A Guide For Family and Friends

Discharge Informational Packet

- Spinal Cord Injury -

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A. Department of Health (DOH)

A Guide for Family and Friends

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Discharge from the Hospital

Prior to discharge...

- Ask that copies of the injured person's **records** and **test reports** be sent to your family doctor or clinic.

- Ask for a set of these records and reports for **yourself** in case you need to refer to them in the future when seeking services.

- Make sure you understand verbal and written **instructions for medications and ongoing care.**

- Are there any restrictions or precautions?

    - Is there a special diet the person should be on?
    - Are there things to be avoided such as alcohol, smoking?
    - What supports or treatment to the injured areas should you provide?
    - Does the person need to avoid bending, lifting, sports, exercise, or other strenuous activities; for how long?
    - Ask what kinds of activities are safe at home or in the community (such as driving, operating equipment/tools, working, traveling)? Remember: avoid further injury by wearing a safety belt in the vehicle, any appropriate headwear and use overall caution.

- Ask for informational materials or handouts.

- Ask the doctor if there are any **signs/symptoms** in the next two weeks you should watch for and if observed should you call the doctor or go to the emergency room?

- Determine whether the person needs to be seen by their **primary physician or clinic** and how soon for any new or current problems.

- Ask what **specialty professional services** will be needed, for what reasons and the potential benefits.
- Schedule **follow-up appointments for tests and services** in your community before leaving the hospital or trauma center.
- Discuss with the hospital's case manager or social worker, the patient's **progress and potential needs** and identify any other **supports and services** that may be available after discharge.
- Determine which ones the person may be eligible for, inquire and apply immediately. Ask for additional information and resources.
- **If a child is injured**, inform the teacher/school about the injury and any changes in the student.
  - Based on information from your doctor, inform the teacher whether it will take a few weeks for usual functioning and behavior to return or whether it will take longer.
  - For serious brain injuries, you should consider asking if a DOE TBI Consultation Team can be involved. Upon the return of the child to school, ask the teacher to report any problems.

Discharge to...

There are several types of nursing facilities.

- **Skilled (Nursing) Care**: extensive nursing care and daily therapy.
- **Acute rehabilitation**: an inpatient program of intense therapy in a hospital. The patient actively participates in several hours of therapy per day (i.e. physical, occupational, speech-language, cognitive, hearing and activity therapies). Some rehabilitation facilities may come to the hospital to see the patient and their medical record before they decide to accept the patient. If accepted, the date for transfer or discharge is set.

- **Intermediate care** provides less extensive nursing care and therapy than skilled nursing; and more extensive nursing care than residential or home care. Such intermediate care facilities exist only in some communities in Hawaii.

- **Residential care** is for those who are fairly independent and not in need of routine nursing care or therapies.

- There are also **assistive living** alternatives to consider such as adult residential care homes (ARCHs) or Extended ARCHs for those needing some supervision, care and assistance with daily living activities.

Discharge to Home...

If the patient goes home, they may still need therapy or other care. Some of the options are:

- **Outpatient therapy:** provided at hospitals, clinics, offices and some nursing homes. The patient needs to be transported to and from home. Outpatient physical therapy will help build up strength and endurance in training sessions several times a week. Others such as occupational therapy, speech-language therapy, physical therapy, cognitive therapy or auditory training may be needed.

- **Home health care** service programs are also available. Some of the services they offer include in-home nursing care, homemaker and health aides, meals-on-wheels, adult day care, home therapy visits, medical equipment rental/ purchase, and transportation.

Making Choices...

- The physician and health care team will make recommendations at discharge about the kind of care the patient will need after discharge. Then the patient and family will choose the agency or individual that is to provide the services.

- Choices might likely be based on insurance coverage, location, the patient's prognosis (potential of recovery), and the patient's or family's feelings about the services provided and the availability.

Insurance Coverage...

- How are your medical expenses being paid? Below are some of the types of insurance policies covering medical care:
    - o Motor vehicle insurance
    - o Personal injury insurance
    - o Health plan
    - o Worker's Compensation or Temporary Disability Insurance
    - o Personal medical insurance plan
    - o Company disability plan
    - o Long-term Care
    - o Other?

- Inquire if the hospital case manager or social worker is familiar with the individual's insurance policy(s) or plan(s), or call the respective insurance company representative. If your injured family member is employed by a company that has a personnel officer, you can also make inquires with that person as well.

- Having found out what insurance policy will be providing immediate medical care coverage, are there any out-of-pocket expenses that will need to be paid by the individual or a family member?

- If the discharge plan indicates a severe injury, slow recovery and need for extensive specialized therapeutic services, find out the limits of the current insurance coverage and what other insurance policies/plans the individual has which would cover additional treatments, staffing or medical supplies. Contact the respective insurance company representative for detailed information.

Hawaii's Living Wills; Advance Directives...

- On being admitted into most island hospitals or a trauma center, admissions staff will inquire if the individual has made a living will or an advance directive. According to Hawaii State Law, the individual has the right to make their own health care decisions. This instruction may be oral or written. The instruction may be limited to take effect only if a specified condition arises.

- Hawaii's Chapter 327E of the Hawaii Revised Statutes contains "Uniform Health-Care Decisions Act" with information on the Advance Directive or is available at website: http://www.capitol.hawaii.gov/hrscurrent/Vol06 Ch321-344/hrs327e/
- A copy of Hawaii's Advance Directive is available through the State's Executive Office on Aging or their website at http://www2.state.hi.us/eoa/elder/advance directives.html

Guardianship in Hawaii...

- "Guardianship is a legal means of protecting children and incompetent adults who cannot take care of themselves, make decisions that are in their own interest, or handle their assets."
- "Whether to seek appointment of a guardian is a complicated question. A petition for guardianship should not be filed simply because a child has reached the age of eighteen. Parents, or other potential guardians, should carefully consider the disabled person's individual circumstances, including strengths and weaknesses, needs and best interests, before beginning a competency proceeding. If the person is disabled but capable of making some but not all decisions, one or more of the alternatives to guardianship…should be considered, including a modified or special guardianship."

- Spain, Spain & Varnet, P.C.

Family Finances...

- Make sure you have **adequate finances** to cover expenses in the next few weeks and beyond.

- Determine what kinds of **income, benefits and resources** will be available.
- Are there **loans or bills** that need to be paid in the next few weeks?
- Are there **legal matters** that need to be addressed?

What You Should Pay Attention To...

- **To help you organize your thoughts**, you are welcome to use the **NOTEPAD** on the reverse side.
- **Get whatever information** about the injury you can so you will know what to expect and how you can help. This is an ongoing process even after leaving the hospital, because as more things are discovered about the injury, your efforts to educate yourself also continues.
- **You should plan to research what this injury is about when you have time.** This packet should help you get started. You can ask your doctor what you should look up or be informed about.
- **Be patient.** There is a great deal that won't be known right away. It takes time for the extent of the injury to be understood as the healing process continues.
- **If you are on medications,** remember to take them as prescribed by your physician.
- **Take care of yourself.** You are under a lot of stress. Get adequate rest, eat healthy and ask for help from others who can support you, such as family, friends, your religious or spiritual group or neighbors. By taking care of yourself, you are in a better position to support your loved one and better state of mind to make decisions as they come along.
- **Creating a phone tree** - being flooded by calls is something most families want to avoid so they may designate one person whom others (friends, outsiders, etc.) can call to make inquires from.
- **Rotating visitors** - depending on your family situation, some families rotate visits among themselves to take the stress and strain off one particular member or to afford each member and their respective families private time with the patient.

Date:

Things I need to do for the Injured Person	Things I Need to Do for Myself
Things I need to ask about or check on: Doctor/Nurse? Case Manager/Social Worker? Insurance company representative? Contact work place or school? Family Member or Friend?	Things I need to check on or take care of: Any medical records or documents you need to bring from home? Any unfinished business at work? Request for vacation time? Any unfinished matters at home? Are all appliances and the stove turned off? Any bills that need to be paid? Any appointments, pick-ups or meetings that need to be cancelled or changed?
Things I need to do for injured person <u>now</u>:	Things I need to do for myself <u>now</u>: Drink fluids/eat? Take medications? Contact doctor/friend/family member/lawyer?
Things I need to do as soon as possible:	Things I need to do for myself, as soon as possible: Get rest? Eat regularly. Change of Clothing?
Things I need to do, but are not urgent:	Things I need to do for myself, but are not urgent:
Deadlines to keep in mind:	Deadlines to keep in mind:

Characteristics of Spinal Cord Injury

Each individual is unique and so is each spinal cord injury. The impairment may be temporary or permanent. You can use this as a checklist to identify problem areas at the time of initial injury as well as to monitor changes that may occur over time.

Physical

- ☐ Muscle paralysis (loss of control over voluntary movement and muscles of the body).
- ☐ Loss of sensations such as touch, pressure, and temperature.
- ☐ Pain.
- ☐ Loss reflex function below the point of injury, including autonomic activity such as breathing.
- ☐ Loss of bowel control.
- ☐ Loss of bladder control.
- ☐ Decrease of breathing capacity; the elimination of the smoking habit is essential for survivors.
- ☐ Loss or impaired cough reflexes.
- ☐ Muscle spasms.
- ☐ Exaggerated reflexes; spasticity (abnormally strong muscle contractions).
- ☐ Sexual dysfunction (may develop over time).
- ☐ Bladder infections (as secondary medical problem).
- ☐ Susceptibility to lung and respiratory infections and diseases (as secondary medical problem).
- ☐ Bed sores/pressure sores; (as secondary medical problem).
- ☐ Pressure sore (as secondary complication).
- ☐ Autonomic dysreflexia. Autonomic dysreflexia is a potentially life-threatening increase in blood pressure, sweating, and other autonomic reflexes in reaction to overfull bladder or bowel impaction or some other stimulus. Those with SCI at or above T6 are likely to have this.
- ☐ Signs of kidney failure.
- ☐ Signs of urinary tract problems (sepsis - a blood stream infection resulting from a symptomatic infection in the urinary tract).
- ☐ Signs of urinary tract infection. Bladder infection (cystitis) is the most common. Symptoms of a bladder infection may include going to the bathroom frequently,

passing blood in the urine, cloudy and odorous urine, increased spasticity in the lower extremities, fever and chills. Depending on your level of injury, you may feel a burning with urination, or discomfort in the lower pelvic area, abdomen, or lower back. Infection of the testicles (epidymitis) can have any of the symptoms of a bladder infection plus the scrotum is swollen, hot and red. An individual with an incomplete injury may feel pain in the testicles.

☐ Kidney and bladder stones (as secondary medical problem); they interfere with the function of the kidney/bladder and cause infection. Incontinence or urine leakage may be a problem for some individuals.

Routine physical exam and laboratory studies are the best ways to find problems early and treat them before they become serious. Your doctor can then treat problems before there are serious complications.

Behavioral/Emotional Changes

☐ Shock
☐ Anger
☐ Denial of functional limitations
☐ Fatigue
☐ Withdrawal; low self esteem; guilt
☐ Increased agitation, overreacting to situation or other emotional changes
☐ Fearing the worse
☐ Depressed, sad or lonely
☐ Sexual dysfunction/reduced sex drive
☐ Lack of motivation or interest; frustration
☐ Inability to cope/decreased emotional control
☐ Apathy
☐ Difficulty relating to others/problems with relationships
☐ Change in behavior, personality or self-image, poor self-management, social skills
☐ Over-dependent, fearful of challenges

General

☐ Unable to find work or function in work environment
☐ Unable to function in school environment
☐ Difficulty performing self-care and activities of daily living
☐ Experiencing lack of privacy due to dependence on others
☐ A growing dependency on drugs and intoxicants

Additional Signs to Watch for in Children

- ☐ Feeling inferior or loss of self-worth
- ☐ Lack of confidence; feeling unworthy
- ☐ Feeling that one doesn't belong anymore
- ☐ Feeling stared at or ostracized
- ☐ Changes in behavior that are not developmentally related
- ☐ Fearful or overwhelmed
- ☐ Feeling alone, ignored and left out
- ☐ Feeling being teased, looked down on, etc.
- ☐ Problems associated with delays in development, learning disability, behavior problems, etc.
- ☐ Difficulty with sibling/peer relationships
- ☐ Diminished school performance

This is based on information garnered from SBI websites. The emotional, behavioral, etc. are pieced together by our staff.

Understanding Spinal Cord Injury & Functional Goals

Any damage to the spinal cord is a very complex injury. People who are injured are often confused when trying to understand what it means to be a person with a spinal cord injury (SCI). Will I be able to move my hands? Will I walk again? What can I do? Each injury is different and can affect the body in many different ways.

This is a brief summary of the changes that take place after a spinal cord injury. It tells how the spinal cord works and what some of the realistic expectations are for what a person should eventually be able to do following a spinal cord injury. Included is a chart of functional goals for specific levels of injury as well as additional information resources.

The Normal Spinal Cord

The spinal cord is a part of your nervous system. It is the largest nerve in the body. Nerves are cord-like structures made up of many nerve fibers. The spinal cord has many spinal nerve fibers that carry messages between the brain and different parts of the body. The messages may tell a body part to move. Other nerve fibers send and receive messages of feeling or sensation back to the brain from the body, such as heat, cold, or pain. 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 nerve fibers that make up the communication systems of the body can be compared to a telephone system. The telephone cable (spinal cord) sends messages between the main office (the brain) and individual offices (parts of the body) over the telephone lines (nerve fibers). The spinal cord is the pathway that messages use to travel between the brain and the other parts of the body.

Because the spinal cord is such an important part of our nervous system, it is surrounded and protected by bones called vertebrae. The vertebrae, or backbones, are stacked on top of each other. This is called the vertebral column or the spinal column. The vertebral column is 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. The cord extends from the base of the brain, down the middle of the back, to about the waist. The bundles of nerve fibers that make up the spinal cord itself are Upper Motor Neurons (UMNs). Spinal nerves that branch off the spinal cord up and down the neck and back are lower motor neurons (LMNs). These nerves exit between each vertebrae and go out to all parts of the body. At the end of the spinal cord, the lower spinal nerve fibers continue down through the spinal canal to the sacrum, or tailbone.

The spinal column is divided into four sections. The top portion is the cervical area. It has eight cervical nerves and seven cervical vertebrae. Moving down the back, the next section is the thoracic area. It includes the chest area and has twelve thoracic vertebrae. The lower back section is the lumbar area and has five lumbar vertebrae. The bottom section has five sacral vertebrae and is the sacral area. The bones in the sacral section are actually fused together into one bone.

The Spinal Cord After an Injury

Damage to the spinal cord can occur from either a traumatic injury or from a disease to the vertebral column. In most spinal cord injuries, the backbone pinches the spinal cord, causing it to become bruised or swollen. Sometimes the injury may tear the spinal cord and/or its nerve fibers. An infection or a disease can result in similar damage.

After a spinal cord injury, all the nerves above the level of injury keep working like they always have. From the point of injury and below, the spinal cord nerves cannot send messages between the brain and parts of the body like they did before the injury.

The doctor examines the individual to understand what damage has been done to the spinal cord. An X-ray shows where the damage occurred to the vertebrae. The doctor does a "pin prick" test to see what feeling the person has all over his body (sensory level). The doctor also asks, "what parts of the body can you move?" and tests the strength of key muscle groups (motor level). These exams are important because they tell what nerves and muscles are working.

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

Level of Injury

The level of injury for a person with SCI is the lowest point on the spinal cord below which there is a decrease or absence of feeling (the sensory level) and/or movement (the motor level).

Tetraplegia [formerly called quadriplegia] generally describes the condition of a person with a spinal cord injury that is at a level from C1 to T1. This individual can experience a loss of feeling and/or movement in their head, neck, shoulder, arms and/or upper chest.

Paraplegia is the general term describing the condition of a person who has lost feeling and/or is not able to move the lower parts of his/her body. The body parts that may be affected are the chest, stomach, hips, legs and feet. An individual with a level from T2 to S5 has paraplegia.

The higher the spinal cord injury is on the vertebral column, or the closer it is to the brain, the more effect it has on how the body moves and what one can feel. More movement, feeling and voluntary control of the body's systems are present with a lower level of injury. For example, a person with a C-5 level of injury has a decrease or loss of feeling and movement below the 5th cervical spinal cord segment. An injury at the T-8 level means the individual has a decrease or loss of feeling and movement below the eighth thoracic spinal cord segment. Someone with a T-8 level of injury would have more feeling and movement than someone with a C-5 level of injury.

Complete or Incomplete Injury

The amount of feeling and movement that an individual has also depends on whether the injury is complete or incomplete. A complete injury means there is no motor or sensory function in the S4 or S5 area, or anal area. If there is evidence of any motor or sensory function in this area, one of three incomplete injury classifications is given.

Some people with an incomplete injury may have feeling, but little or no movement. Others may have movement and little or no feeling. Incomplete spinal injuries differ from one person to another because the amount of damage to each person's nerve fibers is different. This fact makes it impossible to accurately predict how much of an individual's sensory and motor function will return. There is a greater chance of return of some or all of a person's motor and sensory function if an individual is incomplete at the time of injury.

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 or when this will occur. This makes it impossible for medical staff to guarantee how much or when function may 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 can not control this movement.

In addition to movement and feeling, a spinal cord injury affects how other systems of the body work. An individual with SCI learns new ways to manage his/her bladder and bowel. His/her skin and lungs often need special care and attention to stay healthy. There may also be changes in sexual function.

Functional Goals

Functional goals are a realistic expectation of activities that a person with spinal cord injury eventually should be able to do with a particular level of injury. These goals are set during rehabilitation with the medical team. They help the individual with SCI learn new ways to manage his/her daily activities and stay healthy.

Achievement of functional goals can also be affected by other factors, such as an individual's body type and health related issues. By striving to reach these functional goals, the hope is to give individuals with SCI the opportunity to achieve Maximum Independence.

The chart, "Functional Goals for Specific Levels of Complete Injury", shows the expected functional goals for a person with a complete injury at a particular level. Motor and sensory functions improve with lower levels of injury.

Resources

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Spinal Cord Injury Patient Education Manual. 1998. [Available from Penn State Geisinger Rehabilitation Center, 500 University Dr., Hershey, PA. 17033 717-531-8521. Online: http://www.collmed.psu.edu/sciweb/].

Take Control: Multimedia Guide to Spinal Cord Injury-Vol.1. 1996. [CD-Rom programs Available from Arkansas Spinal Cord Commission, 1501 N University Ste 400, Little Rock, AR 72202, 501-296-1788, Email: arkscc@aol.com].

Organizations:
American Spinal Injury Association
345 East Superior Ave, Rm 1436, Chicago, IL 60611
312-238-1242
http://www.asia-spinalinjury.org

National Spinal Cord Injury Association (NSCIA)
870 Georgia Ave, Ste 500, Silver Spring, MD 20910
800-962-9629 or Email: nscia2@aol.com
http://www.spinalcord.org
National Spinal Cord Injury Hotline
2200 Kernan Dr., Baltimore, MD 21207
800-526-3456 - Email: SCIHOTLINE@aol.com
http://scihotline.org
Paralyzed Veterans of America
801 18th St NW, Washington, DC 20006
800-424-8200 or Email: info@pva.org
http://www.pva.org
RRTC on Aging with Spinal Cord Injury
Rancho Los Amigos Medical Center
7601 E Imperial Hwy, 800 West Annex, Downey, CA 90242-3456
562-401-7402

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Medical RRTC on Secondary Conditions of SCI
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(205) 934-3283 or (205) 934-4642(TTD only)

NIDRR

Revised: June, 2000
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This publication is supported by grant H133B980016 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

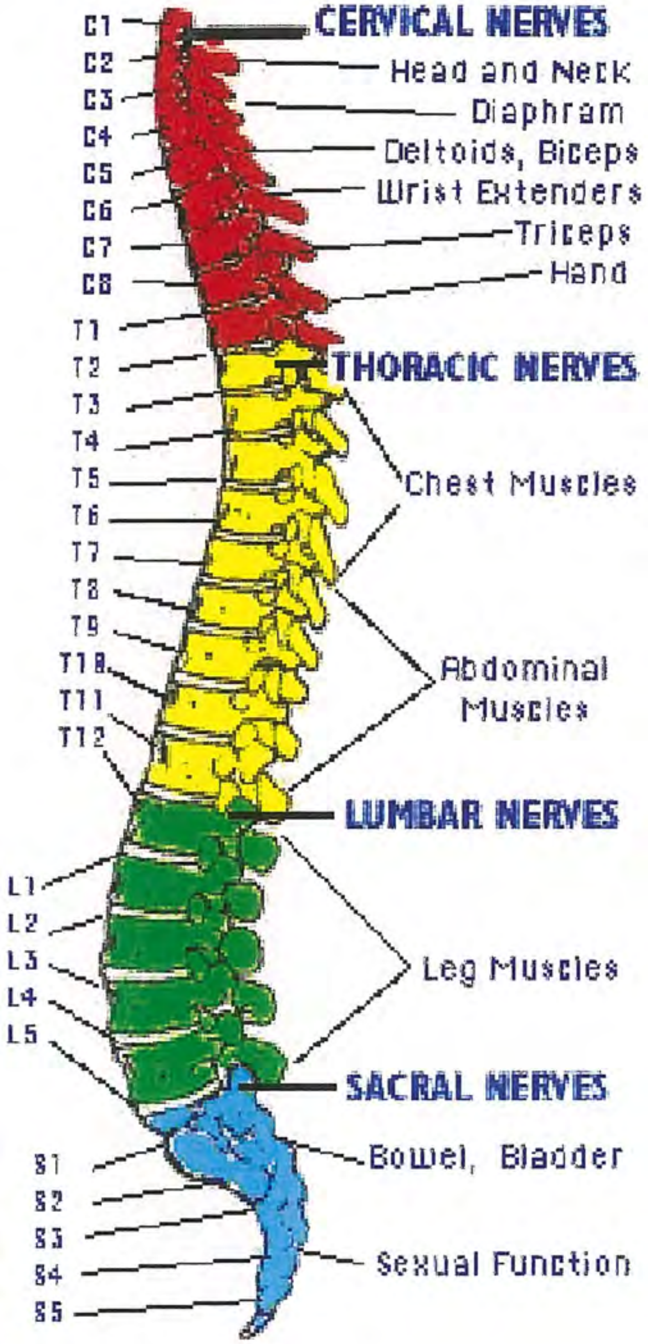
A copy of this article can be obtained at
http://www.spinalcord.uab.edu/show.asp?durki=30166

Functional Goals following SCI - Basic

Spinal Cord injury - Functional Goals for Specific Levels of Complete Injury

Level	Abilities	Functional Goals
C1-C3	C3-limited movement of head and neck	**Breathing:** Depends on a ventilator for breathing.
		Communication: Talking is sometimes difficult, very limited or impossible. If ability to talk is limited, communication can be accomplished independently with a mouth stick and assistive technologies like a computer for speech or typing.
		Effective verbal communication allows the individual with SCI to direct caregivers in the person's daily activities, like bathing, dressing, personal hygiene, transferring as well as bladder and bowel management.
		Daily tasks: Assistive technology allows for independence in tasks such as turning pages, using a telephone and operating lights and appliances.
		Mobility: Can operate an electric wheelchair by using a head control, mouth stick, or chin control. A power tilt wheelchair also for independent pressure relief.
C3-C4	Usually has head and neck control. Individuals at C4 level may shrug their shoulders.	**Breathing:** May initially require a ventilator for breathing, usually adjust to breathing full-time without ventilatory assistance.
		Communication: Normal.
		Daily tasks: With specialized equipment, some may have limited independence in feeding and independently operate an adjustable bed with an adapted controller.
C5	Typically has head and neck control, can shrug shoulder and has shoulder control. Can bend his/her elbows and turn palms face up.	**Daily tasks:** Independence with eating, drinking, face washing, brushing of teeth, face shaving and hair care after assistance in setting up specialized equipment.
		Health care: Can manage their own health care by doing self-assist coughs and pressure reliefs by leaning forward or side -to-side.
		Mobility: May have strength to push a manual wheelchair for short distances over smooth surfaces. A power wheelchair with hand controls is typically used for daily activities.
		Driving may be possible after being evaluated by a qualified professional to determine special equipment needs

C6	Has movement in head, neck, shoulders, arms and wrists. Can shrug shoulders, bend elbows, turn palms up and down and extend wrists.	**Daily tasks:** With help of some specialized equipment, can perform with greater ease and independence, daily tasks of feeding, bathing, grooming, personal hygiene and dressing. May independently perform light housekeeping duties. **Health care:** Can independently do pressure reliefs, skin checks and turn in bed. **Mobility:** Some individuals can independently do transfers but often require a sliding board. Can use a manual wheelchair for daily activities but may use power wheelchair for greater ease of independence.
C7	Has similar movement as an individual with C6, with added ability to straighten his/her elbows.	**Daily tasks:** Able to perform household duties. Need fewer adaptive aids in independent living. **Health care:** Able to do wheelchair pushups for pressure reliefs. **Mobility:** Daily use of manual wheelchair. Can transfer with greater ease.
C8-T1	Has added strength and precision of fingers that result in limited or natural hand function.	**Daily tasks:** Can live independently without assistive devices in feeding, bathing, grooming, oral and facial hygiene, dressing, bladder management and bowel management. **Mobility:** Uses manual wheelchair. Can transfer independently.
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.	**Daily tasks:** Should be totally independent with all activities. **Mobility:** A few individuals are capable of limited walking with extensive bracing. This requires extremely high energy and puts stress on the upper body, offering no functional advantage. Can lead to damage of upper joints.
T7-T12	Has added motor function from increased abdominal control.	**Daily tasks:** Able to perform unsupported seated activities. **Mobility:** Same as above. **Health care:** Has improved cough effectiveness.
L1-L5	Has additional return of motor movement in the hips and knees.	**Mobility:** Walking can be a viable function, with the help of specialized leg and ankle braces. Lower levels walk with greater ease with the help of assistive devices.
S1-S5	Depending on level of injury, there are various degrees of return of voluntary bladder, bowel and sexual functions.	**Mobility:** Increased ability to walk with fewer or no supportive devices.


