of the damaged nerves.

**Eliminate the hostile substances released by the scar that forms after injury:**

Chondroitinase promotes nerve regrowth by preventing the release of unfriendly substances produced by the scar formed on the spinal cord following injury.

So, in summary:

Nerve regrowth has been shown to a maximum of 4 centimeters, but most experiments show 1-2 centimeters or about 1/2 - 1 inch.

Most research has been done on rats. More studies will have to be done on larger animals that more closely resemble humans...monkeys, dogs, cats.

Then, clinical trials will have to be done (and currently are being done) on humans.

Great...I have all this knowledge about cells and nerves...**BUT WHAT ABOUT ME?**  
What does all this research mean for the future of people with spinal cord injuries?  
And who would volunteer for these studies?

Many studies require newly injured patients. However, sometimes, these study results can be difficult to interpret because, was the body just healing naturally or did the

researchers actually make a difference? So, researchers sometimes need newly injured patients, but they also worry about interfering with the natural healing process. And finally, the early phases of spinal cord injury are the best window of opportunity for nerve regrowth, so, this phase would be ideal in some cases to tap into the body's healing potential.

Not always quadriplegic patients...if an intervention was unsuccessful and a patient LOST a level of spinal nerve function, this could be utterly devastating to a quadriplegic patient who has very few functioning muscle groups as it is.

SO, except for Procord trials (which recruit anyone under a C5 level of injury within 14 days of their initial injury), many clinical trials will likely occur in patients injured 18 months or more with thoracic level injuries. If a patient with a T11 injury were to lose a spinal level as a result of a clinical trial, their functional mobility would be virtually unaffected. Thus, there is a much larger room for error at this level of injury.

## [FAMILY ADJUSTMENT]

Spinal cord injury is traumatic for the whole family. Everyone in the family will experience stress, not just the one who has been injured. You may have experienced change in many of the following areas:

- Relationships – physical, emotional, and sexual changes
- Personal time and space – may become smaller because of equipment as well as others now involved in care (therapists, doctors, nurses, personal care assistants)
- Caregiving – can become an intense responsibility with boundaries becoming more blurred as spouses/significant others perform personal care type activities
- Increased Anxiety – regarding infections, pressure sores, medical stability
- Finances – injury may bring about loss of income
- Social – injury may bring about increased isolation

It takes time to adjust to the stress and changes created by injury. Your family member needs your concern and support, but it will not help him or her for you to neglect yourself. Some things which may be helpful for you to remember are:

Your feelings of anger, sadness, confusion, fatigue, denial, guilt, and/or blame can be normal reactions to stress. Talking about your feelings and concerns can help you relieve stress and develop strategies for solving problems. Talk with close friends, your case manager, your minister and attend support groups.

You may try to push yourself to the point of physical or emotional exhaustion. This will not help you! Save your strength and energy for later when you can be more active in you family member's care. It's important that you get enough rest, have regular meals, take some time for yourself and resume your normal routine as much as possible.

Being "strong" does not mean taking everything on yourself. Consider accepting offers of help from other family members or friends. Let others sit with your loved one, fix meals, or run errands. This will help ease your stress and make others feel useful.

You need to recognize that other family members and work responsibilities will continue to need your attention. You may be uncomfortable being away from the patient. You must remember that you are helping your hospitalized family member by taking care of tasks that he or she cannot do right now.

Ask staff members to help you understand what is going on with your family member. Unfortunately, there are some questions that cannot be answered. You are likely to feel less frustrated if you talk openly with staff about your concerns.

You may try to do everything for your family member just because you love him or her. It is important that he or she do as much as possible for him or herself. This will help him or her to progress more quickly.

Remember that in order to be helpful to others, you need to take care of yourself.

## [HELPING YOUR LOVED ONE MEANS HELPING YOURSELF]

by Richard C. Senelick, MD  
from SCI/Life

If you don't know how to help yourself, how can you know how to help anyone else? –  
Anonymous

“Okay, I admit it. Sometimes I hate my husband and his spinal cord injury. I am so tired of taking care of him!”

“There are so many things I have to do, from bathing and grooming to feeding, that there's no time left in the day for me!”