C1
C2
C3
C4
C5
C6
C7
C8
T1
T2
T3
T4
T5
T6
T7
T8
T9
T10
T11
T12
L1
L2
L3
L4
L5
S1
S2
S3
S4
S5
CERVICAL NERVES
Head and Neck
Diaphram
Deltoids, Biceps
Wrist Extenders
Triceps
Hand
THORACIC NERVES
Chest Muscles
Abdominal Muscles
LUMBAR NERVES
Leg Muscles
SACRAL NERVES
Bowel, Bladder
Sexual Function

Adjustment to Spinal Cord Injury

Spinal Cord Injury InfoSheet 20

Level - Consumer

WHAT IS ADJUSTMENT

Adjustment is defined as adapting to a new condition. Everyone makes adjustments during their lifetime. Some of the conditions that you adjust to may be planned and you have time to think about how you are going to react to the situation. For example, you may have to make adjustments in your work hours when you start a new job. Other events may be a surprise, and you are forced to adjust to an unplanned event.

AFTER SPINAL CORD INJURY

A spinal cord injury (SCI) is one of the most devastating of all traumatic events. It results in a loss of some or all of an individual's sensation and movement. It is common for individuals who are newly injured to have health problems. Plus, it takes time to build enough strength to be able to fully participate in daily activities.

Individuals who are newly injured will likely experience *grief*. This is a period of mourning that is similar to that following the death of a loved one. The difference is that you are grieving the loss of your sense of touch along with your ability to walk or use your hands. You will likely experience many different thoughts and feelings after injury. Some may seem extreme and others mild. There is no step-by-step grieving process, but some thoughts and feelings are common after injury.

Denial/Disbelief

You may first react to your injury as if nothing happened. You may refuse to accept that your loss of feeling and movement is permanent. Instead, you may see the injury as an illness similar to a cold or flu that will soon pass with time.

Sadness

Obviously, no one is happy to be injured. It does not matter what your level of injury. Extreme sadness is common after injury because you have experienced a great personal loss. Sadness is that down, or blue feeling that you have when something bad happens. However, do not confuse sadness with depression.

Depression is a medical condition that requires professional treatment. You may be depressed if you have symptoms such as extreme sadness, inactivity, difficulty in thinking and concentrating, a significant increase or decrease in your appetite and/or time spent sleeping, and feelings of dejection, hopelessness or worthlessness. You may even have thoughts about suicide if you have depression.

Anger

Some people react to their injury with strong feelings of displeasure. You might lash out verbally or want to become physically violent towards others. You may feel angry toward yourself if your actions resulted in your injury. You may even feel anger toward God or someone else for causing your injury.

Bargaining

At some time following your injury, you may begin to admit to yourself that you have a serious condition. However, you may still want to hold onto the belief that your injury is not permanent. You may act as if you accept your injury as "the way things are," but your acceptance may come with the belief that you will be rewarded for your prayers and hard work in therapy and eventually recover from your injury at some point in the foreseeable future.

Acceptance

Grieving usually ends as you come to accept a realistic view of your current condition and find meaning in your life. You begin to think about your future as an individual with SCI and set goals to pursue in life.

ADJUSTMENT TO SCI

Individuals who adjust well to unexpected events generally lead healthy, active, and happy lives after their injury. Individuals who do not adapt well to unexpected events tend to be less healthy, less active, and unhappier after their injury. You basically experience two primary issues of adjustment to spinal cord injury.

1 When you are first injured, it takes time to get use to your life after injury. Some people grieve longer than others, so the adjustment period is different for everyone. It may take as much as a year for you to accept the realities of your injury.
2 You will also experience a continued process of adjusting to the unique issues that occur in your every day life as a person with SCI.

Problems Adjusting to SCI

If you have been injured for a year or more and have not come to accept your injury, it is a good idea to look into other areas to find out whether or not you are having problems adjusting to SCI. *You may find it hard to believe upon first thought, but what happens to you is not as important as what you are thinking when something happens to you.* Your thinking directly influences how you feel and react to events that occur in your life. This concept is the basis for Rational Emotive Behavior Therapy (REBT). Many counselors and psychologists teach REBT as a way to help people with and without SCI gain a healthy view of their lives.

You can use Chart 1 as your step-by-step guide showing how events in your life can trigger a "chain reaction" that can have a negative impact on your overall well being.

Event

An event is something that happens to you. It can be something as small as misplacing the keys to your car or something as devastating as a spinal cord injury.

Irrational Beliefs

Anytime an event occurs in your life, you start to talk to yourself about that event. This self-talk is based on what you know or what you believe to be true. For example, a person who gets a promotion at work might think, "I earned it!"

Chart 1

Event > **Irrational Belief** > Emotion = Unhealthy Behavior > Unhealthy Result

There are times when this self-talk is based on completely false or partially false assumptions about an event. If you do not know all the facts involved in the event, your self-talk may be based on wrong information or a series of unrealistic, *irrational beliefs*, about the event. Some examples of self-talk based on irrational beliefs are:

- my life is over because I can never live my life and be happy after a spinal cord injury; and
- I must be able to walk or must be able to use my hands if I am ever again going to be happy.

Although these irrational beliefs are common for individuals who are newly injured, many persons with SCI continue to hold onto these types of unrealistic, irrational beliefs long after their injury. The longer you hold onto such beliefs, the more likely it is that you are not adjusting well to your injury. You may have even adopted other false assumptions that are limiting your acceptance of your injury. Although there are countless possibilities for self-talk, some other examples of irrational beliefs are:

- because of my injury, it is now impossible for me to ever work or have a family;
- I am less of a person because of my injury;
- no one will accept, respect, or love a person with SCI;
- people should feel sorry for me and do things for me because my life has been unfair; and
- everyone will take advantage of me because I cannot defend myself.

Emotion

As you can see in Chart 1, what you are feeling, or your emotional response, depends on your self-talk. For example, individuals who are newly injured may think that their life is over because they cannot live with a spinal cord injury. This unrealistic self-talk may lead to extreme feelings such as anger, fear, and/or other emotional responses. If you have been injured for a year or more, you may feel sad, lonely, hopeless or worthless if you continue to hold onto irrational beliefs such as "no one can possibly accept, respect, or love a person with SCI."

It is also important to know that *feelings are neither good nor bad.* It is normal to feel excited at times and sad at times. You may feel both sad and excited at the same time. Because your self-talk might be different from another person, you may feel differently than others about the same event.

Unhealthy Behavior

If your feelings are based on irrational beliefs, you can follow Chart 1 to see that your reactions to your feelings may result in behavior that is bad for your overall health and happiness. For example, you may not see the need to take proper care of your bladder or skin if you feel worthless. You may isolate yourself from others and avoid spending time with family and participating in other enjoyable activities.

Individuals with a history of **alcohol and/or substance abuse** may return to their old pattern of self-destructive behavior. Others may start drinking or taking drugs. Either way, substance abuse is unhealthy behavior. People who abuse alcohol will deny there is a problem, but it is estimated that individuals with SCI abuse alcohol at about twice the rate of the general population.[1]

Do you have a problem with substance abuse?

1 Have you ever felt you should cut down on your drinking or drug use?
2 Have people annoyed you by criticizing your drinking or drug use?
3 Have you ever felt bad or guilty about your drinking or drug use?
4 Have you ever taken a drink or taken drugs first thing in the morning as an eye opener to steady your nerves or get rid of a hangover?

Professionals often ask these four questions (CAGE Questionnaire) to help identify persons with a drinking problem. If you answered "yes" to one of the above questions, it is a warning sign that you may have a problem with alcohol abuse. If you believe that you or a member of your family has a problem with alcohol or substance abuse, seek help! Ask a family member, doctor, or clergy to help you find help.

Unhealthy Results

Unhealthy behavior almost always leads to unhealthy results. When you neglect your personal care, you put yourself at greater risk for developing a wide range of health problems such as respiratory complications, urinary tract infection, and pressure sores. These problems can limit your ability to participate in activities. In some extreme cases, you may die. Substance abuse can complicate existing medical problems or lead to other health problems. Substance abuse can also lead to other injuries and a loss of personal relationships.

Healthy Adjustment to SCI

No matter what the *event*, you know that it triggers self-talk. These ideas, thoughts, and/or *beliefs* lead to your *feelings*. Your *behavior* and the *results of your behavior* are guided by your feelings.

One of the biggest keys to adjusting to spinal cord injury is personal **motivation**. Individuals who are newly injured are often motivated to attend therapy sessions out of a desire to gain strength and function. You probably have a strong belief that your paralysis is only temporary, and you will soon return to your old, "normal" self. This **hope** is a common reaction after an injury. Unfortunately, it is far more likely for individuals to recover function based on their level and completeness of injury (for information on recovery, see InfoSheet #4). In fact, only a few people actually fully recover from their injury. This does not mean that all hope is lost for a full or partial recovery. Almost all individuals with SCI continue to hope that they will walk again one day. However, a cure for paralysis may or may not come in your lifetime. A healthy approach to this reality is to move forward with your life after injury with the continued hope that advances in medicine will one day lead to a cure. In other words, do not wait on a cure to proceed with your life!

People who adjust well to life after injury are usually motivated to meet personal **goals**. These goals are different for everyone and often change throughout life. For example, your goal today may be to get a job, and you may want to have children in the future. Research from the University of Alabama at Birmingham (UAB) shows that people with SCI who are goal-oriented are less likely to be depressed and more likely to obtain some acceptance of their disability than persons who are not goal-oriented.[2]

However, it is up to you to find **purpose** in your life and the motivation to achieve your goals. It may help to think about what you wanted out of your life before you were injured. For example, you may have once strived for good health, an enjoyable job, and a loving family. There is no reason that you cannot continue to strive for the same things now that you have a spinal cord injury.

Replacing Irrational Beliefs with Rational Beliefs

Once you have motivation for change and set your personal goals, you may find it easier to identify unrealistic, unfounded information and false assumptions. You can help yourself avoid irrational beliefs by not...

... using words like always, never, no one, everyone and other "all-or-nothing" words.
... over exaggerating (making something small into something big or something big into something impossible).
... focusing only on negatives and ignoring the positives.
... thinking things "should" or "must" be a certain way.
... trying to predict the future.

It does not matter what your level of injury, you can challenge your irrational beliefs and replace your false assumptions with information that is based on fact. It is up to you to take time to learn the facts about living with SCI. An individual who is newly injured may want information on bladder or bowel management. An individual who has been injured for a year or more may want information on employment or sexuality.

When you are looking for educational information, only rely on information that comes from a knowledgeable source on issues of SCI. For example, most rehabilitation facilities offer patient education classes for individuals who are newly injured. In fact, you may have been given an informational booklet to take home with you from the rehabilitation center. You can also easily get educational information on the Internet. Web sites such as the National Spinal Cord Injury Association (www.spinalcord.org) and **SPINAL**CORD Injury Information Network (www.spinalcord.uab.edu) have information indexed by topics. These web sites are great starting points for anyone looking for information to assist in everyday living with SCI. You may have access to the Internet at home, school, work or your local library.

Now you can use Chart 2 to help you develop the skills to dispute and replace your irrational beliefs. When you challenge your beliefs, it is important to ask yourself what evidence you have to support your beliefs. Is there evidence to disprove your belief? You can then learn to recognize those beliefs that are based on false assumptions. For example;

Chart 2
Event **>** Irrational Belief
v
Motivation to Challenge & then Dispute Irrational Beliefs
v
Replace with **Rational Belief >** Emotion = **Healthy Behavior** > **Healthy Result**

- "My life is over because I can never live or be happy after a spinal cord injury." Individuals who are newly injured often use this irrational belief as a way to deny the possibility that their injury is permanent. Individuals who have been injured for over a year may use this statement as a reason to do nothing. To dispute this assumption, you focus on the word "never." It is similar to words such as "always," "everyone," "no one," and "must." This is "all-or-nothing" thinking. By using these words you are not allowing yourself to believe that there are other possibilities. According to the National Spinal Cord Statistical Center's "Facts and Figures at a Glance," there are about 243,000 people in the U.S. alone who are currently living with SCI. You are ignoring the fact that many, if not most, of the people living with SCI are happy.

  "Although I hope that my injury is not permanent and I fully recover, I know that many people are happy and living many years with all levels of injury." This type of rational self-talk is supporting your hope for recovery, but it also supports the fact that you can be happy and live with or without an injury. You are recognizing the fact that other people with the same level of injury are alive and happy.

- "Because of my injury, it is now impossible for me to ever work or have a family." This is a false assumption that many people hold onto long after injury. There are some individuals with SCI, family members, friends and others in the community that wrongly believe that "no one" with SCI can work, especially those individuals with high levels of injury. They may wrongly believe that you cannot get married or have children because you have physical limitations. You may even find it hard to imagine that you can work, or your family and friends may try to discourage you from becoming a parent, especially if you need help with your own care. These are all false assumptions that you can challenge with facts.

"Although I have an injury and physical limitations to what I can do, I can put myself in a position to work and have a family if that is what I want." This rational self-talk acknowledges the fact that you have an injury. In reality you may have physical limitations that prevent you from doing some jobs, which may include the same job that you did before your injury. For example, if you were a construction worker before your injury, it is not likely that you can return to that job if you have a high level injury. However, this fact does not mean that you cannot work. With job retraining and support from your family, friends and employer, you may find there are a number of jobs that you can do. As far as having a family, you might about people who are married and have children before their injury. It is *irrational* to think that people who are spouses and parents suddenly become "bad" spouses or "useless" parents simply because they become injured. The facts are to the contrary. Individuals with SCI continue to be loving, caring, supportive spouses and parents, no matter what their levels of injury. This fact also applies to people who want to have a family after injury. Although you may need to find ways to get things done, you need not base your desire to have a family solely on your physical limitations.

Emotion
Once you challenge your irrational beliefs and replace them with beliefs that are based on facts, you will likely *feel* differently. Instead of feeling sad, you might feel hopeful about your future. Instead of feeling worthless, you might begin to feel that you have value as a person, spouse, parent and an employee.

Healthy Behavior
When you begin thinking more rationally and experiencing a change in your feelings, you will usually act differently. If you have set goals for yourself, you may make plans on how you intend to reach your goals. You might then take better care of yourself so that you can reach your goals. This is healthy behavior! It is the action that you take to improve your life.

Different people have their own way of getting things done. You may find that you can no longer get things done the same way as before your injury. It may be necessary to ask someone for help when you need it, but you may want to hold onto your irrational belief that you "must" do "everything" on your own. When you challenge this irrational belief, you may realize that people, both with and without SCI, help each other in many ways. This help may be as little as one person opening a door for another person. Some people simply get more help than others. When you ask for help, you are simply finding ways to overcome obstacles and get things done.

It may be necessary for you to find other ways to get things done. UAB is among the leaders in SCI research. In their studies of individuals with SCI and their family caregivers, evidence shows that good problem solving behavior can help individuals with SCI avoid medical problems, and reach their goals.

Effective Problem Solving

A. Define the problem as clearly as possible.
B. Brainstorm: Make a list of as many possible solutions as you can.
C. Review your list and pick the solution that you think will best solve your problem.
D. Try out your solution.
E. Ask yourself, "Does it work?"
F. Try another solution if your problem is not solved.

Healthy Results
Hopefully, you will notice that healthier behavior leads to healthier results. When you take care of your health, you give yourself more of an opportunity to participate in enjoyable activities. You can solve the problems that prevent you from doing those things that you desire. You may soon discover that you are living a healthier, happier, and more satisfying life. It may take time, but you can reach your goals.

FAMILY ADJUSTMENT

As an individual with SCI, it is important to recognize that your injury also has a tremendous impact on your family. Although they may not have to adjust to losing the use of their hands or ability to walk, your family may experience a loss of the way their life was before your injury. For example, they may have to adjust to the role of caregiver. They may need to work to help with family finances. All of the changes that they face can lead to added stress and anxiety.

Family members also grieve. They may ask questions to try and understand the full impact of the injury and to help ease their feelings of sadness and fear. As your family comes to accept the injury, they face issues of adjustment similar to those you may experience.

Children are naturally curious and adjust to events by asking questions. They ask questions because they make few assumptions about how the injury impacts their life. Therefore, children adjust rather quickly to an injury if their questions are answered in a clear, honest manner.

Problems in Family Adjustment to SCI

As an adult family member, you may have difficulty with adjustment if you have your own irrational beliefs about life after injury. For example, For example, you may hold the false assumption that individuals with SCI cannot work. You may hold the unrealistic idea that "no one" with SCI can or "should" have children. You may hold the irrational belief that you "must" do everything for your loved one who is injured.

Your actions as a family member are reflected in what you say and do around your loved one. If your actions are based on irrational beliefs, you may be unknowingly acting with less than supportive behavior. For example, if you continue to do things for your loved one that he/she can do, your actions may be encouraging your loved one to be overly dependent on others. You may also be reinforcing your loved one's false assumptions that individuals with SCI should be pitied or felt sorry for because life has treated them unfairly. You may be **enabling** your loved one to engage in self-destructive behavior if you ignore or deny the possibility of a problem with substance abuse. Plus, it is also likely that your irrational beliefs will influence your own feelings, which may then lead to unhealthy behavior and unhealthy results. If you experience prolonged feelings of stress and anxiety, you may be putting yourself at risk for serious health problems such as disease or stroke if you do not adjust your views of life after injury.

Healthy Family Adjustment to SCI

If you are a family member, healthy family adjustment is, essentially, taking care of you. For example, you can take time away from your loved one to do those things that you enjoy. You can help minimize your stress and anxiety by working to replace your own false assumptions, unrealistic ideas, and irrational beliefs. You can start by learning the facts about SCI. Then, challenge your irrational beliefs with evidence to dispute your beliefs. Finally, replace your false information with facts. Hopefully, you will soon discover that you too are living a healthier, happier, and more satisfying life.

CONCLUSION

No matter if you have a spinal cord injury or not, you have control over what you feel by choosing how you want to think about your situation. You can be happy and more hopeful about your life, but it will only happen when you work to make it happen. Your thoughts, feelings, and behavior do not change overnight. It takes time to grieve your loss and come to accept the realities of the injury. Then, you face a continued process of adjusting to everyday issues of living with SCI. If you avoid false assumptions, unrealistic ideas, and irrational beliefs, you will give yourself more opportunities to reach your goals and have the life that you desire.

RESOURCES

[1] *Aging with SCI: Alcohol Abuse*, a Modular Educational Tract (MET) produced and available at Craig Hospital. Call 303-789-8202 or go to www.craighospital.org for a copy.

[2] Elliott TR, Uswatte G, Lewis L, Palmatier A (2000). Goal instability and adjustment to physical disability. Journal of Counseling Psychology, 47(2). 251-265.

Published by:
Office of Research Service
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
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Please check out our website at www.spinalcord.uab.edu

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This publication is supported by grant #H133B980016 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Prevention of Pressure Ulcers through Skin Care

Spinal Cord Injury
InfoSheet
13
Level - Consumer

Preventing pressure ulcers is a daily concern for individuals who have a spinal cord injury (SCI). You want to stay healthy and avoid this serious skin problem in order to be free to do whatever life has to offer. This InfoSheet tells you some of the things you need to do to prevent pressure ulcers and how to care for them. Listed at the end are some excellent resources that give additional information on the prevention and care of pressure ulcers.

A pressure ulcer is known by many names, like pressure sore, decubitus ulcer, bed sore or skin sore. No matter what it is called, it is a serious problem that can take days, weeks, months or even longer to heal.

A **pressure ulcer** is an area of the skin or underlying tissue that is dead or dying as a result of the loss of blood flow to the area. It can begin in a number of ways. The most common is when you rest on a bony area for a prolonged period of time. The extended pressure leads to a pressure ulcer.

Risk Factors

Anyone can get a pressure sore, but individuals with spinal cord injury are at high risk. It is estimated that up to 80% of individuals with SCI will have a pressure sore during their lifetime, and 30% will have more than one pressure sore.

There are a number of factors that put you at risk:

- Limited mobility can place extended pressure on an area of your body.
- Moisture from bladder and bowel accidents can further weaken the skin and cause skin to break down more quickly. Perineal dermatitis is the skin damage from bladder and bowel accidents and is not a pressure sore. However, it places the skin at risk for further breakdown.
- A lack of feeling in specific parts of the body can keep you from sensing that your skin has been damaged. A cut or scratch can quickly develop into a larger problem if not properly treated.
- Spasticity or transfers can shear (rub) the skin and cause damage.
- An overall decline in health status caused by poor nutrition, smoking and comorbidities such as diabetes and vascular disease increase the risk of developing pressure ulcers.

Stages

The most common sign that a pressure ulcer is beginning is the appearance of a red area, or red spot, on the skin. Ordinarily, redness should clear within 30 minutes after the pressure is released from the area. If the redness does not clear, a pressure sore has begun. A person with dark skin may also see a change in their skin color. Blanching (turning white) may not be visible, but the color may differ from the surrounding area. There are six identified stages of pressure ulcers:

One

Stage I – The skin is not broken and the redness does not blanch when touched. It usually occurs over a bony prominence. Darkly pigmented skin may not have visible blanching, but the color may differ from the surrounding area and is more difficult to detect. The area may be painful, firm, soft, warmer or cooler as compared to the surrounding skin.

Two

Deep Tissue Injury - Purple or maroon colored area with skin intact or a blood–filled blister as a result of damage to the underlying soft tissue from pressure and/or shear. Before the purple or maroon color changes are seen, the area on the skin may be painful, firm, mushy, boggy, warmer or cooler as compared to adjacent tissue

Deep tissue injury may be difficult to detect in darker skin tones. The area of injury may also evolve to become covered by eschar (a firm tan, brown or black layer). Even with optimal treatment, this evolution of injury may be rapid, exposing additional layers of tissue.

Three

Stage II - Partial thickness loss of the dermis (second layer of skin) presenting as a shallow open ulcer with a reddish wound bed, without slough (generally yellow, moist, loose or stringy tissue in the wound bed). May also present as an intact or open/ ruptured serum-filled blister.

Four

Stage III - Damage extends through all the superficial layers of the skin, a full thickness skin loss. Subcutaneous fat may be visible but bone, tendon and muscle are not exposed. Slough may be present, but the depth of tissue loss is still visible. Undermining and tunneling (damage that exists under intact skin) may occur.

The depth of a Stage III pressure ulcer varies by the location on the body. Areas where there is little subcutaneous tissue, muscle or fat, such as the nose, ear, ankle or back of the head, may have shallow ulcers. Areas where there is significant fatty tissue may have very deep Stage III ulcers. However, bone and tendon are not visible or directly palpable.

Five

Stage IV - Full thickness skin loss with exposed bone, tendon or muscle. Slough or eschar may be present on some parts of the wound bed. Often includes undermining and tunneling.

Again, the depth of the wound varies by the location on the body. Stage IV ulcers can extend into muscle and/or supporting structures such as the fascia, tendon or joint capsule and increases the possibility of bony infection (osteomyelitis). Exposed bone/ tendon is visible or directly palpable.

Six

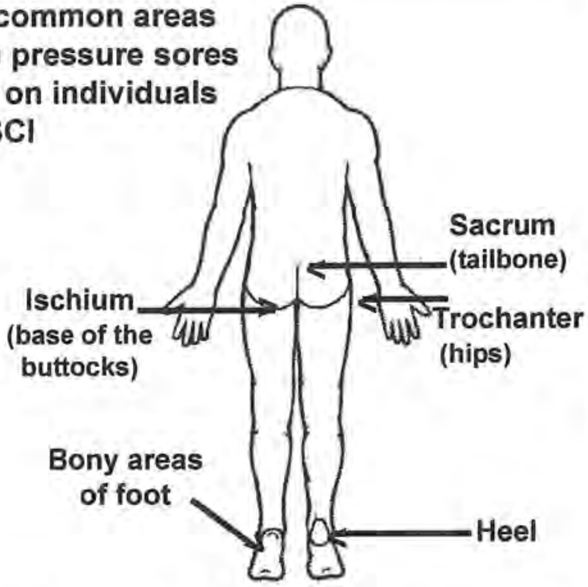
Unstageable - Full thickness skin loss in which the base of the ulcer is covered by slough and/or eschar in the wound bed.

Until the wound bed is clear of enough slough and eschar to determine the true depth, the wound cannot be staged. Stable eschar on the heels serves as the body's natural (biological) cover and should not be removed.[1]

Prevention

1. Check your skin completely twice a day, once in the morning and once at night.
   - Carefully look for skin damage or redness, especially on bony areas.
   - If you have a low level of injury you can use a mirror to inspect areas you cannot easily see. If your injury is at a higher level, have a family member or personal care attendant check your skin.

Most common areas where pressure sores occur on individuals with SCI



2. Know the places on your body that are more likely to get a pressure ulcer (*see picture above*). The four most common areas for pressure ulcers to develop in individuals with SCI are on the sacrum (tailbone), the heel of the foot, the ischium (which is at the base of the buttocks) and the bony areas of the foot. The trochanter or hip is another area at high risk for individuals who spend a lot of time in bed.
3. Always **use proper equipment** when seated or lying down. Have a doctor or qualified professional recommend what specialized equipment you need to protect your skin.
   - Your **seat cushion** needs to fit your body and your chair. It needs to be properly adjusted to offer the best protection against pressure areas.
   - Your **mattress** needs to provide proper support and protection.
   - Use **pillows** to help protect areas of the body that get too much pressure.
4. **Move often.** Sitting or lying in the same position for too long causes the flow of blood to be cut off. The skin or underlying tissue begins to die, and it results in a pressure ulcer. **Do weight shifts** (pressure relief) at least every <u>15-20 minutes</u> when sitting in your wheelchair.
   - If your injury is at level C4 and higher, you can use a power tilt wheelchair for regular pressure relief.
   - With an injury at level C5 or C6, you can usually lean forward or side-to-side for regular pressure relief.
   - If your level of injury is C7 and below you

can usually perform a wheelchair push-up for regular pressure relief.

While in bed it is usually recommended that you change position at least every 2 hours.

5. Keep skin clean and dry. Wet skin can become soft, inflamed and more prone to damage. Moisture weakens the skin and causes it to breakdown more quickly.
    - Wash and dry skin right away after any bowel or bladder accident.
    - Change clothes when they become wet.
    - Use lotion instead of powder on your skin.
6. Eat a well balanced diet. Foods high in protein, vitamins and minerals help your skin stay healthy and heal more quickly.
7. Drink the recommended amount of fluids to help your skin stay soft.
    - Drink at least 8 to 10 glasses of water per day.
    - Limit the number of caffeinated drinks like coffee, tea and soft drinks.
8. Protect your skin from harm.
    - Avoid movement or activities that rub, scratch or cut your skin.
    - Avoid clothes and shoes that are too loose or too tight fitting.
    - Avoid clothes with thick seams, buttons or zippers located in areas where they put pressure on your skin.
    - Take special caution when doing transfers and participating in new activities or sports.
9. Do not smoke. Smoking decreases oxygen to the skin and can make it more difficult for skin to heal.
10. Do not abuse drugs or alcohol. Both can damage your skin and can also lead to other health problems.

Care & Treatment

By the time you realize there is a problem, damage to the skin has already occurred. Once you see signs of a pressure ulcer, **stay off the area** and contact a doctor immediately for advice on treatment.

The treatment for a pressure ulcer ranges from extended bed rest to surgery. You must keep weight off the area for it to heal. This means you must take time off work and limit your activities. When you are less active you are also at higher risk for respiratory problems or urinary tract infections. Pressure ulcers also can lead to infection, surgery or even amputation. Treatment can be very costly in lost wages or additional medical expenses.

Your doctor will determine the best type of treatment needed and instruct you on how to clean and dress the pressure ulcer. Cleaning helps to remove dead tissue, skin or fluid draining from the ulcer.

Remember to always wash your hands (or instruct the person who is changing the bandage to wash their hands) before cleaning the sore and changing the bandage.

Watch for signs of infection such as redness around the edge of the ulcer, warm skin, large amounts of greenish drainage from the ulcer, odor or a fever.

You want to know what caused the ulcer, if possible, so it does not occur again. Questions to ask yourself are:

- Were my clothing or shoes tight in that area? Did they rub or pinch my skin?
- Do I have any new or changed equipment? Something as simple as a change in how your feet rest on your foot rest can cause the skin to become irritated.
- Was there any change in my job or activities that caused a change in my routine of doing pressure reliefs?

The total cost to treat a pressure ulcer depends on how quickly it is treated. It is much quicker and less costly to heal an ulcer when it is in Stage I than it is in Stage IV.

Conclusion

Ninety-five percent of all pressure ulcers are preventable. The key to preventing a pressure ulcer is maintaining healthy skin. For individuals with spinal cord injury the prevention of pressure ulcers is an ongoing, lifelong process.

It is important to always look for better ways to keep skin healthy and protect skin from damage that may lead to a pressure ulcer. After all, healthy skin is always the key to staying on the go.

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[1] National Pressure Ulcer Advisory Panel - Updated Staging System. February 2007. http://www. npuap.org.

Additional Resources on Skin Care and Pressure Ulcers

Secondary Conditions of Spinal Cord Impairment Health Education Video Series - Pressure Sores: Skin Care Prevention and Treatment (2006)
Free video download from the University of Alabama at Birmingham Model SCI System. Available online at:
http://www.spinalcord.uab.edu/show.asp?durki=97417
A 3 DVD series, sold only as a set, is available by mail. Total cost is $30. Make check payable and send to:

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Prevention of Pressure Sores through Skin Care
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Maintaining Healthy Skin: Part 1 & 2
Free online pamphlets from the University of Washington NW Regional SCI System. Available online at:
http://sci.washington.edu/info/pamphlets/skin_1.asp (part 1)
http://sci.washington.edu/info/pamphlets/skin_2.asp (part 2)
To receive pamphlets by mail contact (206) 685-3999.

National Pressure Ulcer Advisory Panel
An online document defining the stages of pressure ulcers (Feb 2007). Availabe at:
http://www.npuap.org/documents/PU_Definition_Stages.pdf
To inquire about mail service call (202) 521-6789.

Spinal Cord Injury Manual
A free online publication from the Thomas Jefferson University Regional Spinal Cord Injury Center of Delaware Valley. Available online at:
http://www.spinalcordcenter.org/manual/index.html
To inquire about mail service call (215) 955-6579.

Reconstruction Surgery for Pressure Sores
An article in the *Pushin' On* newsletter, Vol 23(2), 2005, a publication of the University of Alabama at Birmingham Model SCI System. Available free online at:
http://www.spinalcord.uab.edu/show.asp?durki=84591
To inquire about mail service call (205) 934-3283.

Christopher & Dana Reeve Foundation Paralyisis Resource Center
An online library of skin care books and videos. View for free online at:
http://www.paralysis.org/site/c.erJMJUOxFmH/b.2626671/k.46C2/Skin_Care_Library_Books_and_Videos.htm
To inquire about mail service call (973) 467-8270, extension 7204.

Pressure Ulcer Prevention and Treatment following Spinal Cord Injury
Free online guide from the Paralyzed Veterans of America. Available at:
http://www.pva.org/site/erver?pagename=pubs_generalpubs
May be purchased by mail with payment of shipping and handling. For details contact:

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This document is also available at
http://www.spinalcord.uab.edu/show.asp?durki=21479

Published by: UAB Model SCI System
Office of Research Services
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
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Date: Revised, October 2007

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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Pain Management following Spinal Cord Injury

Spinal Cord Injury
InfoSheet 10
Level - Consumer

WHAT IS PAIN

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage. In general, people can experience *acute* and *chronic* pain. Most people experience acute pain when they have a disease or injury to the body. It usually begins suddenly and acts as a danger signal telling you that something is wrong and that you need help. This acute pain can be severe or mild, but it usually goes away as the body heals. Chronic pain is like acute pain in that it can start suddenly. However, chronic pain differs because it can build up over time and continue long after the body heals.

PAIN AFTER SPINAL CORD INJURY

Acute pain is common after a spinal cord injury (SCI). The pain may occur as a result of the damage to the spinal cord, or it may occur from damage to other areas of the body at the time of injury.

It is also common for many individuals with SCI to experience chronic pain. It can occur in areas where there is normal sensation, and it can occur in parts of the body where there is little or no feeling after injury. The pain is very real and may have a great impact on daily living. A person in pain has difficulty carrying out daily activities. If you have pain, you can take 3 steps to help improve your overall quality of life.

1. *Do not ignore the fact that you have pain!* There are options for you to help manage the pain. Plus, pain can be a sign that there is a serious problem.
2. *Talk to a doctor!* It is important to first find the cause of the pain and the type of pain. Once your pain has been diagnosed, you and your doctor can decide how to best manage your pain.
3. *Learn to manage your pain!* Your goal is to reduce your pain as much as possible. The more you know about how you can help yourself, the better your overall quality of life.

RESEARCH ON PAIN

Research on pain following spinal cord injury is very complicated. Not only are there several types of pain, but people can also describe the same type of pain in different ways. Plus, individuals with SCI can feel pain in areas where there is no damage to the body. You may have severe pain at times and little or no pain at other times. It may change if the weather changes, if you smoke, if you are tired or emotionally upset, or if you have problems with your bowel, bladder or skin. These are only some of the factors that make it very difficult for doctors and researchers to diagnose, classify and treat pain.

Research has shown that your level of injury and how you were injured can have an impact on whether you have pain. Individuals with low levels of injury tend to have more pain than those with higher levels of injury. Individuals who are injured by gunshot have more pain than persons with SCI caused by other factors.

GROUPS OF PAIN

Individuals with SCI can experience several types of pain. The most common can be classified into three groups.

Neuropathic Pain

The types of pain found in this group are common for individuals with SCI. After all, neuropathic pain is caused by damage or dysfunction in the nervous system, which includes the spinal cord. It can generally be described as a sharp, shooting, or burning pain, but the pain is often described in other terms as well.

Spinal cord injury (central) pain is a type of pain that can begin within weeks or months after your injury. You feel this type of pain at or below your level of injury in areas where you have lost some or all of your sensation to touch. It is thought that the pain signals are coming from somewhere other than where you feel the pain. However, central pain is not related to what you do or how you are positioned. Additional terms used to describe central pain include tingling, numbness or throbbing.

Segmental pain often occurs around the border where you have normal sensation and loss of feeling as a result of injury. It can be slightly above your level of injury or slightly below. It usually develops during the first few months after injury. Segmental pain is often associated with *allodynia* and *hyperalgesia* in the painful region. Allodynia is pain caused by something that does not normally cause pain. For example, something cold, warm or a very light touch to the skin can result in pain. Hyperalgesia means an extremely painful response to what is normally only mildly painful.

Nerve root entrapement pain often begins days to weeks after injury and may worsen over time. It occurs at or just below the level of injury and has a distinct pattern. You may feel brief waves of stabbing or sharp pain or a band of burning pain at the point where your normal feeling stops. You may find that light touch makes the pain worse. The pain stems from compression of a nerve root by a bone or disk. Pain from damage to the *cauda equina* (the lower part of the spinal column) is a type of nerve root pain that is described as a burning feeling in the legs, feet, pelvis, genitals, and rectum.

Syringomyelia is a hollow, fluid filled cavity (syrinx) in the spinal cord. It is not common, but sometimes develops months or years after injury. The cavity can slowly increase in size and extend up or down the spinal cord. As the syrinx expands, it can result in pain along with an increased loss of sensory and motor function.

Musculoskeletal

This type of pain is also a concern for individuals with spinal cord injury. It occurs in parts of the body like the bones, joints, and muscles. Musculoskeletal pain is usually worsened by movement and eased with rest. It can generally be described as a dull or aching pain, but the pain can also be described in other terms.

Secondary overuse (*pressure syndromes*) is a very common cause of musculosketetal pain. The pain can occur months or many years after injury. It is caused by the overuse of muscles in any part of the body. For example, many people develop tendonitis of the rotator cuff (shoulder) as a result of pushing a manual wheelchair for a long period of time.

Muscle spasm pain is experinced by some individuals after SCI. The spasms are involuntary movements of the body in areas that have lost some or all motor function. The pain is caused when muscles and joints are strained.

Mechanical instability of the spine is caused by damaged ligaments or fracture of bones. It occurs most often shortly after injury, but it can also develop later. The pain is usually around the area of instability.

Visceral pain

Visceral pain usually begins a short time following SCI. It occurs in the abdomen (stomach area) either above or below the level of injury. The pain is described as burning, cramping and constant.

PAIN MANAGEMENT

Pain management usually includes treatment with medications, modified activities or a combination of both. It may not be possible to completely stop the pain, but an effective pain management program can lessen the intensity of the pain.

Pain management can be a very difficult process. Many times it is hard to know what is causing the pain in individuals with SCI. You should talk with a doctor who knows about pain after SCI before you try any medications or methods of managing pain. It can take time to work out how to best manage your pain. An effective pain management program depends on the type of pain you have.

Spinal cord injury pain is the most difficult to treat. Some neuropathic pain-relieving medications such as neurotin (gabapetin), nortriptyline, and amitriptyline may work in easing the pain. In other cases, a pump can be implanted under the skin to deliver opiates and clonidine to help relieve the pain.

Segmental pain may also be eased with neuropathic pain-relieving medications. Other treatments that may also be effective include spinal cord stimulation and epidural blocks along with sugical proceedures such as dorsal root entry zone lesions and dorsal rhizotomy.

Nerve root entrapment pain stems from vertebral instability. It might be relieved by stabilization, by opiates or by neuropathic pain-relieving medications. If there is bone or disk material present, decompression surgery is usually done to relieve the pain. Treatment to the peripheral nerves is usually needed to relieve pain from damage to the cauda equina.

Syringomyelia is diagnosed by a MR scan and requires surgery to remove the syrinx.

Secondary overuse is often managed by modifying activities that use the joint or body part that is in pain. This may include limiting or stopping activities that make the pain worse. For example, it may help to limit pushing a wheelchair if you have shoulder pain. It may be necessary to switch from a manual to a power wheelchair.

Pacing of Activities

1. List all activities that you frequently overdo that result in an increase in your pain or fatigue. For example, if typing on a computer tends to increase your pain, list "typing on a computer."
2. When doing each activity on your list, make a note of the time that it takes for you to experience an increase in pain or fatigue. For example, make a note if your pain or fatigue increases after 30 minutes of typing on the computer.
3. Set a time limit for doing the activity that is well below the point when you experience an increase in pain or fatigue. When you reach that time, *stop* and *rest*. For example, *stop* and *rest* after 15 minutes of typing on the computer.
4. Return to the activity after your rest period. The time that you spend resting will vary. You want to have enough rest time for you to continue the activity as outlined in numbers 2 and 3.
5. Do not get in a rush to complete any activity. You should *slowly* increase your endurance by increasing the amount of time that you spend doing the activity and *always* include adequate rest periods.

If you are unable to relieve your pain through activity modifications like pacing of activities, it may be necessary to use medication such as opiates or nonsteroidal anti-inflammatory drugs.

Muscle spasm pain is best relieved by treating the muscle spasms. The medications usually prescribed for treating muscle spasms include baclofen or valium.

Mechanical instability of the spine that results in pain can be eased by limiting or stopping activities that make the pain worse. Modifying or pacing of activities can help ease the pain, but opiates and nonsteroidal anti-inflammatory drugs may also be necessary. In some cases, surgery may be needed and is usually effective when other treatments fail.

Visceral pain is best treated by a doctor because it can be caused by a number of factors. The pain may stem from damage to nerves and relieved by opiates and/or by neuropathic pain-relieving medications. The pain can result from damage to organs like the bladder, liver, kidneys, and intestines. Treatment options might include modifying your bowel or bladder management program or through surgery.

KEYS TO SUCCESS IN MANAGING PAIN

To successfully manage pain, you need to:

- Be flexible and cooperative;
- Work jointly with health care professionals to find solutions to managing your pain;
- Follow treatment instructions; and
- Take an active role in treatment by asking questions, such as
  - Are there alternate drugs that are cheaper/safer?
  - Is the prescribed drug or treatment FDA approved?
  - Are there side effects from the medications or treatments?
  - Are there articles about a procedure or medication that you can read more about it?
  - Are there others who have used a treatment you can talk with about their experiences?

PAIN AFFECTS YOU

Pain not only affects the body, it also influences how you think and feel. It is hard to participate in activites if you are in pain. Pain to any part of your body is at best annoying. At its worst, it is so severe that the pain seems almost unbearable.

As an individual experiencing pain, you probably have a hard time thinking about anything but pain. After all, it is hard to think about work, school, or other things when you are thinking about pain.

This negative thinking then affects your emotional responses. The fear that your pain might get worse if you do something may keep you from doing something enjoyable because you do not want more pain. If your pain is annoying, you may feel frustrated when you participate in activities. Pain can also lead to feelings of anger or depression.

What increases pain

Your thoughts and emotions can magnify your pain. One example is when you push yourself until the pain becomes severe. This can lead to fatigue, increased tension, worry/anxiety, a decrease in the ability to do daily activities or avoiding daily activities to avoid pain. Another example of your thoughts and emotions influencing pain is when you experience stress or become depressed as a result of problems that you face while living with your injury. Depression can make pain worse and result in social isolation.

What reduces pain

If you are living with pain, there are some *psychological approaches* that you can take to help reduce your pain. You can learn to better cope with stress and overcome depression through professional counseling, although severe depression may require medication. Some techniques that you might learn through counseling include relaxation training, biofeedback and hypnosis.

The *Distraction* technique may also help reduce chronic pain. When you have pain, it may increase when you are not active or you begin to relax such as before you go to sleep. This increase in pain occurs because you have time to focus on the pain. When you are participating in enjoyable and meaningful activities, your awareness of pain decreases. For example, when you are busy with work, school, or recreational activities, you are not as likely to focus on your pain.

CONCLUSION

Pain management can be very important in improving your overall quality of life. If you are in pain, talk with a doctor. Start first with the simple methods of reducing your pain. You may have to try several treatments before finding one, or a combination, that works for you. Do not treat yourself because you may have a serious health problem that may be causing the pain.

Ultimately, the solution may not be a cure. You may not be able to live completely pain free. You may only be able to reduce your pain. But easing the pain may be enough for you to live a productive, satisfying life.

REFERENCES & RESOURCES

This InfoSheet is based in large part on *Pain Following Spinal Cord Injury: Clinical Features, Prevalence, and Taxonomy** by Philip J. Siddall, Robert P. Yezierski, and John D. Loeser and edited by Michael C. Rowbotham, MD and Annika Malmberg, PhD. It was published in the International Association for the Study of Pain (IASP) newsletter, Issue 3, 2000. www.halcyon.com/iasp

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For additional updated resources on Pain visit the Spinalcord Injury Information Network web site at www.spinalcord.uab.edu/show.asp?durki=21605

*This article introduces a classification system for SCI pain developed by the Task Force on Pain following SCI of the IASP.

Published by:
Office of Research Service
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
Please check out our website at www.spinalcord.uab.edu

Date: **Revised May, 2001**
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This publication is supported by grant #H133B980016 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Pain after Spinal Cord Injury

Spinal Cord Injury Model System Consumer Information

For more information, contact your nearest SCI Model System. For a list of SCI Model Systems go to: http://www.msktc.org/sci/model-system-centers

This publication was produced by the SCI Model Systems in collaboration with the University of Washington Model Systems Knowledge Translation Center with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education, grant no. H133A060070.