“When I close my eyes, I dream of freedom. No one to care for, no one to help. Just me.”

“I'm losing patience with my wheelchair-bound wife. I know she's depressed. I know she can't help herself. But I get angry- and then comes the guilt. A vicious cycle.”

“Call me selfish, but I need some space! Is there anyone out there who can help me?”

These are not the words of tyrants or evil villains. They are the voices of regular people, ordinary people like you and me, who happened to receive a terrible blow: The person they love, their soulmate, husband, wife, friend, had an accident which left them with a spinal cord injury.

Suddenly, their world and their place in it, has turned upside down. It's as if the accident had happened to them. But it didn't. And, somehow, somehow, these

ordinary people, the heroes of everyday life, must find the strength, the energy, and the courage to help their loved one not only to get through the rough spots-but the day-to-day routines. Are you looking? Do you see them? Probably not. Most of us are understandably focused on the person with the spinal cord injury. But these people need help, too. This column is devoted to the caregiver, who is also in pain, to help them find and maintain the compassion, love, and resilience they need to do their best for their loved one.

### A DIFFERENT SCENARIO

Susan had always considered herself a caring person. She was always ready to help her co-workers at the bank; she helped her mother with her chores. She volunteered for almost every committee at her son's school. As busy as Susan was, her husband Dave, was even busier. He not only shared the household chores with his wife, but he, too, worked full-time as an account executive at a local advertising agency. They took family vacations together; he coached his son's Little League. But as filled as Susan and Dave's life was, they always managed to grab a few hours here and there for a quiet dinner out, for a movie. All in all, Susan felt blessed with her life- until it all fell apart with one wrong turn on a dark street.

Dave had been coming home late from work; he'd been working on a presentation that was due the next day. He didn't see the

car whose intoxicated driver neglected to see the stop sign on the corner. The car collided; Dave ended up with a C5-6 spinal cord injury. He needed to learn new skills for getting around, for his activities of daily living, for functional independence. After six months of rehabilitation, the injury was behind him. He had made progress in using his wheelchair; he had his bladder and bowel program down to an efficient routine; he had become a whiz on the computer. Susan had been there, rooting for him, the entire time Dave had been in the hospital. She'd given him the hope and inspiration he'd needed to get through the rough emotional waters. She, too, had gone into therapy to learn how to cope with her new life, to help her plan a new life for her family.

Susan knew that she'd have to curtail some of her volunteer work. Although they could afford a part-time personal care assistant, she still had to take care of grocery shopping, the laundry; she had to add an hour to any scheduled engagements to help Dave get dressed, to help him maneuver. There was the budget to consider. Although Dave was doing well as a consultant, working at home via his computer, he wasn't making as much as he had done at the office. To cut corners, Susan quit her therapy. She also wanted to spend more quality time with their son; he'd begun acting out at school when his father had come home.

Things started to pile up. First it was only dirty clothes and dishes. But the more the

school called Susan about her son, the more Dave asked her to come upstairs and help him, the more bills the postman dropped off, resentment, anger, and depression were added to the pile. Susan was becoming overwhelmed. She began to scream at her son – and her husband. She'd run out to the car and roar out of the driveway without telling anyone where she was going. She never went far. Susan would end up at a mall, or an office parking lot, or a street nearby. She'd sit, her head on the steering wheel, and cry. And cry. Her sobs would fog up the windows. The guilt, the resentment, and the anger were almost palatable. Her once perfect life had turned into a nightmare.

## STRESS , STRESS AND MORE STRESS

Susan's uncontrollable spiral down to overwhelming despair didn't come out of the blue. Although she might be eternally grateful that her loved one is alive, most likely, she, too, has had all-too-human feelings of resentment, anger and their accompanying guilt as the pressures mount.

Think about it. Her world, too, has changed dramatically. Her relationship with her loved one has changed – physically and mentally. Her personal time and space has gotten smaller – as a direct result of the spinal cord damage done. Her friends and family might have good intentions, but they can't completely understand how it feels to have

your sex life, your bathroom routines, your personal time so completely different – and out of your control. There is the endless worry, the financial fears, the burden of responsibility, the anxiety that your loved one might develop an infection, a pressure sore, or autonomic dysreflexia.