The problem of pain after SCI

Pain is a serious problem for many people with spinal cord injuries (SCI). Pain after SCI can occur in parts of the body where there is normal sensation (feeling) as well as areas that have little or no feeling. The pain is very real and can have a negative impact on quality of life. A person in severe pain may have difficulty carrying out daily activities or participating in enjoyable pastimes.

The majority of people with SCI report that they have chronic pain. Chronic pain is pain that does not go away and instead lasts months to years. The cause of the pain may be unknown but is most often related to nerve damage from the SCI or musculoskeletal problems that arise in dealing with an SCI. The pain can come and go. Chronic pain is difficult to completely eliminate but often can be managed or reduced enough so that it doesn't overwhelm your life.

Chronic pain can cause or worsen psychological problems such as depression, anxiety and stress. This does not mean the pain is "all in your head," but rather that pain and distress can make each other worse.

Even though pain after SCI can be complicated and difficult to treat, there are many treatments available that can help. Understanding your pain, working with your doctor and being open to a variety of treatments will help you manage you pain and improve your quality of life. Many people with difficult chronic pain problems after SCI have found relief using techniques described here.

Types of pain

A person with SCI can have many different types of pain in different locations, including areas where there is not usually any feeling. Understanding what type of pain you have is key to choosing the right treatment. Therefore, your doctor will ask you to describe your pain in a variety of ways, including its locations, severity, how long you have had it, what makes it worse or better and so on. Your doctor also may ask you to undergo tests such as an x-ray or MRI (magnetic resonance imaging).

Neuropathic pain

Neuropathic pain ("neurogenic pain") is caused by abnormal communication between the nerves that were damaged by your spinal cord injury and the brain, where nerve signals that inform your brain how your body feels are interpreted. In neuropathic pain, it is thought that the brain "misunderstands" or amplifies the intensity of the signals it is getting from around the area of your injury. This can cause you to experience pain coming from areas of your body below where you have little or no feeling. This is why a person can feel neuropathic pain in an area that otherwise has no feeling.

People often use words such as *burning, stabbing* or *tingling* to describe neuropathic pain, but neuropathic pain varies a great deal from person to person. It is often very difficult to treat, and frequently a combination of treatments must be used.

- *Note*: If pain starts years after injury, it may be due to a new medical problem, such as a syrinx, a fluid-filled cavity that forms in the spinal cord. It is rare but may require surgery. Therefore, it is very important to contact a doctor if you notice any new loss of sensation, especially in areas around the level of your injury, and any muscle weakness that doesn't improve with rest.

Musculoskeletal pain

Musculoskeletal pain is caused by problems in the muscles, joints or bones. It is a common problem for all people as they get older, including those with SCI.

Musculoskeletal pain can be caused by injury, overuse or strain, arthritic changes, or wear and tear of the joints, often from wheelchair use (including inadequate support for sitting) and/or transfers. It usually gets worse with movement and better with rest.

- **Upper limb (shoulder, elbow and hand) pain** is often caused by overuse of the muscles from doing transfers and pressure relief maneuvers and from pushing a wheelchair. It can occur months or many years after injury. People with higher level injuries who use computers or joysticks for many activities (reading, communicating, environmental controls) may develop pain in the hand, arm or shoulder from overuse. Upper limb pain can make it difficult for you to transfer safely and perform other activities of daily living.
- **Back and neck pain** are common problems. In people with paraplegia who have had surgery to fuse their spine, increased motion that occurs just above and just below the fusion can lead to back pain. People with tetraplegia (quadriplegia) may als have back pain, especially if they are able to walk but still have weakness. People who use chin- or mouth-operated joysticks may sometimes develop neck pain.
- **Muscle spasm pain** happens when muscles and joints are strained from spasticity.

Visceral pain

Visceral pain is located in the abdomen (stomach and digestive area) and is often described as cramping and/or dull and aching. It can be caused by a medical problem such as constipation, a kidney stone, ulcer, gall stone or appendicitis. Since a person with SCI may not have the usual symptoms associated with these medical conditions, it is important to see a doctor who has had experience caring for SCI patients in order to get a correct diagnosis and treatment.

Pain that comes from a visceral problem is sometimes felt in an area away from the source of the problem. This is called *referred* pain. One common example is shoulder pain that results from gallbladder disease.

Managing pain after SCI

Since pain can have so many different causes there is no single way to treat it. You and your doctor may need to try a combination of drugs, therapy and other treatments, including psychological treatments, and this may take some time to work out.

Physical treatments and interventions

- **Activity modification for musculoskeletal pain**. Changes in your mobility equipment (wheelchair, sliding board), your wheelchair pushing and transfer techniques, and in the way you do pressure reliefs can significantly decrease pain in your muscles and joints. Exercises that strengthen and balance your joints can also help reduce musculoskeletal pain. For information, please see the supplement "**Activity Modification for Musculoskeletal Pain.**"
- **Physical therapy** is used to treat musculoskeletal pain. Stretching and range of motion exercises may help relieve pain associated with muscle tension. Exercises that strengthen weak muscles can restore balance in painful joints and reduce pain.
- **Therapeutic massage** may help relieve musculoskeletal pain due to muscle tightness and muscle imbalance.
- **Acupuncture** is used to treat musculoskeletal pain. Tiny needles are inserted into the skin at specific points on the body. This method is

thought to work by stimulating the body's pain control system or by blocking the flow of pain.

- **Transcutaneous electrical nerve stimulation (TENS)** is sometimes used to treat musculoskeletal pain. Electrodes are placed on the surface of your skin and send low levels of electrical current into your body. The current blocks signals from the areas of nerve damage that are triggering a pain response.

Psychological treatments for pain

We now know that people can learn to use psychological techniques to help them manage their pain better so it doesn't take over their lives. Psychologists trained in pain management can help with a variety of techniques proven to be effective in reducing the intensity and impact of pain.

- **Relaxation techniques and/or biofeedback** designed to teach you how to reduce muscle pain tension and "mental tension" associated with pain can be helpful in self-management.
- **Self-hypnosis training** has proven helpful for reducing chronic pain in some individuals.
- **Cognitive restructuring**. Learning how to think differently about your pain and its effects can actually lead to changes in brain activity and, in turn, the experience of pain.
- **Individual psychotherapy** designed to help identify desired goals and increase pleasure and meaning in daily life can help reduce pain. Therapy can also help if there is a significant amount of anxiety associated with pain.

Medications

There are many different medications to treat pain. All of the medications listed below have shown some success in reducing pain, but none do so completely in every instance. All have possible side effects, some of which can be serious. Discuss all side effects with your doctor. Sometimes combinations of drugs work better than a single drug.

- **Non-steroidal anti-inflammatory drugs** (also known as NSAIDs) such as aspirin, ibuprofen (Motrin, Advil) and naproxen are most commonly used to treat musculoskeletal pain. Side effects may include stomach upset or bleeding problems.
- **Antiseizure medications** such as gabapentin (Neurontin) and Pregabalin (Lyrica) are used to treat neuropathic pain. Side effects include dizzyness, sleepiness and swelling.
- **Antidepressants** are used to treat neuropathic pain and depression. These medications include selective serotonin norepinephrine reuptake inhibitors (SSNRIs), such as venlafaxine (Effexor), and tricyclics, such as amitripltyline (Elavil). Side effects include dry mouth, sleepiness, dizziness and (with SSNRIs) nausea.
- **Narcotics (opiates)** such as morphine, codeine, hydrocodone and oxycodone are used to treat neuropathic and musculoskeletal pain. These drugs have many side effects, including constipation and sleepiness, and can be habit forming. You may also develop dependency on these drugs and may have withdrawal symptoms if you suddenly stop taking them. However, they can be used effectively for many people, and while not the first consideration for chronic pain management, should not be dismissed because of fears about dependency or side effects
- **Muscle relaxants and anti-spasticity** medications such as diazepam (Valium), baclofen (Lioresal) and tizanidine (Zanaflex) are used to treat spasm-related and musculoskeletal pain. These may be taken by mouth or delivered directly to the spinal cord through an implanted pump (see "Intrathecal pumps" below).These drugs can cause sleepiness, confusion and other side effects.
- **Topical local anesthetics** such as lidocaine (Lidoderm) are used to treat pain that occurs when skin is lightly touched (called *allodynia*).

Surgical Treatments

- **Dorsal column stimulator** is used to treat neuropathic pain due to nerve root damage. A high frequency, low intensity nerve stimulator is surgically placed in the spinal canal next to the spinal cord or nerve roots.
- **Intrathecal pumps** are used to treat neuropathic pain (using morphine) or muscle spasm-related pain (using baclofen) A pump containing morphine or baclofen is surgically placed under

the skin in the abdomen. It delivers the medication directly to the spinal cord and nerve roots.

Prevention and self-care

- **Get treatment for medical problems.** Overall health can have a big impact on pain. Urinary tract infections, bowel problems, skin problems, sleep problems and spasticity can make pain worse or harder to treat. Keeping yourself as healthy as possible can help reduce pain.
- **Try to get as much exercise as possible.** Getting regular physical activity can reduce pain as well as improve mood and overall health. It can also be enjoyable and distract you from pain. Your health provider can help you choose physiccal activities that are safe and appropriate for you. Also see the supplement "**Activity Modification for Musculoskeletal Pain.**"
- **Get treatment for depression.** Depression can make pain worse. It is best treated through counseling and medication. Getting treatment for depression can help you cope with chronic pain and improve your quality of life.
- **Reduce stress.** Stress can make pain worse or make the pain harder to cope with. You can learn to manage stress through counseling and learning techniques to help you reduce stress and tension, such as relaxation training, biofeedback and hypnosis. Exercise helps reduce stress.
- **Distract yourself.** Distraction is one of the best methods for coping with chronic pain. Participating in enjoyable and meaningful activeties can help reduce pain and help you feel more in control of your life, especially when pain is at its worst. When you are bored and inactive, you tend to focus more on your pain, and this can make your pain feel worse.
- **Keep a record.** Everyone's pain is a little different. Keep a record of what makes you feel better and what makes pain worse. Understanding things that affect your pain will help you and your doctor to find effective ways to reduce your pain.
- **Get a wheelchair seating evaluation.** Poor posture and improper seating can cause serious pain problems. Get your seating evaluated by a physical therapist who specializes in wheelchair seating. If you use a manual wheelchair, try to get a high-strength, fully customizable chair made of the lightest material possible (aluminum or titanium). Learn the proper wheelchair propulsion (pushing) technique from a physical therapist. (See the supplement "**Activity Modification for Musculoskeletal Pain.**")
- **Do not use alcohol to ease pain.** Using alcohol as a pain medication can lead to alcohol abuse and other serious problems. Some medications should not be mixed with alcohol. Ask your doctor about drinking alcohol, and always read the labels of your prescriptions.

Finding help

If you have pain, it is important to get treatment for it. The ideal source of help would be a physiccian and psychologist familiar with SCI and pain management, working together.

If you do not have easy access to such experts, the next best alternative is to seek help from a multidisciplinary pain clinic where physicians and psychologists are available. Work closely with a health care provider with whom you are comfortable and who understands your condition.

Chronic pain is not hopeless. Try not to become discouraged if one treatment doesn't work, and be open to trying a variety of different techniques. While complete relief from pain may not be possible, living better despite pain is a realistic goal.

Resources

- Pain Connection, *www.painconnection.org*
- American Pain Society, *www.ampainsoc.org*
- American Pain Foundation,*www.painfoundation.org*
- CareCure Community Moderated Forums, including a pain forum. *http://sci.rutgers.edu/forum/*

Source

Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the SCI Model Systems.

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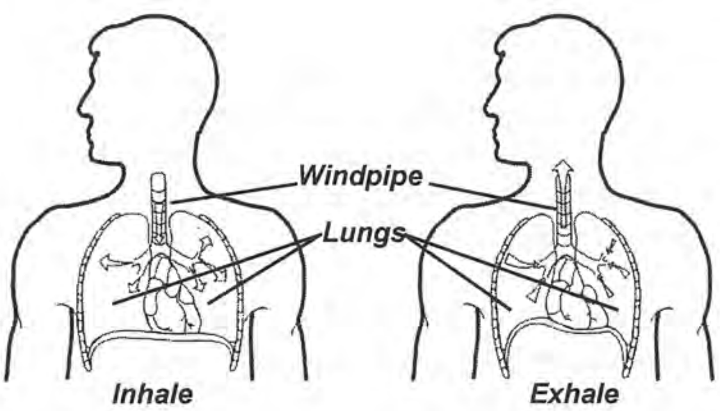
Portions of this document were adapted from materials developed by the UAB SCI Model System, University of Michigan Model SCI Care System, Northwest Regional SCI System, and Craig Hospital.

Understanding and Managing Respiratory Complications after SCI

Spinal Cord Injury InfoSheet 19

Level - Consumer

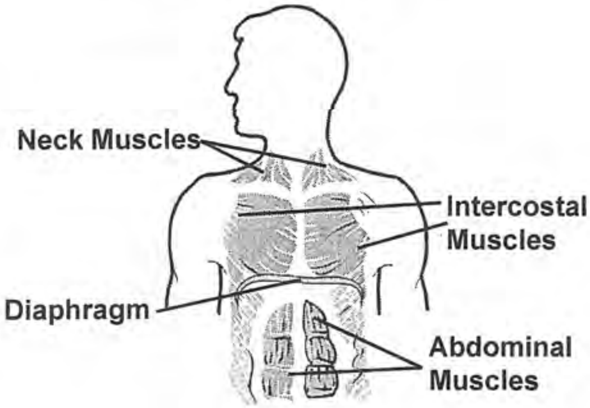
RESPIRATORY SYSTEM



The respiratory system, also known as the pulmonary system, is used for breathing. The windpipe and lungs are the two main parts of the respiratory system. When you inhale, or breathe air in through your mouth or nose, oxygen travels down your windpipe and into your lungs. Your lungs then filter the oxygen and send it through your blood stream to all your body parts. When you breathe out, or exhale, you send the left over carbon dioxide out of your body, through your windpipe and out of your mouth or nose.

RESPIRATORY MUSCLES

When you exhale, it does not require any effort from the body's muscles. However, you normally use a combination of four respiratory muscle groups to breathe air into your body.



The diaphragm, a strong, dome-shaped muscle that separates the abdominal and chest cavities, is normally the main muscle that you use when you inhale. The intercostal muscles are located between the ribs. These muscles help to expand your ribs as you inhale. The neck muscles normally work to expand your upper chest when inhaling. The abdominal muscles work with these other muscle groups to help you breathe deeply and cough.

ROLE OF THE SPINAL CORD

The brain normally sends signals through nerves in the spinal cord to control the four respiratory muscle groups. When everything is working properly, the pulmonary system and respiratory muscles work together allowing you to breathe in and out without much effort. In fact, most people breathe without ever thinking about it.

AFTER SCI

The windpipe and lungs are not typically affected by a spinal cord injury. However, respiratory problems may occur when the signals sent from the brain can no longer flow through the spinal cord to control the respiratory muscles.

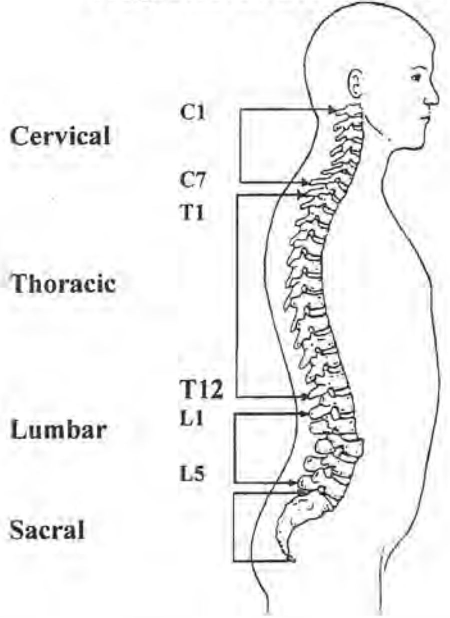
The amount of muscle control that is lost after a spinal cord injury depends on the level of the injury, along with the completeness of the injury. Individuals with injuries below the T12 level do not usually lose any control of the four respiratory muscle groups needed for breathing. This means the respiratory system is not usually affected by injuries in the lumbar or sacral regions of the spinal cord.

Individuals with complete thoracic or cervical injuries do experience a loss of their respiratory muscle control. The higher the level of injury, the greater the loss of respiratory muscle control.

Complete injuries in the thoracic or cervical regions usually result in the permanent loss of respiratory muscle function below the level of injury. However, if that injury is incomplete, it is impossible to predict whether individuals will regain some or all of their respiratory function below the level of injury.

Injuries in the thoracic area (T1-T12) of the spinal cord affect the control of the intercostal and abdominal muscles. A lower level of injury, such as a T10, results in the individual losing a small amount of muscle control. With a higher level of injury, such as a T2, individuals will lose most of their intercostal and abdominal muscle control.

Regions of the Spinal Cord



Complete injuries in the cervical region usually result in a total loss of intercostal and abdominal muscle control. Again, the higher the level of injury, the greater the loss of additional muscle control. For example, a complete injury between levels C3 and C5 loses all control of the diaphragm muscles. With a complete injury at level C3 and higher, the individual loses control of all four muscle groups that are needed for breathing. A ventilator is then needed to assist in breathing.

The **ventilator** does the work of the absent muscles and forces air into the lungs. Many people with a C4 level of injury, and even some people with a C3 level of injury, can eventually breathe without the aid of a ventilator or may only need it for part-time assistance. Those individuals with complete injuries above C3 need a ventilator for full-time assistance.

RESPIRATORY COMPLICATIONS

Individuals with a spinal cord injury are at increased risk for developing respiratory complications. Any loss of respiratory muscle control weakens the pulmonary system, decreases one's lung capacity, and increases respiratory congestion. It does not matter what the level of injury is or if the injury is complete or incomplete. However, the risk for complications is greater for persons with a complete injury and for persons with tetraplegia.

For persons with high level tetraplegia (C5-C1), **ventilatory failure** is a common complication after injury. The person typically lacks the ability to breathe without assistance. Another common problem is **atelectasis**. This is when the lungs partially collapse because not enough air is getting into them.

Persons with all levels of injury are at risk for **pulmonary embolism**. Pulmonary embolism is a blockage in the blood vessels of the lungs by a blood clot, and it is the second leading cause of death for persons with SCI within the first year after their injury. In addition, individuals with high tetraplegia (C1-C4) are about 100 times more likely to die from diseases of pulmonary circulation, regardless of time after injury, when compared to the general population (See Chart A). Those individuals with paraplegia (T1-S5) are almost 50 times more likely to die from pulmonary embolism.

Chart A **Standardized Mortality Ratio* for Diseases of Pulmonary Circulation**

Time Since Injury	*SMR
< 1 Year	210.0
1 - 5 Years	19.1
> 5 Years	8.9

Injury Level	*SMR
C1 - C4	105.0
C5 - C8	64.0
T1 - S5	48.6

** from National SCI Statistical Center, 1995*

Ventilatory failure, atelectasis and pulmonary embolism are all very serious, life-threatening respiratory complications. However, ***pneumonia is the leading cause of death for all persons with spinal cord injury***. This is true regardless of your level of injury or how long you have been injured.

Chart B **Standardized Mortality Ratio* for Pneumonia and Influenza**

Time since Injury	*SMR
< 1 Year	83.8
1 - 5 Years	26.3
> 5 Years	19.0

Injury Level	*SMR
C1 - C4	151.7
C5 - C8	58.7
T1 - S5	12.8

** from the National SCI Statistical Center, 1995*

Chart B shows that when compared to the general population, individuals with SCI are more than 80 times more likely to die of pneumonia or the flu within the first year after their injury. Also, persons with high level tetraplegia are about 150 times more likely to die of pneumonia at any time after injury, and persons with paraplegia are more than 10 times more likely to die of pneumonia or flu.

Be aware of the **symptoms for pneumonia.** They include shortness of breath, having pale skin, a fever, along with a feeling of heavy chest, coughing, and an increase in congestion. If you have symptoms of pneumonia, call a doctor immediately for advice on treatment.

PREVENTION OF RESPIRATORY COMPLICATIONS

ACUTE AND REHAB CARE

Because persons with SCI are more likely to develop respiratory complications within the first year after injury, it is very important to take steps to prevent complications during the acute care and rehabilitation stays.

- Treat all symptoms of respiratory complication aggressively to help prevent further complications from developing.
- Everyone with SCI should be vaccinated against (pneumococcal) pneumonia and annually for influenza.[1]
- Avoid the buildup of secretion in the lungs. It can be helpful for persons with high level tetraplegia to receive regular treatments with a cough assist machine. Individuals with tracheostomies who are on a ventilator need to have secretions suctioned from their lungs on a regular basis.

LONG-TERM CARE

Individuals with SCI should also have an ongoing, life-long plan to help prevent respiratory complications.

- **Maintain proper posture and mobility**. Sit up in your wheelchair everyday and turn regularly in bed to prevent buildup of congestion.
- **Cough regularly**. You can use a machine to help you cough, have someone perform manual assist coughs, or perform self-assist coughs.
- **Wear an abdominal binder** to help assist your intercostal and abdominal muscles.
- **Follow a healthy diet and manage your weight**. Weight management is important because respiratory problems are more likely to occur if you are too underweight or too overweight.
- **Drink plenty of water.** This helps your body in many ways, and water helps to keep congestion from becoming thick and difficult to cough up.
- **Do not smoke.** Smoking not only causes cancer, but other harmful effects include a decrease of oxygen in the blood, an increase in congestion in the chest and windpipe, a reduction in your ability to clear secretions from your lungs, a destruction of lung tissue, and an increase in the risk for respiratory infections such as pneumonia and bronchitis.
- **Live sensibly.** Avoid close contact with people who may have a cold or flu. Avoid areas with dust, smog and other air pollutants.
- **See a doctor at least once per year.** Your doctor may recommend that you get a chest x-ray or a flu shot.
- **Exercise.** Every person with spinal cord injury can benefit from some type of exercise. However, it is important to first talk to your doctor to find the right exercise program for you. Participation in athletics and other cardiovascular activities can improve strength and endurance while helping to keep the pulmonary system strong. If you have a

high level of injury or do not like strenuous exercise, it may be helpful to do breathing exercises.

BREATHING EXERCISES

Here are five breathing exercises that you can do at least two times a day to help your pulmonary system.

1 Take a deep breath and hold it for a few seconds before slowly breathing out.
2 Take a deep breath bringing in as much air as you can and as fast as you can before pushing the air out as fast as you can.
3 Take a deep breath and hold it, take another breath and hold it, and take one more before slowly breathing out.
4 Take a deep breath in then breathe out counting as long and as fast as you can.
5 If you have a spirometer, use it to both exercise and keep a measurement of your progress.

SLEEP APNEA

Sleep apnea is a growing respiratory concern for persons with spinal cord injury. Sleep apnea is a type of breathing disorder. Typically, it is a stop in breathing during sleep. However, apnea can include other respiratory difficulties. Increased research in this area suggests that persons with weakened respiratory muscles may be at high risk for developing sleep apnea, so persons who are older and persons with tetraplegia may be at a very high risk. Symptoms include irregular breathing or snoring, daytime sleepiness, problems with memory or concentration, waking up often during the night, and waking up tired or with a headache. If you think you may have sleep apnea, talk to your doctor for advice on treatment.