Social isolation. Continuous anxiety. A lack of boundaries. Traumatic change. All these contribute to an unbearable feeling of psychic pain. Out-of-control and out of your element, you might find yourself sinking into a terrible depression-where no one gets better. Although these feelings make sense, they don't have to be a fait accompli. They are not etched in stone.

It doesn't have to be this way.

#### HOPE: FUEL FOR THE SOUL

Fortunately, Susan's story has happy ending. She finally realized that she couldn't handle the stress on her own. She joined a support group which helped her find new resources: a quality therapist, discount supplies, and a wide network of new friends. Susan was no longer alone. She had people around her who understood. Her stress levels relieved, Susan was able to handle her responsibilities at home. Everybody benefited.

Although Susan's story is not an unusual one, not every one ends on an uplifting note. Many caregivers do not get the help they need. They become more and more

depressed until they flee or get mired down in a life of despair – all the while the person with the disability they'd once loved feels trapped, angry, hopeless, and resentful as well.

Your situation doesn't have to have the sad ending. You can be an excellent caregiver – without giving up your life. You can be loving and compassionate-and selfish. Everyone can wind up happy. Here are some suggestions, "caregiver credos" that have helped many of our family members:

#### CAREGIVER CREDO #1: TIME OUT!

The phone doesn't ring when it's convenient for you. Your job doesn't start when you feel like coming into the office. You don't get a cold or flu when you could use a few days off. Never! Life's routines, its vicissitudes, its comings-and-goings, are not governed by you-unless you grab some control for yourself.

Making time for yourself is a way of gaining that control-which is especially important if you are a caregiver. When you are administrating to someone else's needs, it's easy to forget yours. Time has a way of slipping through you fingers as you make dinner, transfer your husband or wife from wheelchair to bed, as you deal with all the other daily odds and ends.

Arrange for a personal care assistant to come over for a few hours in the morning or

afternoon, whichever time is best for you. Use this free time selfishly and completely for yourself. Put the answering machine on and turn off the phone's ringer. Take a bath or use this quiet time reading or taking a nap. Learn how to meditate. If it's a beautiful day and the house is feeling cramped, get out! Go for a walk or a massage. Get your hair done. Take a class in a subject you've always wanted to learn: watercolor, pottery, or even 18th century English lit! Whatever. The important message in this credo is the medium: you. It's your time out to refuel, replenish and, regroup.

#### CAREGIVER CREDO #2: A PHYSICAL LABOR OF LOVE

It's not just the disabled person who needs to exercise and eat right. You do, too. More and more people are beginning to realize that it's not enough to study hard and work the brain. Your body needs muscle, too. A sound body will help calm your mind. Exercise not only help relieve some of the frustration and stress you feel, it also makes you stronger—and better able to handle the physical aspects of your care giving role.

Eating a well balanced, nutritious diet will also help keep your strength up—and your stress levels down. Sugar may make you jittery—a quick surge and an equally quick slump. Better to eat complex carbohydrates, such as whole grain breads, sweet potatoes, rice, protein and plenty of sweet fruits and

vegetables. You'll get the vitamins, minerals and fiber you need—without the “sugar drop.” Suddenly, you'll also find that you are able to make that bed with gusto, tell a funny joke and really laugh, and help with range-of-motion exercises with a lot more energy than you ever thought you had!

#### CAREGIVER CREDO #3: EDUCATION IS POWER

In this column we have frequently talked about the strength found in knowledge. If you've learned nothing else from these columns, we hope you'll have taken away the need for more information, for education. Individuals with disabilities need this knowledge in order to facilitate the rehabilitation process. The more that know, the better it will work—and the more motivated they will stay.

The same goes for you. Take advantage of your loved one's rehabilitation center. Ask your case manager and other on the rehabilitation team any questions you might have. Don't be embarrassed; they've most likely heard it all before!

Join a disability network, such as the National Spinal Cord Injury Association, National Stroke Association, or the Brain Injury Association. They can find you good sound advice on everything from personal care assistants to financial aid.

Read this column regularly—and others. Learn as much as you can. The more you

know, the better you'll understand—and the stronger you will feel.