CONCLUSION

A number of respiratory complications can occur after spinal cord injury. This places all individuals at risk for developing complications regardless of level of injury or whether the injury is complete or incomplete. Therefore, it is important to understand these potential respiratory complications and what you can do to help prevent them from developing.

RESOURCES

Secondary Conditions of Spinal Cord Impairment Health Education Video Series - Respiratory Management (2006)
Free video download from the University of Alabama at Birmingham Department of Physical Medicine and Rehabilitation. Available online at:
http://www.spinalcord.uab.edu/show.asp?durki=97417

Respiratory Management Following Spinal Cord Injury
Guidelines from the Paralyzed Veterans of America designed to meet the needs of persons with recent onset spinal cord injury. Free download at:
http://www.pva.org/site/PageServer?pagename=pubs_main

Common Respiratory Problems in SCI - What You Need to Know *(2004)*
SCI Forum Reports, University of Washington School of Medicine, NW Regional SCI System
http://sci.washington.edu/info/forums/reports/common_respiratory.asp

CoughAssist MI-E Cough Machine
Information on a cough assist machine by Respironics, Inc. 1-800-345-6443 or visit http://coughassist.respironics.com/

Vent Users' Support Page
Web site that links to information related to ventilators, tracheostomy care and supplies, respiratory care and supplies, research, articles, newsletters, bulletin board and much more.
http://www.makoa.org/vent/index.html

SCIRE Respiratory Management Following SCI *(2005)*
From the Spinal Cord Injury Rehabilitation Evidence report, a review of scientific and professional information regarding respiratory management after SCI. Available free online at:
http://cord.ubc.ca/scire/pdf/SCIRE_CH8.pdf

REFERENCES

1. Waites KB, Canupp KC, Edwards K, et. al. Immunogenicity of pneuococcal vaccine in persons with spinal cord injury. Arch Phys Med Rehabil 1998; 79:1504-09.

Published by: Office of Research Services
619 19th Street South - SRC 529
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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Bladder Care and Management

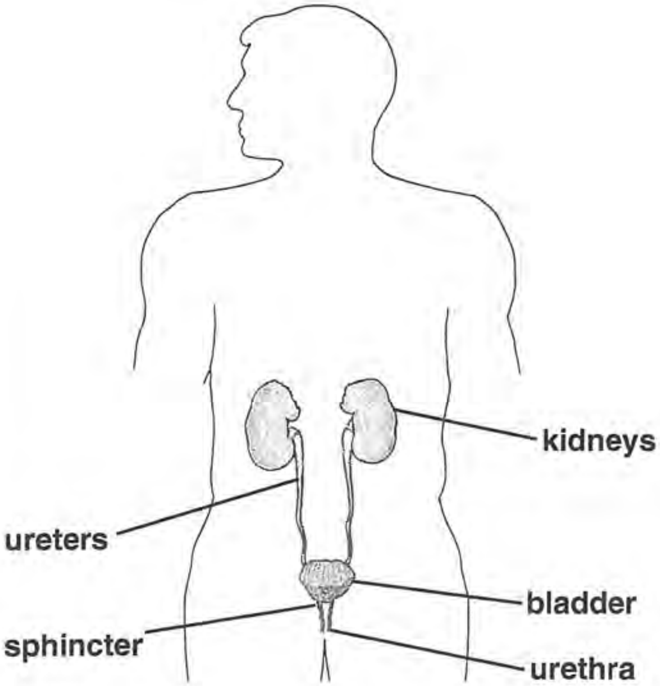
Spinal Cord Injury InfoSheet 11

Level - Consumer

THE URINARY SYSTEM

The 5 parts of the urinary system work to excrete waste (urine) and keep the chemicals and water in your body balanced. The kidneys are bean-shaped organs about the size of a fist. Urine is made in the kidneys and travels down two thin tubes called ureters to the bladder. The bladder is a muscular organ shaped like a balloon. The urine is stored in the bladder until it gets full. The sphincter muscles close tightly like a rubber band around the opening of the bladder to help keep urine in the bladder. As the bladder fills with urine, the sensation to urinate becomes stronger. At the point when the bladder reaches its limits, nerves from the bladder send a message to the brain that the bladder is full. To urinate, the brain signals the sphincter muscles to relax. At the same time, the brain signals the bladder muscles to tighten, squeezing urine out of the bladder. When all the signals work normally, the urine exits the bladder through the urethra.

5 Parts of the Urinary System



AFTER SPINAL CORD INJURY

After a spinal cord injury (SCI), 3 parts of the urinary system continue to function normally. The kidneys continue to make urine, and urine continues to flow through the ureters and urethra. These functions are involuntary responses, meaning they act without the need for the brain to tell them to act.

The bladder and sphincter are voluntary muscles that need the brain to coordinate the emptying of the bladder. Such messages are normally sent through nerves near the end of the spinal cord (the sacral level of the spine). However, those messages may no longer travel through the spinal cord after an injury. This means that individuals with SCI may not feel the "urge" to urinate when their bladder is full. They also may not have voluntary control of their bladder and sphincter muscles.

The bladder is usually affected in one of two ways:

1 **Spastic (Reflex) bladder** is when your bladder fills with urine and a reflex automatically triggers the bladder to empty. One major problem with a spastic bladder is that you do not know when, or if, the bladder will empty.

2 **Flaccid (Non-reflex) bladder** is when the reflexes of the bladder muscles are sluggish or absent. If you do not feel when the bladder is full, it can become over-distended, or stretched. The urine can back up through the ureters into the kidneys. Stretching also affects the muscle tone of the bladder.

The sphincter muscles may also be affected after injury. **Dyssynergia** occurs when the sphincter muscles do not relax when the bladder contracts. The urine cannot flow through the urethra. This results in the urine backing up into the kidneys. This is called "reflux" action. The bladder also may not empty completely. Treatments include medications or surgery to open the sphincter.

UAB Department of Physical
Medicine & Rehabilitation
Spain Rehabilitation Center

BLADDER MANAGEMENT METHODS

Although you probably lack the sensation, or "urge" to urinate, you still need to empty your bladder. If not, the bladder muscles stretch as the bladder fills, and urine backs up into the ureters and kidneys. This is called *Reflux*. Reflux damages the bladder, ureters and kidneys. Failure to empty the bladder to relieve pressure can result in serious health problems, even death.

Everyone is different, so you and your doctor will work together to choose a **bladder management method** that is convenient for you to empty your bladder. Keep in mind that an effective management program helps you avoid bladder accidents and prevent complications such as infections. You might also consider your mobility, finger dexterity, daily lifestyle, loss of normal urinary system function, and your susceptibility to infections.

If you have a Spastic (Reflex) bladder, your bladder management method will likely be an intermittent catheterization program (ICP), indwelling catheter (Foley or Suprapubic), or a male external condom catheter. ICP is usually the method of choice for individuals to empty a flaccid bladder.

URINARY SYSTEM CARE

As an individual with spinal cord injury, you are at risk for a number of potential urinary system complications. Proper bladder care is the best way to prevent problems and maintain your short- and long-term health. Following a self-care checklist is a great way to help you prevent potential complications.

✓ Drinking the proper amount of *water* is one of the most important factors for bladder care. You might first consider your bladder management method to determine how much water you typically need daily.

- Indwelling Catheter - it is recommended that each day you drink about 15 (8oz) glasses of water, which is about 3 quarts.
- Condom and Intermittent Catheterization - it is recommended that you drink between 8 to 10 (8oz) glasses of liquid per day, which is about 2 quarts.

There may be circumstances when you need to drink more water than is recommended. For example, you need to drink more water if you also drink beverages that contain sugar, caffeine or alcohol. You need more water because these drinks cause you to urinate more often, which means the body absorbs less water.

There may also be circumstances when you need to drink less than the recommended amount of water.. You may need less water if you have another health condition such as congenital heart failure. Of course, you should always consult your doctor if you have any questions.

✓ Although a regularly scheduled ICP is preferred, there is really no "recommended" time between intermittent catheterization. If you drink the recommended amounts of water each day, you may only need to catheterize every 3 or 4 hours. You will need to catheterize more often if you drink more liquids or if your bladder capacity is less than normal (13-16 ounces).

Generally speaking, it is ideal to drink most of your fluids between breakfast (6am) and dinner (6pm). This time frame allows you to get your daily intake of liquids and empty your bladder just before going to bed (10pm). Because your body's organs usually slow while you sleep, you can usually sleep through the night without the need to catheterize before the next morning. If the 6 to 6 time frame does not suit your lifestyle, you can adjust the time frame to fit your schedule.

Using a "sterile" ICP technique can help you stay as germ-free as possible. Sterile ICP kits are one-time use catheters. These ICP kits are also known as "touch free" or "touchless," which refers to the ability to catheterize yourself without the need to touch the insertion tube.

Due to a revised reimbursement policy covering the use of intermittent catheters, most people who have insurance can now get a maximum of 200 intermittent catheters per month instead of the 4 catheters per month under previous policy. The change should allow most users to obtain the closed, sterile ICP kits. Ask your health care provider or contact your insurance provider for more information.

Although a closed, sterile system is preferred for ICP, many individuals with SCI still use a "clean" catheterization technique.

Step by step ICP process for men:

1 Assemble all equipment: catheter, lubricant, drainage receptacle (container).
2 Wash your hands thoroughly with soap and water and clean the penis and opening of the urethra.
3 Lubricate the catheter.
4 Hold the penis on the sides, perpendicular to the body.
5 Begin to gently insert and advance the catheter.
6 You will meet resistance when you reach the level of the prostate. Try to relax by deep breathing, and continue to advance the catheter.
7 Once the urine flow starts, continue to advance the catheter another 1 inch. Hold it in place until the urine flow stops and the bladder is empty.
8 Remove the catheter in small steps to make sure the entire bladder empties.
9 Wash the catheter with soap and water. If the catheter is disposable, discard it right away. If it is reusable, rinse the catheter completely and dry the outside. Store the catheter in a clean, dry location.

Step by step ICP process for women:

1 Assemble all equipment: catheter, lubricant, drainage receptacle.
2 Wash your hands thoroughly with soap and water and clean the vulva and opening of the urethra.
3 Lubricate the catheter.
4 Locate the urethral opening. The opening is located below the clitoris and above the vagina.
5 Spread the lips of the vagina (labia) with the second and fourth finger, while using the middle finger to feel for the opening.
6 Begin to gently insert the catheter into the opening. Guide it upward as if toward the belly button.
7 Once the catheter has been inserted about 2 - 3 inches past the opening, urine will begin to flow.
8 Once the urine flow starts, continue to advance the catheter another 1 inch and hold it in place until the urine flow stops and the bladder is empty.
9 Withdraw the catheter in small steps to make sure the entire bladder empties.
10 Wash the catheter with soap and water. If the catheter is disposable, discard it right away. If it is reusable, rinse the catheter completely and dry the outside. Store the catheter in a clean, dry, secure location.

✓ Change condom and Foley catheters regularly. Condoms are usually changed daily - every other day at the longest. As for a Foley, there is no real guideline for how often it should be changed, but changes are commonly made monthly. A Suprapubic catheter is typically inserted by a qualified physician or other health-care provider. A trained professional will also change the suprapubic catheter when needed. You and your doctor should discuss when changes should occur.

✓ Keeping personal urinary care supplies clean. Before you start, you need a:

- cleaning area such as a sink or wash pan;
- strong disinfectant solutions such as liquid bleach or Pine Sol;
- small funnel or syringe (not required, but it helps to clean inside the bag, connector & tubing; and
- place to hang leg and bed bag for drying.

Step by step process for cleaning urinary supplies:

1 Unplug the dirty bag, tubing and connector from the catheter.
2 Attach a clean bag, tubing and connector to the catheter.
3 Completely empty urine out of dirty bag.
4 Clamp the drainage valve closed.
5 Use a small funnel or syringe to pour a mixture of water and disinfectant solution through the connector and tubing into the bag (1 part disinfectant to 8 to 10 parts water - less water makes for a stronger disinfectant, but too strong a solution can damage your skin on contact).
6 Shake bag gently so solution cleans all parts of the inside of bag.
7 Open drainage clamp to empty solution from bag.
8 Wash off outside of bag with fresh solution.
9 Repeat steps 4-8 using water without solution.
10 Hang bag up to dry.

Clean your urine drainage bag each day, and check your tubing and connectors every 2 to 3 days for sediment buildup. If you see mineral build up after cleaning, soak the tubing and connector in bacteria killing solution for 6-8 hours. If this does not remove the buildup, replace the tubing or connector.

✓ Keeping skin clean is another element for good health. First, always wash your hands before and after any bladder management method. To care for the indwelling catheter (Foley or Suprapubic), cleanse the urethral area (where the catheter exits the body) and the catheter itself with soap and water every day. After removing a condom, wash the entire genital area with soap and water before putting on a new condom. Finally, change your clothes and wash well immediately after any urine leakage or bowel movements.

✓ Getting a yearly medical check-up should be a part of your long-term care. The check-up should include a urologic exam to see that your urinary system is healthy. This usually includes a renal scan or ultrasound to determine whether or not the kidneys are working properly. The exam may also include an X-ray of the abdomen (KUB). This check-up helps your doctor ensure your urinary system is acting appropriately and identify other potential problems as early as possible.

POTENTIAL URINARY COMPLICATIONS

You can help prevent most complication with proper urinary system care. However, individuals with SCI are likely to develop a **urinary tract infection (UTI)** even if with the best bladder care, Not only are you at high risk for UTI, but complications due to UTI are also the #1 medical concern and more likely to affect your overall health and health care costs.

Bacteria are tiny, microscopic single-celled life forms that group together and form colonies. Different bacteria can live in various systems of the body. Those bacteria living in the urinary system can quickly multiply and lead to infection or disease.

As an individual with SCI, you should watch for early signs of an infection that include:

- sediment (gritty particles) or mucus in the urine;
- cloudy urine;
- bad smelling urine (foul odor); and
- blood in the urine (pink or red urine).

Then, you might avoid the onset of an infection by:

1 drinking more water;
2 avoiding beverages with sugar, caffeine and alcohol; and
3 emptying your bladder more often.

Antibiotics are used if you actually do get an infection. Antibiotics are prescribed by a doctor and essentially kill the "bad" bacteria causing the infection.

You should always follow your doctor's advice on treatment of UTIs. On the other hand, many doctors do not know that individuals with SCI have special considerations when it comes to he use of antibiotics for UTIs. Your doctor needs to know four facts:

1 - Most (80%) individuals with SCI have bacteria in the urinary system at any given time. The presence of bacteria is common because bacteria from the skin and urethra are easily brought into the bladder with ICP, Foley, and Suprapubic methods of bladder management. Also, many individuals with SCI are not able to completely empty their bladder, leaving some bacteria in the urine remaining in the bladder.

2 - Whereas bacteria identified in a urine culture is commonly cause for treatment by doctors, you do not necessarily need treatment for an infection. Antibiotics are only recommended for treatment of UTIs if you actually develop one or more symptoms of infection that include:

- fever;
- chills;
- nausea;
- headache;
- change in muscle spasms; and
- autonomic dysreflexia (AD).

Depending on your level of injury, you may also feel burning while urinating or discomfort in the lower pelvic area, abdomen, or lower back.

3 - When you show symptoms of illness, it is highly recommended that you get immediate advice on treatment from your doctors. Your doctor should also get a urine sample prior prescribing a treatment. These two actions are recommended so that your doctor can first rule out any other health problems. Second, your doctor can prescribe the most effective antibiotic to treat your specific infection (bacteria type). Finally, antibiotics should be taken exactly as prescribed and for a sufficient duration to fully kill the bacteria.

4 - Use of antibiotics as a prevention method for UTIs should be avoided unless there is an overriding medical need to prevent an infection. Although there are some circumstances, such as pregnancy, when prevention of infection is needed to avoid unwanted medical complications, antibiotic resistance is a major concern for individuals with SCI. Each time you take an antibiotic, the bacteria have the opportunity to change in some way that reduces or eliminates the effectiveness of that antibiotic to kill the bacteria in the future. So it becomes harder and harder to get an effective antibiotic when you actually get sick from a bacterial infection.

Whereas bacteria found in the urinary system can cause illness, there are also "good" bacteria found in your digestive system. These bacteria are actually beneficial for maintaining the natural balance of organisms (microflora) in the intestines. Maintaining this proper bacterial balance can help individuals with SCI in their bowel management.

Anytime you take antibiotics, you kill both the good and bad bacteria. Therefore, *probiotics* are sometimes recommended by doctors during and/or after a course of antibiotics to replenish and restore the numbers of beneficial bacteria lost to antibiotic use. Probiotics are dietary supplements containing potentially beneficial bacteria or yeast. The most common sources for probiotics are yogurt, but other dairy products such as cheese, milk, sour cream and kefir are also probiotics.

Although it is likely that you have a UTI when you have symptoms of illness, it is possible that you actually have another health problem. Therefore, it is highly recommended that you call your doctor immediately for advice on treatment if you develop any symptoms. It is recommended that you provide your doctor with a urine sample before treatment. These two actions are recommended so that your doctor can rule out any other health problems and prescribe the most effective antibiotic to treat your specific infection (bacteria type) if you do have a infection, making them more susceptible to infection.

There is some debate as to whether or not *cranberry juice compounds* can somehow help prevent bacterial infections. When it comes to urinary tract infections in the general population, there is evidence that compounds in the juice block some types of bacteria from sticking to the cells in the body. This would make it easier for the body to flush out the bacteria. However, there is also evidence to show that cranberry compounds offer no benefit in reducing the number of bacteria in the urine of individuals with spinal cord injury. In other words, cranberry juice compounds may benefit people without SCI but not people with SCI.

Although the benefits of cranberry juice are debatable, there is no harm in drinking it. The only recommendation is that you drink the all-natural, sugar-free juice to avoid unnecessary additives.

If you become ill with two or more UTIs per year, it can be an early sign of other problems with the urinary system. A complete urologic examination may be necessary to find out if you have a more serious problem. You may then choose to see a urologist, a doctor specializing in the treatment of the urinary system. Remember, any doctor you see should be familiar with the medical issues of individuals with SCI.

Kidney (Renal) failure was once the leading cause of death for individuals with SCI. Today, improved methods of bladder management have resulted in fewer and less severe complications with the kidneys. A more common cause of death related to the urinary tract is now sepsis (a blood stream infection resulting from a symptomatic infection in the urinary tract).

Kidney and **bladder stones** can form in the urinary system. Such stones usually hinder the kidney/bladder functions and can cause infection. Most individuals with lower levels of injury will notice pain associated with a stone. Those with higher levels are not likely to feel the pain. Blood in the urine is also a common sign that a stone has developed. If you have reoccurring or prolonged symptoms of AD that seem to be without cause, it may also be a sign that you have a stone.

Urine leakage or incontinence is a problem for some individuals. Treatment can include both drugs and surgery. Medications are often used to control bladder spasms and tighten the sphincter muscles. Several surgical options are available for treating urine leakage. A new urinary reservoir ("pouch") is made from bowel tissue. The ureters are implanted into the new bladder "pouch." The urine is drained with a catheter through an opening (stoma) in either the navel or stomach wall. Another surgical method is bladder augmentation cystoplasty. Here the bladder is enlarged using bowel tissue. Since surgery involves both the urinary and gastrointestinal systems, recovery time is longer.

Bladder cancer is another concern for some individuals with spinal cord injury. Research in aging with SCI shows a small increase in the risk of bladder cancer among individuals with SCI who have been using indwelling catheters for a long period of time. Smoking further increases this risk. If you have used an indwelling catheter for at least 10 years, it is strongly recommended that you have regular cystoscopic evaluations.

Treating other problems of the urinary system is important. Many times these problems do not have any symptoms. This means they can go undetected until they one-day become serious. Your annual physical exam and laboratory studies are the best ways to find problems early and treat them before they become serious.

Conclusion

The keys to a healthy urinary system are taking all the proper steps to prevent complications and identifying any complications as early as possible for treatment. This includes learning proper bladder management techniques as well as proper bladder care. If you learn these skills, you help improve your chances for lasting long-term health.

RESOURCES

Bladder Cancer
A pamphlet that discusses the higher risk of bladder cancer in individuals with SCI.
www.craighospital.org/SCI/METS/bladderCancer.asp

H20: Hydration
A pamphlet that reviews the importance of drinking enough water & the problems that occur with dehydration.
www.craighospital.org/SCI/METS/h2o.asp

Bladder Cancer: Who's at Risk?
An article from PN/Paraplegia News, April, 2ooo that reviews results fo a recent bladder cancer survey by individuals with SCI.
http://www.pvamagazines.com/pnnews/magazine/article.php?art=815

Bladder Management
Pamphlet reviewing the urinary system and methods for voiding for individuals with SCI.
http://sci.washington.edu/info/pamphlets/bladder.asp

Living Well: Bladder Management
An article from PN/Paraplegia News, March, 2001, focusing on common conditions plaguing the gastro-urinary system after SCI & treatments.
http://www.pvamagazines.com/pnnews/magazine/article.php?art=699

Bladder Management (33 minute video)
This video outlines the importance of bladder management on QOL. The types of bladder management programs and techniques are illustrated (Male and female anatomical models utilized to demonstrate proper techniques). Prevention and treatment of UTI Risks for stone formation are also discussed. 55.2 mb download or watch on streaming real media.
http://www.spinalcord.uab.edu/show.asp?durki=97417

Additional Information: For more information on bladder management, go to www.spinalcord.uab.edu/show.asp?durki=21544 or contact the Office of Research Service via the information below.

Published by:
Office of Research Service
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
Please check out our website at www.spinalcord.uab.edu

Date: Created 2001
Developed by: Linda Lindsey, MEd; Phil Klebine, MA
Updated: Phil Klebine, MA (2008)

This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Bowel Management following Spinal Cord Injury

Spinal Cord Injury InfoSheet

9

Level - All

THE DIGESTIVE SYSTEM

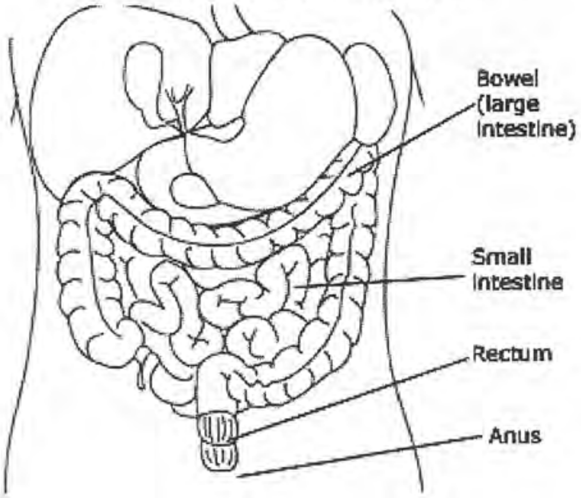
The digestive system has both upper and lower digestive tracts. The upper digestive tract breaks down the food that you eat into the nutrients that fuel your body. The digestion of waste begins in the lower tract small intestine and large intestine. In a wave-like action, called *peristalsis,* the waste is moved through the large intestine where water is removed, resulting in the left-over stool.

A bowel movement (BM) is normally initiated when enough stool collects in the rectum. The urge to empty your bowel intensifies as the rectum fills with stool. When you go to the bathroom, your brain then signals the release of the anal sphincter muscle, and muscle action pushes the stool out through the anus.

The frequency between each BM normally differs greatly among people. Some people will normally have 1 to 3 movements per day. Normal frequency for some people can be as few as 3 times a week.

Normal consistency of the stool can also vary. Although a normal BM should be easy to pass, some people may have harder or softer stools than others. Color ranges from brown to golden brown. The shape is usually similar to a sausage.

THE LOWER DIGESTIVE TRACT



Graphic Source: *Taking Care of Your Bowels - The Basics*

FOLLOWING SPINAL CORD INJURY

Following spinal cord injury (SCI), messages from your body are not able to reach your brain like before your injury. This usually means a loss of sensation that your bowel is full, the "urge" to empty your bowel, and loss of voluntary sphincter muscle control.

When normal bowel function is lost due to an injury to the nervous system (spinal nerves), bowel function is commonly referred to as a *neurogenic bowel.* In general, two types of neurogenic bowel can occur after SCI. The type depends on the level of injury.

A *reflex* bowel is common with injuries above T-12 (Upper Motor Neuron injuries). With a reflex bowel, the anal sphincter remains closed. However, a reflex BM can still occur at any time and without warning when the stool fills the rectum.

With injuries below T-12 (Lower Motor Neuron injuries), there is usually a loss of reflex response, or *flaccid* bowel. Although there is reduced peristalsis and a loss of anal sphincter tightness with a flaccid bowel, the bowel does not usually empty itself. However, the loose sphincter means mucus and fluid can seep around stool and leak out the anus.

BOWEL PROGRAMS

Stool absolutely must be removed regardless of your injury level. So, you need to establish a *bowel program* based on your bowel type.

A reflex bowel program may be done daily, every other day, or even as few as 3 times a week. There are 8 general steps in a reflex bowel program.

1 Wash hands thoroughly.

2 Prepare your supplies. You will need:

- gloves (powder and latex free are preferable)

- lubricant (water-based or anesthetic only)
- toilet paper and/or blue underpads (Chux)
- stimulant (Enemeez® mini-enemas or Magic Bullet Suppositories® are generally accepted for regular use by individuals with SCI)
- assistive devices (a suppository inserter, finger extension, and digital stimulator)

3 Get into a comfortable position. When possible, it is best if you sit on a toilet or commode chair so that gravity can help move the stool down and out.

If you cannot sit, lay on your bed with your body turned on the left side. Use underpads (Chux). Do not use a bed pan because it may damage your skin.

4 Manual stool removal. The lining of the rectum is delicate. Insert a gloved, lubricated finger into the rectum and gently hook your finger around any reachable stool and remove it from the rectum.

5 Insert stimulant. Using gloved hand, gently squirt the lubricated mini-enema as high as you can into the rectum. Likewise, place the lubricated suppository high into the rectum, leaving the suppository touching the wall of the rectum.

6 Digital rectal stimulation. Sometimes referred to as "Digi-stim," this process promotes peristalsis and the relaxation of the sphincter muscle. A good time to begin digital rectal stimulation is once the stimulant starts to act. Mini-enemas will probably start to act within 15 to 20 minutes after the insertion. The suppository will probably start to act within 20 to 30 minutes after insertion. Passing of gas or stool may also indicate a readiness for digital stimulation.

Insert a gloved, lubricated finger into the rectum and gently start moving your finger in a circular pattern for 20 to 30 seconds, keeping the finger in contact with the rectal wall. Repeat the process every 5 to10 minutes until the BM is complete.

7 Know when the BM is over. You can usually be fairly confident that the BM is over if:

- there is no more stool after 2 consecutive digital stimulations;
- there is mucus coming out without any stool; or
- the rectum is closed tightly around the finger.

8 Clean up. Wash and dry the anal area.

A flaccid bowel program is usually done one or more times daily. There are 6 general steps in a reflex bowel program.

1 Wash hands thoroughly.

2 Prepare your supplies. You will need:

- Gloves (powder and latex free are preferable)
- Lubricant (water-based only)
- Toilet paper

3 Get into position. Most individuals with a flaccid bowel are able to sit on a toilet or commode chair.

4 Manual stool removal. Stimulants are not usually effective for a flaccid bowel, so manual removal of stool is done (as with reflex bowel) about every 5 minutes until the BM is over.

Between each 5 minute removal time, you can promote stool movement by:

- digital rectal stimulation (as with reflex bowel);
- firmly rubbing (clockwise) your abdomen with your hand; and
- movement of the body. The four most common body actions are;
  1) leaning forward and side-to-side;
  2) body push-ups to reposition and vary pressure areas;
  3) tightening and releasing of abdominal muscles;
  4) "bearing down" to force stool out (known as a valsalva maneuver and should be avoided if you have a heart condition); and
  5) inhaling air deeply followed by forcing air out by increasing abdominal pressure.

5 Know when the BM is over. The BM is probably over when you have no stool results after 2 manual removals, which is about 10 minutes without results.

6 Clean up. Wash and dry the anal area.

BOWEL MANAGEMENT

Bowel management is essentially your ability to maintain control over your bowel movements. Simply put, bowel control means:

- retraining your bowel to empty at a planned, regularly scheduled time;
- avoiding any accidental, unplanned BM;
- avoiding leakage between each bowel program;
- maximizing stool removal during each bowel program;
- maintaining normal stool consistency;
- finishing each bowel program within a reasonable time (within 60 minutes);
- feeling secure to fully participate in all desired activities of daily living; and
- keeping your body's digestive system healthy.

As an individual with SCI, your bowel program is only 1 element of bowel management. There are other essentials to successful bowel management.

Schedule: Before your SCI, your body was probably trained to have bowel movements that were fairly predictable. For example, you may have had a BM each morning at roughly the same time of day or every other day. Following injury, you essentially retrain your body to respond with a BM only when stimulated during your bowel program.

You will need to select a time of day when having a BM best fits your lifestyle. If you are newly injured and it is at all possible, you should maintain the same schedule that you began during rehabilitation. You will need to follow your schedule until you are accident free between multiple bowel programs.

Once your body has adjusted and is well trained to respond with a BM only when stimulated, you may then adjust your bowel program schedule if needed. For example, you may prefer to change your bowel program from morning to night or choose to perform a bowel program every other day instead of every day. Whether you change your schedule or not, you should be able to eventually feel fairly secure in maintaining a regular, predictable bowel program.

Nutrition: When and what you eat greatly influences your bowel program. For example, eating a meal, high fiber snack, or drinking a warm liquid (such as hot tea, hot apple cider, etc.) initiates peristalsis in a reflex bowel. If you eat or drink something warm about 30 minutes prior to starting your bowel program, you will likely have more effective results.

Your *fiber* intake helps maintain the health of your entire digestive system. Although some individuals take a fiber supplement, vegetables, fruits and whole grain foods are the recommended sources for getting your daily fiber intake. You need about 25 to 35 grams(g) of fiber each day. However, you need to gradually make changes to your fiber intake because sudden increases in fiber intake can cause diarrhea and decreases in fiber intake can cause constipation.

Some foods, especially eaten in excess, are more likely than others to cause common bowel problems. For example, dairy products, white potatoes, white bread and bananas can contribute to constipation. Fruits, caffeine and spicy foods can cause diarrhea. Beans, corn, onions, peppers, radishes, cauliflower, sauerkraut, turnips, cucumbers, and apples can cause excessive gas buildup.

Water should be your beverage of choice for many reasons. A big reason is that water helps regulate your body's digestive system, keeps your stool from getting too hard, and prevents constipation and impaction. Although fresh vegetables and fruits are good sources for water as well as fiber, you still need to drink the proper amount of water. Generally, your bladder management method will determine how much water you typically need daily.

- Indwelling Catheter - it is recommended that each day you drink about 3 quarts, or 15 (8oz) glasses of water.
- Condom and Intermittent Catheterization - it is recommended that you drink about 2 quarts, or between 8 to 10 (8oz) glasses of liquid per day.

Physical Activity: This promotes easier passage of food through your digestive system.

Medications: Many over-the-counter and prescription medications can influence your bowel program. These include bowel-related medications that you take by mouth (orally) or by suppository, and some medications that you take for other reasons can influence your bowel function. Therefore, you should always talk with your health care provider before taking any medication.

Constipation and diarrhea are common side-effects of medications. For example, codeine, ditropan, probanthine, and aluminum-based antacids can cause constipation. Magnesium-based antacids can cause diarrhea.

Stool softener and *laxative* use are common among individuals with SCI. Although Colace® (stool softener) and Peri-Colace® (stool softener with added laxative) are mild and may be well tolerated by most people, too much or too little dosage may result in diarrhea or constipation.

Antibiotics, which are commonly taken to kill the bacteria that causes urinary tract infection, can also kill the "good" bacteria found in your digestive system. These bacteria are actually beneficial in maintaining the natural balance of organisms (microflora) in the intestines. Maintaining this proper bacterial balance is one key to maintaining and preventing bowel problems. Therefore, *probiotics* are dietary supplements containing potentially beneficial bacteria or yeast. Probiotics are sometimes recommended by doctors during and after a course of antibiotics to replenish and restore the numbers of beneficial bacteria lost to antibiotic use. A popular dietary source for probiotics is yogurt, but other dairy products such as cheese, milk, sour cream and kefir also offer probiotic benefits. A probiotic supplement (pill) is another option.

Regularity: Every individual with SCI is unique, but you will likely agree that an unplanned BM is one of the most embarrassing things that can happen. Your best chance to avoid accidents is with consistent bowel management and established bowel program. For example, you should maintain your routine even if your normal routines get interrupted by travel, sickness or the like. If you have an unplanned BM, you still need to continue your bowel program when it is scheduled. When you do need to make adjustments, talk to you doctor first.

RESOLVING PROBLEM ISSUES

Problem issues can occur even with the best bowel management. It helps to know those common issues and how to manage occasional problems.

Although the following recommended actions are intended to help you resolve problem issues, you should consult your doctor if problems continue. You should also talk with your doctor if you are sick, making changes to your bowel management program, or you have questions.

Constipation: The prominent symptom of constipation is hardened, stone-like stool. Other symptoms of constipation include irregular bowel movements, no BM for several days, swollen or hardened abdomen, and lack of appetite.

Action list until the issue is resolved:

1) Increase your water intake.
2) Do your bowel program on a daily basis.
3) Add or slightly increase the dose of a stool softener (Surfak or Colace).
4) Increase your fiber intake by no more than 5 grams(g) every other day.
5) Increase your physical activity.
6) Avoid bananas, cheese and other foods that can harden your stool.

Impaction: The prominent symptoms of impaction (blockage) are relatively similar to constipation.

Action list until the issue is resolved:

1) Physical (manual) removal of the stool from the rectum. Using a gloved, lubricated finger, gently hook your finger around any stool and remove the reachable stool from the rectum.
2) Increase your water intake.

Diarrhea: The prominent symptom of diarrhea is watery or runny stool.

Action list until the issue is resolved:

1) Increase your water intake.
2) Increase the frequency of your program *only* if

you are having accidents,

3) Temporarily stop taking any stool softener or laxative (if effective, you may need to adjust your dose until your stool is of proper consistency).
4) Increase your fiber intake by no more than 5 grams(g) every other day.
5) If the diarrhea lasts longer than 24 hours or there is blood in the stool, call your doctor.

Diarrhea may even be caused by an impaction (blockage) of stool. This may be the case if you have recently had hardened, stone-like stool or no results from your past several bowel programs.

Autonomic Dysreflexia: AD is a response to a painful or irritating stimulation, which might include an over-extended bowel, rough digital rectal stimulation, or a number of other causes. If you are an individual with a T6 level of injury or above, you should know and be able to recognize the signs and symptoms of AD along with when to take emergency action.

Current research has shown that significant elevations in blood pressure can occur without the signs and symptoms of AD. Called "Silent" AD, it appears that people at risk for AD are also at risk for "Silent" AD, and it seems to be a common occurrence during routine bowel programs. Although "Silent" AD may not prove to be dangerous, you may want to take preventive actions if you are at risk.

Action list until the issue is resolved:

1) Talk to your doctor about prescribing an anesthetic lubricant such as Lidocaine Gel 2%.
2) Insert a small amount of anesthetic lubricant into your rectum prior to starting your bowel program.
3) Get into a comfortable position.
4) Increase the frequency of your bowel program to prevent rectal over extension.
5) Maintain normal stool consistency.
6) Contact your health care provider.
7) Always seek emergency treatment if needed.

Frequent Accidents: Once your bowels are retrained to empty at a planned, regularly scheduled time, unplanned bowel movements and mucus drainage should rarely occur. If there are more than 1 or 2 accidents per year, you should probably take action.

Action list until the issue is resolved:

1) With a reflex bowel, make sure you are completely empty of stool and mucus at the end of your bowel program.
2) Review your entire bowel management program and adjust your schedule (individuals with a flaccid bowel may consider a more frequent bowel program), food/water intake, physical activity and medications if needed.

Little or No BM: Again, the frequency between each BM differs greatly among people, so you will need to consider what is normal for you when determining if this is a problem. Although you will have occasions when you get limited or no BM results, you should probably be concerned if you have limited or no BM results after 2 days if you have a daily bowel program or 4 days if your bowel program is every other day.

Action list until the issue is resolved:

1) If you have little or no BM results 1-2 days past your normal bowel program schedule, follow the recommended actions for constipation.
2) Contact your health care provider after 3 to 4 days of little or no BM results past your normal bowel program schedule.

Bleeding: This is usually caused by hardened stool or too vigorous or under lubricated digital stimulation.

Action list until the issue is resolved:

1) Follow the recommended actions for constipation if your stool is hardened.
2) Keep fingers well lubricated when physically removing stool or performing digital stimulation.
3) Be less aggressive with digital rectal stimulation.
4) Keep finger nails trimmed.
5) Contact your doctor if there is heavy bleeding.

Excess Gas: Build-up of gas in the digestive system can result in feeling full, tight or bloated, and excess passing of gas is socially embarrassing.

Action list until the issue is resolved:

1) Limit yourself when eating gas causing foods (see page 3 for list)
2) Try eating cumin, coriander, or caraway because

these spices have been reported to counteract the production of intestinal gas.

3) Take an over-the-counter, anti-gas medication.
4) Add or increase your probiotic intake to help reduce flatulence by restoring balance to the normal intestinal flora.

Bowel Program takes too Long: Your bowel program should last no longer than 1 hour once you have worked out your bowel management routine.

Action list until the issue is resolved:

1) Review your entire bowel management program and adjust your schedule (individuals with a flaccid bowel may consider a more frequent bowel program), food/water intake, physical activity and medications if needed.

COLOSTOMY

A colostomy is a surgically-created hole leading from the large intestine to the outside of the abdomen. Typically, a bag is placed over the abdomen hole to collect the stool before it gets to the rectum.

Do not necessarily rule out a colostomy on first thought. They seem to be becoming more popular among individuals with SCI, especially people with constant bowel problems. In such cases, a colostomy can greatly improve quality of life.

You might start by researching colostomy use and how it works as a bowel program option. If it is an option you are interested in, talk first with someone with SCI who has one. Then, talk to a physiatrist (doctor in rehabilitation medicine) to discuss your options.

GETTING OLDER

Like everyone else, individuals with SCI can experience changes in bowel function as they get older. Some changes such as the frequency of bowel movements can be common with aging. However, you should talk to your doctor if you notice any changes to make sure there is not some other problem.

CONCLUSION

Following SCI, bowel management is a life-long balancing act to maintain control over your bowel movements. You may work as long as a year to figure out what is and is not effective. Once you find that balance, however, you will see that it is one of the most important aspects to maintaining your quality of life.

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Published by:
Office of Research Service
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
Please check out our website at www.spinalcord.uab.edu

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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Weight Management following Spinal Cord Injury

Spinal Cord Injury InfoSheet 8

Level - Consumer

INTRODUCTION

Weight management is more than losing weight. It is a lifestyle that requires a commitment to promote improved long-term health. You have to learn and use skills to lose and maintain weight loss through proper nutrition, behavioral changes, participation in physical activities, and long-term planning.

As a person with spinal cord injury (SCI), you can benefit in many ways from a healthy weight management program. You may help...

... lower your risk for premature death and the development of some forms of cancer, heart disease, high blood pressure, diabetes, respiratory illness, pressure sores, urinary tract infection and urinary stones;

... decrease feelings of anxiety, loneliness and stress;

... improve muscle strength, endurance, self image, and your ability to fall asleep and to sleep well; and

... manage your muscle spasms, chronic pain and bowel program.

At this time there are no national guidelines on weight management for individuals with SCI. Therefore, it is essential that you talk to your doctor before changing or modifying your diet and exercise regimens. Everyone has individual health concerns. Your doctor can make suggestions regarding your individual situation and your specific medical conditions.

AFTER SPINAL CORD INJURY

People usually experience dramatic weight changes after SCI. The body is under great stress at the time of the initial trauma, so the body's metabolism (how fast the body burns calories) works quicker to provide energy and nutrients to try to heal the body and fight infections. As a result, individuals who are newly injured commonly experience weight loss. Over time, the body's metabolism slows due to inactivity and a decrease in muscle mass. The body needs fewer calories each day. This change in the body's metabolism contributes to weight gain for many individuals living with SCI.

If you want to lose weight, you first reduce your daily calorie intake. Most men with SCI and women who are physically active can probably lose weight with a limit of 1,800 calories per-day. Most women with SCI and men with small body frames can probably lose weight with a limit of 1,500 calories per-day.

UNDERSTANDING NUTRITION

Most everyone benefits from proper nutrition. Overall, healthy nutrition can help to:

- give you energy;
- fight infections;
- maintain proper body weight; and
- keep all your body systems working properly.

Choosing Healthy Foods

You may not know it, but you can probably lose weight and improve your health by simply making healthier food choices. In general, there are 5 food groups. You want to choose foods that offer the greatest nutritional value with the fewest calories: you want to eat more vegetables than fruits, more fruits than starches, more starches than meat and dairy foods, and more meat and dairy foods than fats.

5 FOOD GROUPS
Vegetables
Fruits
Starches & Grains
Meats & Dairies
Fats & Oils

Your body actually needs vital nutrients from all 5 food groups, but you can make the healthiest choices within each group. Fresh vegetables and fruits are healthier than canned items that contain added salt and preservatives. Whole grain breads and cereals are healthier than regular. Fish, skinless poultry, lean meats, low-fat dairy and soy products are healthier than veal, peanut butter and regular eggs, cheeses and milk. Foods higher in monounsaturated and polyunsaturated (specifically omega-3) fats are healthier than foods high

Nutrient	Natural Function in Overall Health (Source: Report of the Dietary Guidelines Advisory Committee on the Dietary Guidelines for Americans, 2005)
Vitamin A	Plays a significant role in vision, gene expression, cellular differentiation, morphogenesis, growth, immune function, and maintenance of healthy bones, teeth, and hair.
Vitamin C	As a dietary antioxidant, vitamin C counteracts the oxidative damage to biomolecules, strengthens blood vessels, maintains healthy gums, and aids in the absorption of iron.
Vitamin D	Helps maintain normal blood levels of calcium and phosphorus.
Vitamin E	As a dietary antioxidant, vitamin E counteracts the oxidative damage to biomolecules; in addition, vitamin E helps in the formation of red blood cells and muscles.
Magnesium	Plays a key role in the development and maintenance of bones, as well as activates enzymes necessary for energy release.
Potassium	Assists in muscle contraction, maintaining fluid and electrolyte balance in cells, transmitting nerve impulses, and releasing energy during metabolism. Diets rich in potassium lower blood pressure, blunt the adverse effects of salt on blood pressure, may reduce the risk of developing kidney stones, and may decrease bone loss.

in saturated and trans fats (any food having the word "hydrogenated" on its ingredients list contains trans fats, which are the unhealthiest of all fats).

No matter what your level of impairment, you can improve, control or prevent many health problems with a proper balance of nutrients. However, there are specific nutritional needs that you need to know.

Fiber

Vegetables, fruits and starches are the best natural sources for fiber. It helps maintain the health of the digestive tract and proper bowel functioning. You need about 25 to 35 grams(g) of fiber each day. However, you need to gradually make changes to your fiber intake because sudden increases or decreases in fiber intake can cause irregularities in your bowel program.

Protein

Meat, beans and dairy products are the main sources for protein, and the healthiest sources include eggs, fish, seafood, lean meats (90% fat-free by weight or higher), low fat milk (1%) and low fat cheese (2%). Protein is essential for healthy muscles and skin and helps fight infections. Normally, you need 70g to 90g of protein per day, but you need to avoid high protein, low carbohydrate diets because such diets put you at higher risk for kidney problems.

Calcium

Dairy products are the best source for calcium, which is the key nutrient in developing and maintaining bones mass. Calcium also helps in blood clotting and muscle and nerve functioning. In general, you need about 1,200 milligrams (mg) of Calcium daily. People with osteoporosis as well as adults over 50 (especially women) need to consult their doctors regarding their daily calcium intake.

Sodium

Sodium (most commonly found in salt) is needed for the regulation of your body's fluid balance, contraction of muscles and conduction of nerve impulses. Adults should normally limit sodium to between 500mg and 1,000mg per day. Too much sodium causes your body to retain water and puts you at higher risk for swelling, heart or kidney disease and stroke. Limited sodium intake reduces the risk for health problems and swelling.

Water

Water should be your #1 beverage choice! In general, water helps regulate the body's temperature and the digestion of food. For individuals with SCI, water helps prevent urinary tract infections as well as kidney and bladder stones. Water is also important in regulating bowel management. Although fresh vegetables and fruits are good sources for water, it is generally recommended that individuals with SCI drink at least 8 cups (64 ounces) of water per day.

BEHAVIOR CHANGES

Planning Meals

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

When you plan meals, you should consider 6 factors:

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

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

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

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

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

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

Shopping

In general, groceries have a similar layout. The outer perimeter of the store has fresh foods, which are usually the healthiest. Foods are usually not as healthy on inside aisles. Therefore, you want to buy most of your foods from the outer perimeter.

You might also buy convenience foods to keep on hand for quick meals. You might like healthy "ready made" meals that are easily cooked in the microwave. You might buy canned beans, vegetables, fruits, soups and tuna. However, you want to buy pre-cooked and canned foods with little or no salt and sugars added and avoid those foods with preservatives.

You need to compare Nutrition Facts labels of similar products to make healthier choices. In general, it is best to buy foods lower in cholesterol, fats, sugars and sodium. Compare labels and choose foods higher in the healthier monounsaturated and polyunsaturated fats and lower in the unhealthiest saturated and trans fats.

Cooking

The key to healthy cooking is to reduce the fat. While some fats are healthier than others, all fats are high in calories. The healthiest way to reduce fats is by eating more fruits and vegetables and less meats and dairy products. When cooking, you can substitute oil or butter by using a small amount of water, wine, flavored vinegar, or fruit juice. Instead of bacon or ham to add flavor, try bacon bits or lean lunch meat slices of ham. Fat-free chicken, beef, or vegetable broth is a great alternative for flavor. When oil must be used, olive and canola oils are more nutritional choices. Bake, broil, grill, roast, steam and sauté your foods. You might also use a rack or broiling pan when roasting meats and poultry to allow excess fats to drain away from meat.