#### CAREGIVER CREDO #4: THERAPY

A good counselor to help you discover coping strategies is vital for your well being—and, ultimately, the well being of your loved one. Your rehabilitation hospital can help you find someone who specializes in the needs of survivors and their caregivers. In fact, a good rehabilitation hospital will have a counselor on staff as a part of the team.

Support groups are also part of the therapeutic process. You are not only among people who understand what you are going through—they are going—they are going through it themselves! Support groups can help relieve your isolation. They can act as a “pressure cooker valve,” giving you a chance to vent your feelings.

Even more important: a support group made up of your peers will be a valuable resource for you, a place to share and find out information. You'll be able to find out, firsthand, if a particular personal care assistant is good, if a certain van is the best buy for the money, if the contractor you found to add handicap features to your home is reliable.

These are only a few “caregiver credos,” but they all come down to one thing: are you taking care of yourself. Take a moment and think about it. Use your common sense—and your instincts. What do you want to do? How can you fit it into your life? Remember, if you aren't making yourself happy, you won't be any good to anyone else. No one likes a martyr—especially the survivor who loves you.

## [PERSONAL ASSISTANCE SERVICES]

When you incur a severe disability, you must come to terms with many issues. You may need to rely on others to accomplish the basic tasks of daily living. Independent living is encouraged, but what does this mean? Because of physical limitations you may be unable to do certain tasks. Does the fact that you will have to rely on others to meet some of your needs mean that you have failed at independent living? Not at all. Many people with no injury or illness rely on others to fulfill needs. Thus, independence should be seen as being able to control what is done, how it is done, who does it, and when. A personal assistant is there to provide physical assistance with tasks you are unable to do on your own. You make the decisions and the assistant provides his or her physical ability. The use of personal assistants to meet your needs in no way takes away from your independence. Several types of assistance services are available:

- Personal services – including assistance with bathing, personal hygiene, bowel and bladder care, dressing, grooming, transferring, feeding and giving medications.
- Household services – including assistance with meal preparation, shopping, cleaning and laundry
- Communication services – including assistance with reading and writing
- Mobility services – including escort and driving services

## NEEDS INVENTORY

Communicating your needs clearly is very important when working with an attendant. To communicate clearly, you must be specific and make sure your needs are as well defined and as detailed as possible.

## PERSONAL CARE NEEDS

- Bathing:  
Type of bath (shower, bed bath, set-up)?  
How often? What time of day? How long does it take?
- Dressing:  
Complete help? Partial help? Special considerations? How long does it take?
- Bowel care:  
Type of bowel program, if any? How often? Time of day? How long does it take?
- Bladder care:  
Type of bladder program, if any? How often? Times of day? How long does it take?
- Toileting:  
Bedpan, bedside commode, toilet?
- Eating:  
Other than meal preparation, any special help? Special diet?
- Transferring:  
Type of transfer? When needed? Special considerations?
- Medication:  
Type? How often needed? Who administers? Attendants may or may not be able to assist with this.

- Exercises:  
Type? How often? How long does it take?

## H O M E M A K I N G N E E D S

- Laundry:  
How often? Where done?
- House cleaning:  
How often? How many rooms? Specific chores?
- Meal preparation:  
Times of meals? Who will plan?
- Grocery Shopping:  
How often? Where? Who will go?

## O T H E R N E E D S

- Job or school:  
Schedule of work or classes? Help needed?
- Social needs:  
Activities? Help needed?
- Financial:  
Help with banking, checking, or correspondence?
- Transportation:  
Special equipment needs, equipment maintenance?

Because you will be working so closely with an attendant, it is important that you have not only a clear understating of your needs, but also an awareness of your own personal habits and skills. For example:

- Do I smoke, drink, or take drugs?
- Do I like to sleep late in the morning or get up early?
- What time do I usually go to bed at night?

- Will I want to entertain friends in my home?
- What hobbies do I have?
- Do I like a quiet atmosphere?
- Is there a spiritual aspect to my life that is important?

## T H E J O B D E S C R I P T I O N

Before you begin the advertising and interviewing process, you must know the kind of help you need. You should list your needs, such as dressing, using the bathroom, and washing as well as cleaning and washing the car, mowing the lawn, or defrosting the freezer. Include all your needs and what you expect from the personal assistant. This list will be part of the job description. A complete job description includes these six sections.

**Job Title:** The title “personal assistant” is used most often. Other titles may be personal care attendant, companion, homemaker, or driver.

**Summary of Work:** This is a brief description of the type of services you need.

### **Qualifications for a Personal Assistant:**

When you interview a person for the job, these are some qualifications you may want to consider: certification, training and/or experience; dependability; respect for you and your property; cleanliness; drug and alcohol use/history; physical strength; and ability to follow directions.

**Duties:** This is where you will include the complete list of your needs.

**Schedule:** You should list the hours you want your assistant to work. Also, set up a system to make changes in the schedule.

**Salary:** You have three choices: list a set salary, list a salary range, or state that the salary will be based on qualifications and experience.

## OPTIONS FOR FINDING PERSONAL ASSISTANTS

When you are ready to use personal assistance services, your first task, after learning what kind of help you need and for how many hours, is to find assistants. The use of hired personal assistants, rather than nurses or family members, will afford you the most control. Nurses have been trained to perform tasks in a set manner and may be unwilling to take directions from you. They may also feel that household tasks are not their professional job. Family members may tend to take control and resist your input. They may do “for you” instead of doing “with you.” A hired assistant must take directions from you or be fired. You can choose to hire through an agency, or you can advertise on your own.

## HOME HEALTH AGENCIES

Home health agencies often provide personal assistants, as well as nurses. There are many good reasons to use an agency. First, they can provide an assistant within several days of your request. Second, they can provide backup assistance on an emergency basis. Third, agencies are a good choice if you are unsure about training and directing your own assistant. You will also not have to handle the financial details. However, there are bad points to using an agency. You will be giving up much of the direct control over your assistant. The agency nurses will train and manage your assistant. You may be seen as a patient, rather than an employer. Another bad point of using an agency is the high cost. You can expect that the cost will be about twice that of hiring an assistant on your own.

## HIRING PERSONAL ASSISTANTS ON YOUR OWN

If you decide that you want to hire on your own, there are many issues to think about:

- How many hours of help do you need?
- Do you need a person who lives nearby or has his or her own transportation?
- Do you need a driver?
- Do you want a male or female personal assistant?
- Do you need personal care, homemaking, or both?

- Can you offer room and board in exchange for personal assistance?
- How much can you pay?

After thinking about these points you may want to try a “word of mouth” approach. For example you can speak with friends, neighbors and professionals. Consider the following resources:

- College job placement office and/or training programs such as PT, OT and nursing.
- Local bulletin boards in supermarkets, libraries, churches and other public places
- Hospital and nursing home bulletin boards
- Local newspapers
- Local independent living centers for the disabled
- State unemployment offices
- County or local offices for the disabled

If this does not work you may consider placing an advertisement. It is important to keep the advertisement short and to the point. Remember, the more you publicize the job, the more responses you will receive and the better your chance of finding the right assistant to match your needs.

## INTERVIEWING

The interview process should have two steps: a short telephone interview to see who might be good for the job and a face-to-face interview to make your final choice.

## THE TELEPHONE INTERVIEW

This is an important tool that can help you save time and energy by ruling out those not suited to your needs. When a person calls in response to your advertisement, give the key information: the schedule you will need, the salary you are able to pay, and a list of your needs. Ask other questions as needed.

If you decide to interview the person, ask the applicant to bring the following:

- Proof of citizenship (birth certificate, passport, etc.)
- Proof of address (driver’s license, utility bill)
- Social Security number
- Two references

## THE FACE - TO - FACE INTERVIEW

Keep a record of each person, including name, address, phone number, good points, bad points, and your overall view. The list can be helpful in the future. When the person arrives, begin the interview in a friendly manner. Have a list of questions ready to ask the applicant.

Get to know the person. Discuss the person’s work experience. Length of time on each job is helpful for showing dependability. Discuss his or her personal history and habits, such as social problems, health problems, hobbies, driving record, criminal convictions. Discuss transportation issues and their other responsibilities.