Microwave cooking can also reduce fat. You can cook foods quickly without losing a lot of nutrients. You can cook healthy precooked meals or create your own microwave dishes. When you create great tasting dishes, write down and reuse your recipes.

Dining Out

Some foods are healthier than others no matter what

Sample of How Portion Sizes Have Changed

Food Item	**Calories per Portion 20 Years Ago**	**Calories per Portion Today**
Bagel	140 calories (3 in. diameter)	350 calories (6 in. diameter)
Fast food cheeseburger	333 calories	590 calories
Fast food French fries	210 calories (2.4 oz)	610 calories (6.9 oz)
Bottle soft drink	85 calories (6.5 oz.)	250 calories (20 oz.)
Turkey sandwich	320 calories	820 calories (10 inch sub)

restaurant you visit. One key to healthy dining is to avoid over eating. Many people like to visit family-style restaurants that feature food buffets. However, people who eat from buffets have a tendency to over eat. You want to also limit portion sizes when dining out. If possible, you might reduce your portion size by ordering an appetizer or lunch portion. You might split a main course with someone or eat half and have the rest wrapped up to take home. Never "up-size" meals!

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

The average fast food meal contains about 1200 calories! It is best to limit your meals to approximately 500 calories and 15 - 20 grams of fat. You should ask for the nutritional guide and select foods lower in calories, cholesterol, fat, sugar, and salt. Add flavor and bulk to sandwiches with lettuce, tomatoes, sprouts, pickles, peppers, or onions. Choose grilled chicken, baked potato, or salad instead of hamburgers and fries.

You also want to make healthy beverage choices. Water is best. You might try 1% or fat-free milk, low-calorie soft drinks or unsweetened tea or coffee. Avoid high-calorie soft drinks, milkshakes and drinks with alcohol.

Improving Self-Talk

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

- *"I can't exercise because I'm in a wheelchair"* or
- *"I'll never be healthy because of my condition."*

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

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

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

Ultimately, it is really up to you to take control of your life. With practice, you can improve your self-talk to improve your overall health.

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

Reducing Stress

Managing stress is an important key to maintaining healthy behaviors because your eating behaviors often change when you're under stress. People who constantly experience symptoms of stress are often at higher risk for serious health problems including illness, addiction and depression.

Symptoms of Stress

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

No one is going to be stress free, but you can minimize the impact of stress. There are many things you can do to feel better emotionally and physically.

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

Setting Goals

Realistic goals help give you direction and purpose. Short-term goals usually take no more than a couple of weeks to achieve, and long-term goals take longer.

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

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

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

Body Mass Index

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

Source: National Heart, Lung and Blood Insitute

PARTICIPATING IN PHYSICAL ACTIVITIES

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

No matter what your level of impairment, do not limit your physical activities solely based on the fact that you have limited mobility. You can get substantial health benefits from 20 to 30 minutes of moderate physical activity every other day. Moderate activities require some physical exertion, but you should be able to comfortably carry on a conversation while participating.

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

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

MAINTAINING LONG-TERM SUCCESS

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

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

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

This InfoSheet briefly outlines the ***EatRight***™ *Home-Based Weight Management Program for Individuals with Spinal Cord Impairment* funded by the PVA Education Foundation and developed by the UAB Department of Physical Medicine & Rehabilitation in cooperation with the Department of Nutrition Sciences. ***EatRight***™ is a comprehensive program on the 12 proven elements of effective weight management. The home-based program utilizes video lessons and workbook assignments to guide consumers through the 12-week weight management program. It can be purchased from the UAB Office of Research Services at 205-934-3283.

Published by: Office of Research Service
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Date: **January, 2005**
Edited by: Phil Klebine, MA; Linda Lindsey, MEd; Yuying Chen, MD PhD; Suzanne Henson, MS RD LD; Christina Oleson, MD; Shirley Estill, BA

This publication is supported by grant #H133B980016 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Challenges of Spastic Hypertonia

Spinal Cord Injury InfoSheet 16

Level - Consumer

WHAT IS SPASTIC HYPERTONIA?

Spastic Hypertonia (SH) is a term that doctors are now using to offer a more complete description of spasticity and various conditions of extreme muscle tension. Spastic Hypertonia refers to uncontrollable "jerking" movement (muscle spasms), stiffening or straightening out of muscles (rigidities), shock-like contractions of all or part of a muscle or group of muscles (myoclonus), and abnormal tone in the muscles (dystonia).

UNDERSTANDING SENSATION & REFLEX

When people touch something hot, their first reaction to the sensation of heat is to quickly jerk away from the heat. This is an example of a reflex reaction to touch or pain. The body reacts to signals that are sent through nerves from the area of sensation to the various reflex centers of the body. The reflex center in the brain works best at identifying sensations and sending signals back through nerves in the spinal cord to tell your body how to react. Other reflex centers are located at different levels of the spinal cord, but these reflex centers are not as accurate as the brain in identifying sensations and telling the body how to react to those sensations. The body reacts best when all of the body's reflex centers are working together to identify sensations and tell the body how to react.

AFTER A SPINAL CORD INJURY

Spastic Hypertonia does not occur immediately after spinal cord injury. When individuals are first injured, their muscles are weak and flexible because their body's reflexes are absent below the level of injury. This condition is known as "spinal shock," which can last for a few weeks or several months.

Once the spinal shock is over, reflex activity returns. However, the normal flow of nerve signals below the level of injury is interrupted. Those signals may not reach the reflex center of the brain. If all of the body's reflex centers cannot work together to moderate the body's response to those signals, the reflex centers of the spinal cord attempt to moderate the body's response. Because the spinal cord is not as efficient as the brain, the signals that are sent back to the site of the sensation are often over exaggerated. This is an over active muscle response and now referred to by doctors as Spastic Hypertonia.

Most individuals with SCI experience Spastic Hypertonia in some form, but they do not necessarily experience SH all of the time. Persons with tetraplegia and persons with incomplete injuries are more likely than persons with paraplegia and persons with complete injuries to experience SH. It is most common for individuals with SCI to experience muscle spasms that bend the elbow (flexor) or extend the leg (extensor). These spasms usually occur as a result of an automatic response to painful sensations. Many individuals who are newly injured often mistake their first movements caused by SH as a return in motor movement.

EFFECTS OF SPASTIC HYPERTONIA

Many individuals with SCI take advantage of their muscle spasms to help them perform activities of everyday living. For example, some individuals learn to trigger spasms in their hands and fingers to help pick up light items such as a pencil or magazine. Some people may learn to use their spasms to help empty their bladder, do pressure reliefs, transfer, dress, and even stand or walk.

It is normal for individuals who are newly injured to experience changes in their muscle tone and central nervous system soon after injury. However, a change in your spasms after your initial injury can act as a warning sign that there is a problem in areas where you may have no feeling. If you do not normally have SH and start to experience muscle spasms or if your spasms get worse or even decrease, you should talk to your doctor. Any type of change can be a warning sign for problems such as a pressure sore, urinary tract infection, ingrown toenail, tight clothing or constipation. It may also be a warning for autonomic dysreflexia, a broken bone, a tumor or cyst, transverse myelitis or a spinal cord stroke.

Possible Advantages of Spastic Hypertonia

1. Maintain muscle tone and mass.
2. Reduce bone loss and decrease the risk for osteoporosis.
3. Increase metabolic requirements such as promoting blood circulation and improving breathing.
4. Better perform daily self-care routines such as assisting in pressure reliefs to prevent pressure sores and emptying reflex bladder and bowel.
5. Better perform daily functions such as picking up items, transferring or walking with braces.
6. Warn when there is a problem in areas where the body has no feeling.

GETTING TREATMENT

You do not necessarily have a medical problem simply because you have Spastic Hypertonia. It is usually treated when the spasms interfere with normal range of motion or regular daily activities. For example, upper extremity muscle spasms may keep an individual with tetraplegia from dressing, eating or performing other daily grooming routines.

Possible Disadvantages of Spastic Hypertonia

1. Limit range of motion.
2. Cause pain due to stress put on joints and muscles.
3. Interfere with daily functions such driving, walking with braces, and other activities.
4. Cause unwanted bladder or bowel release.
5. Interfere with other activities such as sexual activity, sleeping, changing position, sitting or transferring.
6. Affect posture and ability to sit comfortably, maintain balance or change positions.
7. Cause scraping of the skin and increase the risk for pressure sores.
8. Add to cost of medications and attendant care.

The National Spinal Cord Injury Statistical Center (NSCISC) keeps a national database recording the incidence of medical complications for individuals with spinal cord injury. According to NSCISC, 42.7% of individuals with SCI are treated for "spasticity severe enough to have warranted a trial of medication or surgical treatment at admission, at discharge and at annual follow-up" within one year after injury.

QUALITY OF LIFE

The goal of all treatments is to improve quality of life (QOL). However, many individuals do not know when treatment is necessary. It may be hard to decide if SH is having more of a positive or negative impact on your QOL. You can ask yourself the following questions to help you decide whether or not treatment is right you:

- Do your spasms limit your independence by keeping you from doing things for yourself and participating in activities that you want to do?
- Do you need more personal assistance because of your Spastic Hypertonia?
- Do your spasms put you at risk for losing control of you power chair, car or van?
- Do you lose sleep because of your spasms?
- Do your spasms put you at risk for other medical problems such as a pressure sore?

TREATMENT FOR SPASTIC HYPERTONIA

If you decide that treatment for Spastic Hypertonia may improve your QOL, you should talk with a doctor who is familiar with individuals with SCI. Some treatment options can be dangerous, and even life-threatening, if not properly monitored by a doctor. There are other important factors to consider in deciding on treatment.

- What is the cause (etiology) of your SH?
- Do you have a support network if you need help in taking your medication or applying a splint?
- Do you need transportation to and from the doctor to get treatment and follow-up examinations?
- Do you have other current medical problems such as a lack of balance, numerous infections, high/low blood pressure, depression?
- Do you live in an area where you can get treatment?
- What treatments are covered by medical insurance or will you have to pay for treatment?

TREATMENT OPTIONS

Rehabilitation

Daily *Range of motion* and regular stretching as prescribed by a physical therapist can promote relaxation of the spastic muscles. *Standing devices*, or standing frames, have shown to be a helpful treatment in reducing SH for some individuals because standing can counteract the flexor tendency promoted by sitting.

Medications

The most widely used option for treating SH is medications. Some medications are taken by mouth (oral) or by feeding tube (enteral feeding). One medication , *Clonidine* (Catapres-Tts®), can be delivered by a skin patch (transdermal system). This method provides a more balanced blood drug level throughout the day. Your doctor may first prescribe oral medications because they are usually effective for individuals with SCI.

Benzodiazepines [*Diazepam* (Valium®), *Clonazepam* (Klonopin® or Rivotril®)] act on the central nervous system and result in a decrease of overactive muscles and fewer painful spasms. These drugs are sedative/ hypnotics and used mainly for nighttime spasms and sleep disturbances. Common side effects are dizziness, drowsiness, impaired memory and attention, and loss of strength. These medications can be addictive for some individuals, so a sudden stop in use may cause symptoms of withdrawal.

Baclofen (Lioresal®) is another medication that works through the central nervous system. It helps to improve passive range of motion and reduces muscle spasms, pain and tightness. Daily functioning and activities of daily living may not improve with baclofen use. Some individuals reported side effects such as dizziness, drowsiness, weakness, fatigue and nausea.

Dantrolene sodium (Dantrium®) is a medication that works differently than benzodiazepines and baclofen. It acts at the muscle, rather than on the central nervous system, where it interferes with muscle contraction. Dantrolene improves passive movement, decreases muscle tone and reduces muscle spasms, tightness and pain. Its use has been limited with individuals with SCI because it is not selective for spastic muscles. Dantrolene can cause generalized weakness to all muscles, including the respiratory muscles. This drug is metabolized in the liver and requires a blood test to monitor liver enzymes. The most common side effects are dizziness, drowsiness, diarrhea, fatigue and weakness.

Tizanidine (Zanaflex®) is a medication that reduces SH by acting on the central nervous system. It does not reduce the strength of muscles as much as other types of oral or transdermal medications. It is a short acting drug and should be taken during daily activities when the relief of SH is most important. Some individuals may experience side effects such as sedation, dizziness, and low blood pressure.

Several other drugs are currently being studied to determine their effectiveness on spastic hypertonia. These include *Gabapentin* (Neurotin®) along with *Clorazepate* (Tranxene®), which has been reported to have less of an effect on sedation, memory and recall.

Motor Point Blocks

Chemodenervation is the use of chemicals injected directly into the muscle to interrupt the flow of nerve impulses to the spastic muscles. Some of these chemicals include Botulinum Toxin Type A (BOTOX® and Dysport®), Botulinum Toxin B (Myobloc®), and Phenol and Alcohol. They work by reducing muscle contractions and allowing a more normal position or function of the involved limb. The overall effect is a temporary, localized muscle weakening. Each chemical has advantages and disadvantages, so you should talk to your doctor about any possible risks or side-effects to the treatment.

Surgical

Individuals who choose surgery as an option should understand that most of these procedures are nonreversible. For example, once a nerve is cut, there is no procedure to restore the nerve function.

Orthopedic surgery is done to correct or counterbalance the effects of SH through various procedures to muscles, tendons or bones. There are four common types of these orthopedic surgeries.

1 <u>Contracture release</u> either partially or completely cuts a tendon to release a contractured muscle. A contracture is an abnormal joint posture due to persistent muscle shortening. When muscles are not stretched regularly, the tendons shorten and tighten, which limits the muscle's full range of motion.

2. Tendon transfer moves the attachment point of a spastic muscle. This means that the muscle can no longer pull the joint into a deformed position.
3. Osteotomy is removing a small wedge from a bone to allow it to be repositioned or reshaped.
4. Arthrodesis is the fusing together of bones that normally move independently.

Dorsal root rhizotomy is a treatment rarely used for individuals with SCI. The procedure interrupts the reflex arcs or sensory inputs to the spinal cord when the nerve roots are cut, burned or chemically injured.

Intrathecal

Intrathecal medication is a fast growing treatment option. First, an Intrathecal Pump (IP) is surgically implanted into the abdomen. The difference in the IP and other surgical options is that the IP surgery is reversible. Second, the IP has a reservoir of medicine (usually the same baclofen used as an oral medication). The medicine is pumped through a small tube directly to the fluid surrounding the spinal cord.

Advantages of the Intrathecal Pump

1. Medicine is sent directly to the nerve cells where it is needed.
2. Medicine dosage can be adjusted as needed.
3. Much less medication is needed than if it were taken orally, which reduces side effects.
4. Reservoir is easily refilled by injection when needed.
5. Surgery is reversible.

Disadvantages of the Intrathecal Pump

1. Requires surgery to implant the pump.
2. Expensive.
3. Tubing can become disconnected or kinked.
4. Risks include infection, baclofen overdose, pump dysfunction, and developing symptoms of withdrawal.

EVALUATING TREATMENT

You should keep in close contact with your doctor and continue to reevaluate your current quality of life (QOL). Your doctor may know of new treatment options that may improve your QOL. When evaluating your treatment, ask yourself;

a) Am I more or less independent in my daily activities since I began treatment?
b) Do I have problems with concentration or memory?
c) Do I have more or less pain than I did before treatment?

You may decide that your current treatment is not improving your QOL. You may want to consider another treatment option, or you may also decide that no treatment is the right option for you.

AGING AND SPASTIC HYPERTONIA

It is believed that aging results in an overall decrease in Spastic Hypertonia. In the normal process of aging, your nerve conduction slows down, muscle mass and size decrease, and blood circulation within the spinal cord can diminish. Plus, many individuals become more comfortable with their SH as they get older. They know what triggers their spasms. They either try to avoid those triggers or learn to use their spasms to improve their ability to perform everyday activities. Finally, NSCISC reports the number of individuals treated for spasticity gradually declines from 42.7% in the first year after injury to under 35% after 10 years of follow-up.

CONCLUSION

Spastic Hypertonia is common for individuals with SCI. However, not all individuals choose treatment. If you decide that treatment for SH might improve your quality of life, it is up to you and your doctor to choose the treatment option that is best for you.

Published by:
Office of Research Service
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
Please check out our website at www.spinalcord.uab.edu

Date: **December, 2001**
Developed by: Jay M. Meythaler, MD, JD
Editors: Linda Lindsey, MEd; Phil Klebine, MA

This publication is supported by grant #H133B980016 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Heterotopic Ossification

Spinal Cord Injury
InfoSheet 12
Level - Professional

INTRODUCTION

Heterotopic ossification (HO) is the development of bone in abnormal areas, usually in soft tissues. Heterotopic ossification develops most commonly in individuals who have an injury, such as spinal cord injury, that results in neurologic deficits. It is therefore referred to as ***neurogenic heterotopic ossification***.

CLASSIFICATION

Samuel L. Stover, M.D. developed a classification that differentiates between myositis ossificans and heterotopic ossification. The four types of soft tissue ossification are:

1- myositis ossificans progressiva which occurs in childhood and progresses until death (often in the early 20's);
2- myositis ossificans traumatica which follows injury to muscle tissue;
3- myositis ossificans non-traumatica which has an unknown etiology and
4- neurogenic heterotopic ossification.

CAUSE / ETIOLOGY

No one is quite sure what causes heterotopic bone formation. Many reports propose it is related to a type of mesenchymal metaplasia, meaning that connective tissue cells change their characteristics into bone forming cells. It is not known why the cells change function but it is thought to be some type of inflammatory reaction.

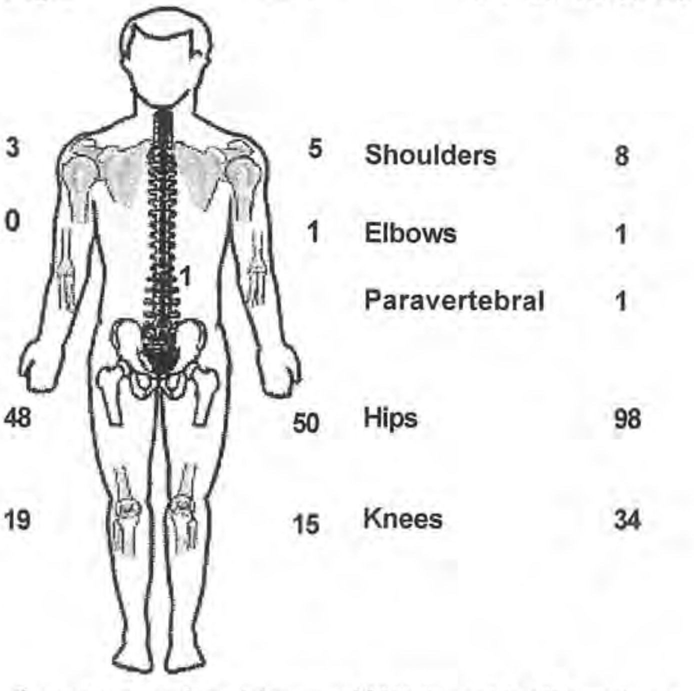
In individuals with spinal cord injury, heterotopic ossification will usually begin forming in the intramuscular connective tissue within four months of the injury. When the reaction begins, there will be a deposition of calcium phosphate in the intramuscular tissue. However, ossification occurs only when the calcified material goes on to form hydroxyapatite crystals. Once bone formation has occurred, it rarely disappears spontaneously.

INCIDENCE AND LOCATION

The incidence rate of heterotopic ossification in individuals with spinal cord injury is approximately 16 to 53 percent. It will always occur **below** the level of injury.

Heterotopic ossification may occur anywhere in the body but is most frequently found around the joints or long bones. HO is most commonly found around the hips, followed by the knees, shoulders and elbows and sometimes in the paravertebral area. It has also been reported to occur at the ankles and at the base of pressure sores. In the hips it is most common in the flexor or adductor areas. In the knees it occurs along the medial-collateral ligament. Heterotopic

Location & Incidence of HO



Right	Left	Joints	Involved
3	5	Shoulders	8
0	1	Elbows	1
		Paravertebral	1
48	50	Hips	98
19	15	Knees	34

Location and incidence of HO found in 77 patients by prospective x-ray survey of 250 SCI patients. Some patients had multiple joint involvement.[3]

ossification in the shoulders is usually mild and does not cause much clinical difficulty with function.

DIAGNOSIS

If only a small amount of bone is forming there may not be any clinical signs or symptoms. If it is a large formation, the patient may experience all the symptoms of an inflammatory process. When heterotopic ossification occurs around the hip, there is usually swelling of the leg (most pronounced around the hip area). There may be redness, heat in the leg, and the patient may have a low grade fever. The physician will then have to differentiate between other problems which can cause leg swelling, particularly thrombophlebitis, deep venous thrombosis, cellulitis, joint sepsis, hematoma, fracture and trauma. Most can be easily distinguished on a clinical basis or by routine x-ray, however a venogram and bone scan are needed to differentiate between deep venous thrombosis and early heterotopic ossification.

A negative venogram will generally rule out deep venous thrombosis, but does not automatically confirm a diagnosis of heterotopic ossification. Conversely, a negative bone scan will rule out heterotopic ossification, but does not give a conclusive diagnosis of deep venous thrombosis. Both tests are required because deep venous thrombosis and heterotopic ossification may occur in the same patient in the same extremity; therefore having one condition does not preclude the other condition.

In addition, the bone scan will show heterotopic ossification seven to ten days earlier than an x-ray. The three-phase bone scan is perhaps the earliest method of detecting heterotopic bone formation. However, in some cases, an abnormality may be detected in the early phase which does not necessarily mean it will go on to form heterotopic bone. Another finding, often misinterpreted as early heterotopic bone formation, is an increased (early) uptake around the knees or the ankles in an early spinal cord injured patient. It is not clear exactly what this means because these patients do not develop heterotopic bone formation. It has been hypothesized that this may be related to the autonomic nervous system and its control over circulation.

When heterotopic bone forms a year or more after spinal cord injury, it is usually caused by some other predisposing factors. It is most frequently the result of infection, either localized or generalized. If a septic hip develops, heterotopic bone often forms around the joint. A severe systemic illness occasionally will cause this type of reaction. Also, surgery to the area or a more distant area may induce late onset heterotopic ossification. The hip is particularly susceptible in these cases.

PREVENTION AND TREATMENT

Preventing heterotopic ossification should be the primary focus of treatment. Resulting complications of severely decreased range of motion and contractures can interfere with an individual's mobility and self-care. This can cause problems with sitting and activities of daily living.

Once HO forms, surgery is the only viable option. Anti-inflammatory agents, calcitonin, diathermy, and ultrasound have not been effective in treating heterotopic ossification once it is formed. Evidence supporting radiation therapy as an effective method of preventing heterotopic ossification is increasing. It seems to be particularly helpful for patients who have had total hip replacement surgery. Patients receiving radiation therapy during the first week to ten days following surgery appear to have less heterotopic bone formation than those who do not, but more research is needed in this area.