Keep in mind the qualities you like in other people. This person does not have to become your best friend, but should be someone you can like and respect. Most likely you will want them to be punctual, trustworthy and honest, able to follow instructions, comfortable with following a routine, good natured and patient. During the interview, you should do the following:

- Let the person get to know you. Talk about your disability and your needs.
- Describe the job in detail.
- Ask the person's thoughts about these duties.
- Review the person's transportation needs.
- Ask for references.
- End by describing your hiring process.

## MAKING THE JOB OFFER

You might hire an individual for a few days on a trial basis. This gives them a chance to see if the job is really what they want. It also gives you time to see how you get along.

Once ready to hire someone, have a written contract that specifies the job duties, hours of work, days off, wages and reasons for termination. Both parties need to agree to the terms of the contract.

## EMERGENCY BACKUP ATTENDANT CARE

What do you do when you suddenly find yourself without an attendant? This can be one of the more frightening, disconcerting, unnerving, anxiety-producing situations anyone can face. Planning ahead is the answer.

An attendant is unlikely to be healthy and able to work 365 days per year. Therefore, it is essential that you have an available list of people to call in an emergency. To prepare for the time when for any reason, you find yourself without an attendant, you can take certain steps:

- Take time to review what your essential personal care needs are and prepare a brief description of these needs
- Develop a list of people who can be available as emergency backup attendants for you – family, friends, former attendants, etc.
- Develop a short, descriptive letter to recruit other emergency back up attendants that can be sent out quickly if needed.
- Update your information and backup lists about every six months.

## COMMUNICATING WITH YOUR ATTENDANT

Learning good communication skills and using those skills are keys to working effectively with an attendant. Attendant work is usually not well paid and offers few, if any, fringe benefits. Therefore, those who take this kind of job often do it because it has other rewards, such as personal satisfaction or a chance to work closely with other people. That makes the work environment an important factor in keeping your attendant.

Good employers create a work environment that will bring out the best an attendant has to offer. To create a good work environment: reward your attendant for the work they are doing. Besides paying them it is important to praise them frequently, as well. When you must criticize something your attendant has or has not done, it is important to be open and honest and to criticize the action, not the person. Don't let small irritations build up until an angry explosion occurs. Respect your attendants. Attendants have their own lives too; respect their privacy, leave them alone during their time off, and realize that unexpected events sometimes disrupt their schedules. Ask your attendant how he or she feels about the work and about you as an employer. Set a regular time to share feelings about your relationship.

When things don't work out even after repeated attempts, it is time to terminate the agreement. There are good and poor ways to do this:

- Do state your reasons clearly without attacking him or her personally.
- Do give a period of notice, usually two weeks.
- Do not withhold payment of wages even if you are not satisfied with his or her work.

## WHO PAYS FOR PERSONAL ASSISTANCE SERVICES?

**Healthcare Insurance:** Most insurance policies **DO NOT** cover personal assistance.

**Auto Insurance:** In certain states, no-fault auto insurance may help pay for personal assistance if you are injured in an automotive accident.

**Medicare:** Over the years, Medicare has greatly decreased the amount of home care it provides. Home health aide services are limited to 3x/week and aides will come out only to assist with bathing and dressing tasks for as long as it takes to complete those tasks. Home health aides typically **DO NOT** provide housekeeping, cooking or cleaning assistance.

Medicaid: North Carolina has a Community Alternatives Program for Disabled Adults (CAP/DA) run through Medicaid that can provide up to eight hours of assistance/day. PCA services are also available and are similar to home health aide services through Medicare.

Department of Veterans Affairs (DVA): While the DVA does not directly provide personal assistants, there are two benefits that may assist you.

Aid and attendance benefits: The DVA will provide more income than your pension if you need assistance. If you were not injured in the service, this amount is minimal and will not be enough to cover the cost of your care.

Fee based benefits: If you are receiving a pension and have nursing needs, such as assistance with bowel and bladder care, the DVA will pay for services to meet these needs.

Crime Victim's Compensation: Some states provide compensation to victims of crimes. This could include cash and/or services, such as personal assistance.

Workers' Compensation: May cover some expenses related to personal care services as approved by Claims Adjustors and Workers' Compensation Case Managers.

Source: Schust, Christina S. Ed., Spinal Cord Injury: Patient Education Manual. Aspen Publishers, Inc., Gaithersburg, MD 1997.

**[PERSONAL CARE NEEDS WORKSHEET]**

Personal Care Needs	Issues to Consider	Patient Care Needs	Special Considerations
Bathing	Type; how often; time of day; how long		
Dressing	Complete or partial help; how long		
Bladder Care	Type of program; how often; time of day		
Bowel Care	Type of program; how often; time of day		
Toileting	Bedpan; Bedside Commode; toilet		
Eating	Special diet; special equipment		
Transferring	Type of transfer; special equipment		
Medications	Types; how often; who administers		
Exercises/ Range of Motion	Type; how often		
Laundry	How often; where done		
Housecleaning	How often; specific chores		
Meal Preparation	Times of meals		
Grocery shopping	Who will go; how often		
Transportation	Special needs; reservations		

[CAP-DA]

**Community Alternatives Program for Disabled Adults**

Disabled persons who are currently receiving or have filed for Medicaid can apply for CAP funds. Depending upon the level of care needed, CAP can provide up to eight (8) hours of assistance in the home. This includes therapy, nursing, nursing aide and other services. For further information or to get on the waiting list, please contact:

CHATHAM COUNTY (919) 542-8220

CUMBERLAND COUNTY (910) 677-2388

DURHAM COUNTY (919) 596-5076

EDGECOMB COUNTY (252) 641-7518

FRANKLIN COUNTY (919) 496-5721

HARNETT COUNTY (910) 893-7596

JOHNSTON COUNTY (919) 989-5300

NASH COUNTY (252) 641-7518

ORANGE COUNTY (919) 245-2882

WAKE COUNTY (919) 872-7933

## [WHAT IS THERAPEUTIC RECREATION?]

**Therapeutic Recreation** (also known as Recreational Therapy) uses leisure and recreational activities to help meet the personal needs of patients in their effort to recover and return to their previous leisure lifestyle. The Therapeutic Recreation program addresses all aspects involved with a patient's leisure lifestyle, including social, emotional, mental, and physical. The program is goal-directed and personalized to meet each indicated patient's needs. The TR Department promotes and encourages patient independence, positive leisure choices, diversified interest, and FUN!

Therapeutic Recreation involves:

- Skill Development – helps the patient learn skills/abilities needed to participate in old or new leisure interests.
- Adaptive Equipment – specialized equipment that will allow a patient to participate in leisure activities.
- Leisure Education – increases the patient's knowledge of leisure activities including attitudes, beliefs, values, opportunities, and resources.
- Lifestyle Management – helps the patient identify strengths and needs of his/her personal leisure lifestyle and ways to improve it.
- Barrier Education – allows the patient to identify potential obstacles to home/community re-entry.
- Community Re-Entry – gives the patient an opportunity to access the community before going home.
- Diversional Activities – beneficial games, special events, activities that help the patient pass the time while in the hospital.

## [NUTRITION IN SPINAL CORD INJURY]

After a spinal cord injury your body systems such as bowel, bladder and skin have been altered due to paralysis. You may need to change your intake of fiber, fluids, or other nutrients to help correct or prevent any problems. Eating the right amount of foods each day provides your body with all the nutrients it needs. A well balanced diet is important for:

- Good health
- Healing process and rebuilding
- Preventing illness and skin breakdown
- Proper body weight
- Good bowel function

### A WELL BALANCED DIET

How much food do you need to eat every day? Here is a guide to choose a well balanced diet. Each day should include at least:

- **Meat or Meat Substitutes**

*2-3 servings of a good protein food*

Protein, Vitamins, and Minerals for strong muscles, healthy blood, and repair and building new cells

Select from meat, fish, poultry, eggs, egg substitutes, soy, dried beans peas, nuts

\* To limit saturated fat and cholesterol in your diet avoid fried foods, choose lean cuts of meat, trim fat and remove skin, limit egg yolks to 3 per week.

- **Fruits/Vegetables**

*5 servings of fruit and vegetables*

Minerals and Vitamin C to keep you trim and for healthy skin, eyes, and gums

Be sure to include yellow and green vegetables (Vitamin A) and a food sources high in Vitamin C such as citrus fruits, strawberries, tomatoes

- **Milk**

*2-3 servings of milk products*

Protein and Calcium for strong bones, teeth, and muscles

Select milk, other foods made from milk, soymilk fortified with calcium

- To limit saturated fat and cholesterol in your diet choose low fat or skim milk products, non-fat or low fat cheese or yogurt.

- **Bread/Cereals/Grains**

*6-10 servings bread and cereal products*

Vitamins and minerals, fiber, energy for the body

Select whole grain breads, high fiber cereals, brown rice, bran, oats, whole wheat pasta

- **Fluids**

*8-10 glasses spaced throughout the day*

Hydration, healthy skin, digestion, prevents bladder and kidney stones, and urinary tract infections)

Make water your Number 1 choice

- **Fats and sugar**

Use sparingly especially to lose weight

## MAINTAIN A HEALTHY WEIGHT

After a spinal cord injury weight loss and muscle loss are common. At first, the spinal cord injury puts stress on the body and this means the body burns calories faster. Muscle mass is lost which causes additional weight loss.

However, there seems to be a tendency to gain weight over time due to changes in lifestyle and activities. With less physical activity your body burns fewer calories, resulting in weight gain.

If you are underweight or eat poorly this is not good for you. You may be more susceptible to infections, skin breakdown, and decreased strength.

If you were already overweight before your injury, the same is true. It may be difficult to lift yourself or be lifted from place to place, and this puts you at risk for heart disease and other health problems.

Your body may carry, gain, or lose weight in a new way than it did before. If your weight becomes a problem, talk with your dietitian. Balancing the right amount of calories you eat with the calories you burn is the key to maintaining a healthy weight.

## PROTEIN

Adequate protein intake is important to help prevent tissue muscle breakdown. Protein is especially important to heal a pressure sore. Open pressure sores can involve tissue fluid loss, which will cause increased protein loss. If you have a pressure sore you will need to eat foods high in protein. A blood test can determine if you need to increase protein in your diet. A nutritional supplement may be recommended to increase your protein levels. Here is a list a high protein foods: (Figures are approximate)

Item	Serving Size	Grams
Meat, poultry, fish	3 ounces	21
Egg	1	7
Dried Beans & Peas	1/2 cup	7
Peanut Butter	2 Tbsp	8
Peanuts	1 ounce	7
Milk	1 cup	8
Cheese	1 ounce	7

## F I B E R

Dietary fiber and plenty of fluids helps promote normal bowel function and prevent problems of constipation and diarrhea.

Foods high in grease and fat may make it difficult to regulate your bowel program.

Aim for 25 – 35 grams of fiber every day.

Add it slowly. Replace low fiber foods with high fiber foods a little at a time. This will give your digestive tract a chance to adjust.

Drink more fluids when you eat more fiber, otherwise fiber can be constipating.

Dietary fiber is only found in plant foods – fruits, vegetables, nuts and grains. Most refining processes decrease fiber in food. For example, whole wheat bread contains more fiber than white bread and a fresh apple contains more fiber than apple juice. Look for the words 100% whole grain or wheat on the nutrition label when purchasing whole-wheat foods.

The following is a list of high fiber food choices:

- Fresh fruits and vegetables (including the skin)
- Dried beans and peas (cooked)
- Bran or bran cereals
- Oatmeal
- Bran or whole wheat muffins
- Whole grain bread, crackers, rolls
- Other whole grains (brown rice, oat bran, wheat germ)

- Popcorn
- Raw nut and seed mixes with dried fruits (trail mixes)
- Whole-wheat pasta
- Prunes and raisins

## F L U I D S

The amount of fluid you drink is important. You need to understand how much fluid to drink each day to manage your bladder program. Fluids are important to prevent dehydration, prevent the formation of kidney stones or bladder stones, and prevent urinary tract infections (UTI). Drink extra fluid when you have a pressure sore that is draining. A high fiber diet needs adequate fluid to prevent constipation or impaction.

A high fluid intake is recommended to treat urinary tract infections (UTI).

Water is the best. You can also drink cranberry juice (regular or reduced calorie). Cranberry juice makes the bladder wall slippery so bacteria cannot stick to it and multiply. Remember to space your fluids throughout the day.