Because of the pain associated with myositis ossificans traumatica, some feel the initial treatment should call for bedrest. However, with loss of sensation in spinal cord injury patients, a reasonably aggressive passive exercise program to maintain range of motion should be continued.

Certain antiinflammatory agents, such as indomethacin, ibuprofen and aspirin, have shown some effect in preventing reoccurence of heterotopic ossification after total hip replacement. Although not evaluated in persons with spinal cord injury, these agents may also have some value in preventing the initial formation. The drug etidronate disodium (Didronel) was one of the first therapeutic agents that seems to have a definite effect on preventing heterotopic bone. A multi-center, double-blind, placebo controlled study was conducted with 181 participants. Treatments were given 21 and 120 days after injury for 12 weeks. For two weeks a dosage of 20mg per kilogram per day was given and this was followed by ten weeks of 10mg per kilogram per day.

By the end of the twelve weeks, those in the placebo group showed much more bone formation than the patients in the drug treated group. At nine months after ending treatment, both groups still had some increase in heterotopic bone formation, but the treatment group never developed as severe heterotopic ossification as the placebo group. Overall, the treatment does not affect the incidence of bone formation, but the severity of heterotopic ossification appears to be less for those patients receiving etidronate disodium. The drug does not prevent the inflammatory reaction but it does help prevent ossification during the initial few months when heterotopic bone formation is most likely. Thus, the predisposition for ossification is decreased.

Should the patient develop an inflammatory reaction or show definite signs of recurrence during the twelve weeks of prophylactic treatment, medication should be continued for six months to a year if a large amount of heterotopic bone is forming.

The most common side effects of the drug are nausea and occasional vomiting. About 15 to 20 percent of patients will suffer from these problems, which are often relieved by dividing the dosage in half and administering the medication twice daily. The medication should also be given when the patient has an empty stomach. Symptoms are fully relieved once the drug is discontinued. Most patients will also develop hyperphosphatemia, because the drug increases the serum phosphate level. This also returns to normal once the drug is discontinued. Another possible complication may be osteomalacia. If the etidronate disodium is given for six months or more, osteomalacia may develop. However, there is no evidencwhen the drug is continued for a prolonged period.

More recently, initial intravenous etidronate disodium has been advocated. Antiinflammatory agents and radiation therapy may actually prevent the inflammatory reaction and matrix formation, whereas disodium etidronate prevents the ossification of the matrix.

If ossification continues during treatment, the most likely answer may be lack of drug compliance. First determine whether the patient is actually taking the medication and then make sure the drug is being absorbed. Checking the serum phosphate level will give a good indication as to whether the etidronate disodium is being absorbed. If the serum phosphorus level had not increased, it may mean the drug is not being absorbed.

SURGICAL INTERVENTION

When surgery is indicated to remove heterotopic ossification, first eliminate all signs of infection in the patient. Any pressure ulcers or skin lesions should be completely healed before undertaking surgery. Also, a urine culture and sensitivity should be done two weeks before surgery. A sterile urine should be obtained before surgery, because the literature suggests that an infected bladder may lead to an infection in the hip. In addition these patients should be placed on prophylactic antibiotics which should be continued postoperatively.

No matter which joint is operated on, during surgery remove enough bone with a wedge resection so that functional range of motion will be achieved. Attend to hemostasis during surgery and use suction drainage postoperatively. During recovery, start graduated range of motion exercise very slowly. In patients injured for several years, there will be severe osteoporosis of the bone from disuse, so extreme care is necessary during surgery and postoperatively to prevent fractures.

After surgery, careful observation is warranted for recurrence of the heterotopic bone, infection, and hemorrhage. Many times the recurrence of heterotopic bone may be avoided if surgery is deferred until the bone is mature; however, the problem is in assessing whether the bone is mature. X-rays and biopsies do not give an accurate determination of maturity. It is also very difficult to get an accurate maturity reading from a bone scan because each scan must be replicated at the same point of bone in order to quantify whether the bone is in a plateau phase. In addition, there is some indication that even when the bone is shown to have a plateau uptake of radionuclide on the bone scan, sometimes this bone has variable turnover rates and what was thought to be a plateau phase becomes active several months later.

To minimize recurrence of heterotopic bone after surgery, etidronate disodium is given 20mg per kilogram per day for two weeks prior to surgery and 10mg per kilogram per day postoperatively. However, some patients, particularly those with total hip replacement, must be maintained on 20mg per kilogram per day postoperatively because the lower dosage will not be enough to prevent recurrence. In addition, because of the risks and frequency of postoperative recurrence, radiation therapy and indomethacin should also be given as recommeded in the total hip replacement literature. It is suggested that the patient be kept at rest for the first week post surgery, then begin passive range of motion exercises as part of physical therapy.

CONCLUSION

In conclusion, more information is needed about the basic pathophysiology of heterotopic ossification, its causes, prevention and treatment. Until more is known, continuing range of motion exercises and treatment with etidronate disodium and antiinflammatory agents seems to be the best course of prevention. These measures minimize development of heterotopic bone in newly injured spinal cord patients and also postoperatively in individuals with SCI.

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Published by:
Office of Research Service
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Review Date: March, 2009
Reviewed By: C.T. Huang, MD
Developed by: Samuel L Stover, MD (1997)
Edited by: Linda Lindsey, MEd, Media Specialist (1997)

UAB PHYSICAL MEDICINE AND REHABILITATION
SPAIN REHABILITATION CENTER

Sexuality for Women with Spinal Cord Injury

Spinal Cord Injury
InfoSheet
21
Level - Consumer

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

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

Sexual Function

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

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

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

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

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

Fertility

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

Sexual Adjustment

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

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

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

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

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

You and Your Partner

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

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

Areas of Concern

Table 1 ranks ten common areas of concern for women with SCI. While these concerns may be more common right after injury, these are life long issues that may always need special attention. The best way to feel good about these concerns are to discuss them with your partner ahead of time, be aware of what could happen and be prepared to deal with any problems that arise. In time, you and your partner will become more at ease in dealing with these issues.

Table 1

Areas of Concern about Sexual Activity

- Urinary Accidents
- Bowel Accidents
- Not satisfying a partner
- Feeling sexually unattractive
- Others viewing me as sexually unattractive
- Not getting enough personal satisfaction
- Preparation too much trouble
- Hurting self
- Loss of interest
- Not liking methods for satisfaction

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

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

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

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

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

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

Other Potential Problems

Autonomic Dysreflexia **(AD)** is a life-threatening condition for women at the level of T-6 injury and above. Although sexual activity normally results in a rise in blood pressure, which is one sign of AD, women at risk and their partners should be watchful for other signs such as irregular heart beat, flushing in the face, headaches, nasal congestion, chills, fever, blurred vision, and/or sweating above the level of injury. While AD has not been noted in lab studies of sexual response in women with SCI, if you experience multiple signs of AD during sexual activity stop immediately. If symptoms continue after stopping, it is crucial to contact a doctor immediately for advice.

Verbal and physical abuse is an unfortunate reality in some relationships. Women who are in an abusive relationship can talk to friends, family, doctors or clergy to find local agencies that help women escape abusive relationships. Seek help from the agency of your choice. However, if needed, the National Domestic Violence Hotline is 1-800-799-SAFE (7233) or TTY 1-800-787-3224.

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

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

Conclusion

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

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

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Resources

Secondary Conditions of Spinal Cord Impairment Health Education Video Series - Sexuality and Sexual Function (2006)
Free video download from the University of Alabama at Birmingham Model SCI System. Online at:
http://www.spinalcord.uab.edu/show.asp?durki=97417
A 3 DVD series, sold only as a set, is available by mail. Total cost is $30. Make check payable and send to:
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Enabling Romance: A Guide to Love, Sex, and Relationships for People with Disabilities (and the People who Care About Them)
By Ken Kroll and Erica Levy Klein, book, approx 220 pages, available for purchase online, $15.95 plus S&H:
https://www.newmobility.com/bookstore-romance.cfm?type=REG&order_id=new
Or contact No Limits Communications, Inc. at (888)850-0344

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

Spinal Cord Injury Manual
A free online publication from the Thomas Jefferson University Regional Spinal Cord Injury Center of Delaware Valley (includes a section on Sexuality).
Available online at:
http://www.spinalcordcenter.org/manual/index.html
To inquire about mail service call (215) 955-6579

Spinal Cord Injury: Sexuality
Article from the Rehabilitation Institute of Chicago LIFE Center, reviewed November 2006.
Available free online at:
http://lifecenter.ric.org/content/2560/?topic=3&subtopic=163#pagetop
Or contact (312) 238-LIFE (5433)

Sexuality Reborn
Video available for purchase from Kessler Medical Rehabilitation Research & Education Center. Online order form at:
http://www.kmrrec.org/nnjscis/consumer.php?cnav=5
Or call (973) 243-6812

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

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

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

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

Published by: Office of Research Services
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283
Email: sciweb@uab.edu

Date: Revised November 2007
Developed by: Phil Klebine, MA with contributions by Linda Lindsey, MEd; Patricia Rivera, PhD
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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily

Sexual Function for Men with SCI

Spinal Cord Injury InfoSheet 3

Level - Consumer

INTRODUCTION

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

NORMAL SEXUAL FUNCTION

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

SEXUAL FUNCTION AFTER INJURY

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

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

MEDICATIONS FOR ED

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

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

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

ALTERNATIVE TREATMENTS FOR ED

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

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

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

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

Surgical implantation is often the last treatment option for ED because it requires a permanent penile prosthesis. The procedure involves inserting an implant directly into the erectile tissues to obtain an erection. Three types of implants are available: semi-rigid or malleable rods, fully inflatable devices, and self-contained unit implants.

ED TREATMENT RISK FACTORS

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

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

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

FERTILITY

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

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

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

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

FERTILITY TREATMENTS

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

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

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

SEXUAL ADJUSTMENT

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

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

Sexual adjustment is essential to the overall adjustment to life for men following injury. It is common for men with SCI to be unsure as to whether or not they can give or receive physical pleasure. They may experience a loss of self-satisfaction, confidence, and self-worth. As time passes, many men with SCI begin to experience a greater appreciation for sexuality as a whole. Hopefully, they will regain any lost feelings of self-satisfaction, confidence, and self-worth as they become more comfortable with their bodies. They often find pleasure in holding hands, hugging and kissing in addition to sexual intercourse. Many men also experience a greater emotional closeness with loved ones.

RELATIONSHIPS

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

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

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

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

SMART SEX

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

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

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

CONCLUSION

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

RESOURCES

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

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

Sexuality, Fertility, & Parenting
http://depts.washington.edu/rehab/sci/forum_reports.html#sexuality

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

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

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

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Published by: Office of Research Services
619 19th Street South - SRC 529
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Revised: April, 2007
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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Pregnancy for Women with Spinal Cord Injury

Spinal Cord Injury InfoSheet 14

Level - All Audiences

INTRODUCTION

Women with spinal cord injury or dysfunction (SCI/D) face a number of unique health care needs. Because women represent only about 20 percent of all individuals with SCI/D, there is limited information on their unique health and wellness issues. Much of the available information is also outdated, especially the information related to pregnancy, labor and delivery.

First, the facts are simple. No matter what the level of injury or dysfunction, women with SCI/D...

- can, and do, have children.
- share the same parental responsibilities of all women.
- must decide whether they are physically, emotionally, and financially prepared for the responsibilities of a baby.
- must know how their bodies will change and how to best avoid complications during pregnancy.
- need birth control if they do not want to become pregnant.

Second, it is essential for women with SCI/D as well as doctors and other healthcare providers to know all of the facts related to pregnancy, labor and delivery.

UNDERSTANDING PREGNANCY

Education is the key for women with SCI/D to understand pregnancy. With the proper education, you can make an informed choice on whether or not to become pregnant. If you become pregnant, you will be better prepared to manage your pregnancy.

You can begin your education by *talking with a rehabilitation physician (physiatrist) who is very familiar with the reproductive health concerns of women with SCI/D.* A physiatrist can explain the many unique medical, psychological and social issues that you may face. You can learn about potential complications during pregnancy and delivery and ways that you might prevent and manage them.

Your physiatrist can help you find an obstetrician to help you manage your reproductive health. You want to find an obstetrician who understands, or is willing to learn, your unique needs. This is important because many doctors and other health care providers are not familiar with the issues of women with SCI/D. Those who do not know about women's issues might encourage you to not become pregnant. Some may even recommend an unnecessary, undesired abortion if you do become pregnant.

PREPARING FOR PREGNANCY

Once you have an obstetrician, there are a number of concerns that need to be addressed if you are thinking about having a baby. If you become pregnant before talking to your obstetrician, you should contact your obstetrician immediately.

Medications

Many prescribed and over-the-counter medications normally used by women with SCI/D can cause, or add to, problems during pregnancy. Some medications can also have an adverse affect on fetal growth. Therefore, it is essential that all medications (including vitamin supplements) be evaluated by your obstetrician before pregnancy and continually re-evaluated each trimester. Some conditions that you might manage with medications include bowel management, pain, sexual dysfunction, muscle spasms, and urinary tract infection (UTI).

Urologic Check-up

You should first have a complete urologic exam if you are planning to have a baby. X-rays should not be taken during pregnancy unless absolutely necessary. They can harm the fetus. You and your obstetrician can discuss what type of urologic follow-up care that you need during your pregnancy.

Physical Changes
Some women with SCI/D have skeletal abnormalities such as curvature of the spine, pelvic fracture, or hip dislocation. These conditions can limit the space in the abdomen necessary to carry a full-term fetus. These abnormalities can also make vaginal delivery difficult.

Team Approach
If your obstetrician has limited experience managing pregnancies of women with SCI/D, it is recommended that you take a "team" approach to your pregnancy. You and your obstetrician can consult with an experienced physiatrist, nurse, urologist, anesthesiologist, neurologist, respiratory therapist, physical therapist, and occupational therapist on specific concerns about pregnancy, labor and delivery.

PREGNANCY

"High risk" describes an increased chance for complications during pregnancy. Women with SCI/D may be considered to have "high risk" pregnancies. However, it does not mean that pregnancy should be avoided. It simply means that you need to take precautions to prevent and treat complications.

It is impossible to predict if, or when, complications will occur. Some complications are easier to manage than others. Some may occur early on in pregnancy and go away in time. Others may continue to be a problem throughout pregnancy and delivery.

Each trimester brings the possibility of new challenges. Therefore, it is very important for you and your obstetrician to be aware of the potential problems that may occur. Both of you should work together to develop a plan to prevent medical complications when possible and be aware of ways to manage problems if they occur.

1ST Trimester
Mood swings, dizziness, headaches, fatigue, heartburn, indigestion and **nausea** are some of the natural changes that most women experience during their first trimester. These natural changes usually go away in time. As a woman with SCI/D, however, you should know that some of those natural changes can also be signs of complications. For example, a headache can be a symptom of autonomic dysreflexia (AD). A headache with nausea might be a symptom of a UTI. Therefore, you should keep your obstetrician well informed on symptoms that might suggest other problems.

Bowel Management can be a problem as early as the first trimester. Two of the most common changes that occur during pregnancy include constipation or diarrhea. Depending on the problem, your obstetrician may suggest that you increase or decrease your water or fiber intake. It may also be necessary to empty the bowels more frequently or take a stool softener or laxative - but only if prescribed by your obstetrician. (see InfoSheet #9 for more on bowel management)

2ND Trimester
The potential for complications increases during the second trimester. As you and your obstetrician work to manage complications, it is important to remember that methods of managing a complication can change from trimester to trimester. In other words, your method for managing your bowel program in the first trimester may not be as effective in the second or third trimester. Therefore, you may need to find different solutions for the same problem.

Weight gain is a major concern. It can interfere with your ability to perform everyday activities. For example, you may have difficulty transferring or pushing your wheelchair. You may quickly tire from doing activities that you did with ease before pregnancy.

The solution to problems related to weight gain will vary. You might reduce the number of times that you transfer if that becomes a problem. You can rent or purchase a power wheelchair if you have trouble pushing your manual wheelchair. It may also be necessary to get assistance from others or find new ways to accomplish everyday tasks.

Bladder management is a common complication. As the fetus grows, there will likely be increased weight on the bladder. The pressure decreases bladder capacity, which can lead to an increase in bladder spasms.

Women using intermittent catheterization will likely need to catheterize more often, or it may be better for some women to switch to an indwelling catheter during pregnancy. However, women with indwelling catheters may experience leaking.

Urinary tract infection may be a problem. As a woman with SCI/D, you have a greater chance of getting a UTI during pregnancy. In fact, a UTI might actually trigger premature labor if not properly managed.

Prevention is the best way to manage a UTI. Obviously, you need to drink plenty of water and avoid drinking beverages with sugar, caffeine and especially alcohol. You can also catheterize more often. If you have a history of infection or get a UTI, your obstetrician may prescribe an antibiotic to prevent or manage an infection.

If you experience symptoms of infection (fever, chills, nausea, headache, changes in spasticity, unusual pain/burning, or AD), your obstetrician should get a urine sample before treatment. This helps to identify the most safe and effective antibiotic for treating the infection. Plus, it can confirm that you have no other health problem. (** see InfoSheet #11 for more on bladder management and UTI)

Pressure sores are always a concern for women with SCI/D, but women who are pregnant are at an even greater risk for developing pressure sores. This increase in risk is primarily due to weight gain and/or posture changes.

It is essential to prevent pressure sores when possible. You should take special care to prevent abrasions when doing transfers. It also helps if you increase the number of pressure reliefs. You need to check your skin more often and get help with pressure reliefs and skin checks if needed. You should watch for posture changes while sitting in your wheelchair and talk with a physical therapist to change your seating position if needed. If you notice signs of a pressure sore, stay off the area, and call your doctor right away for advice on treatment. Your obstetrician can also include skin inspections as part of your prenatal examinations starting in the second trimester. (**see InfoSheet #13 for more on pressure sores)

Muscle Spasms may or may not be a concern during pregnancy. If you normally experience muscle spasms, there is a chance of an increase or decrease in your muscle spasms during pregnancy. If you do not normally have muscle spasms, there is a chance that spasms will develop.

Typically, muscle spasms are only treated if they interfere with your everyday activities or put you at greater risk of a pressure sore. As a precaution, however, you should talk to your obstetrician if you notice any changes in your muscle spasms. Chances are it is simply a result of your pregnancy, but a sudden change in muscle spasms can sometimes be a sign that there is some other health problem. (** see InfoSheets #16 for more on muscle spasms)

3<u>RD</u> Trimester

Respiratory complications can be a problem for some women. If your injury or dysfunction is in the cervical and thoracic areas of the spine, you likely have a loss of respiratory muscle control. A higher level of injury results in a greater loss of muscle control, and any loss of respiratory muscle control weakens the pulmonary system, decreases lung capacity, and increases respiratory congestion. As a result, it is more difficult to take deep breaths and cough, which increases the risk for respiratory complications such as pneumonia. In addition, growth of the fetus puts pressure on the diaphragm, which can further decrease lung capacity and expansion in women with cervical and thoracic injuries. Therefore, the risk for respiratory complications increases even more.

The best way to prevent serious respiratory problems is through proper positioning and added rest. If you normally wear an abdominal binder to improve your diaphragm function, you may need to loosen the binder or not wear it during pregnancy. Your obstetrician might suggest breathing exercises. If you have a high level of injury or dysfunction, your obstetrician may need to monitor your ventilatory function and provide ventilatory assistance if needed. (** see InfoSheets #19 for more on breathing exercises and other respiratory issues)

Blood flow is another problem that develops in the last months of pregnancy. Pressure from the growing fetus can hinder blood flow in the lower extremities, so you may have swelling in your legs and feet.

To help improve blood flow and reduce swelling, you can wear circulation-promoting hose, get extra rest, and do passive range of motion exercises. If you have a history blood clots, your obstetrician can prescribe a medication to help prevent clots from forming.

LABOR & DELIVERY

Again, you and your obstetrician should plan well before your expected due date on how to prevent or manage possible problems during labor and delivery. First, bowel and bladder management, UTI, muscle spasms and blood flow can continue to be problems during labor and delivery. You need to also pay careful attention to your skin care and watch for problems with high or low blood pressure. Second, you should go to labor and delivery classes if possible. These classes can be very helpful in informing you on issues that all women face. Third, the labor, delivery and patient rooms should be made fully accessible if needed.

Labor

Some women with SCI/D notice normal signs of labor, but others do not. You may not feel labor pain if your injury or dysfunction is level T-10 and above. On the other hand, you might experience uterine contractions if your injury or dysfunction is lower than T-10, but the feeling is usually different from able-bodied women. Although some women may feel the initial contractions, that sensation may pass as labor progresses. Therefore, you and your obstetrician might discuss if, or when, to induce labor.

As a precaution, you and your obstetrician should watch for signs of labor starting at around 28 weeks. Your obstetrician might perform a weekly cervical examination. Women with paraplegia should learn how to do uterine palpation to help detect labor. Some women with tetraplegia might request a home uterine contraction monitor. Plus, all women with SCI/D need to watch for common signs of labor that include:

- feelings of fear and anxiety;
- changes in spasticity or breathing;
- backache;
- abdominal tightening;
- pelvic pressure;
- unusual feelings of pain; and
- autonomic dysreflexia.

Autonomic dysreflexia is common during labor and can be life-threatening if not managed properly. AD is most common for women with injury or dysfunction at levels T-6 and above. However, there is some evidence that AD can occur during labor in women with SCI/D much lower than T-6. Although some women might not need anesthesia due to a lack of sensation, a continuous epidural anesthesia is considered to be the most effective method of preventing AD during labor.

Delivery

Typically, your delivery should be beautiful and natural. Most women can, and should, deliver vaginally whenever possible. Some may deliver with ease, and some may need the assistance of a vacuum device or forceps. Although you and your obstetrician might discuss the possibility of Caesarean section (C-section), neither of you should assume that a C-section is preferred simply because you have SCI/D.

AFTER DELIVERY

There are a few concerns for women with SCI/D after delivery. First, if you had an episiotomy, do not use a heat lamp on an area with no sensation to aid in healing. You may get burned. Second, you may feel faint or dizzy when you try to sit up after delivery. To ease this problem, you can sit up slowly, wear elastic hose, or use an abdominal binder. Finally, you have to decide whether or not **breast feeding** is right for you. Although breast feeding is possible for most women, you may notice an increase in your spasticity as you breast feed. Also, breast feeding normally stimulates the production of breast milk, so women with limited sensation in their nipples may notice a reduction in milk.

CONCLUSION

As a woman with spinal cord injury or dysfunction, do not rely on assumptions when it comes to pregnancy, labor and delivery. Do not let friends, family members and even doctors convince you to not have a baby simply because you have SCI/D. Instead, you should rely on the facts about pregnancy from health care professionals that clearly understand the reproductive needs of women with SCI/D. Although there are risks for complications related to pregnancy, you can reduce and manage those risks with proper prenatal care and adequate planning.

Once you know the facts, it is up to you to decide if, or when, you want to have a baby. If you choose to have a baby, you can enjoy everything that being a Mother has to offer.

WOMEN W/DISABILITY RESOURCES

Center for Research on Women with Disabilities
3440 Richmond Avenue, Suite B
Houston, Texas 77046
Phone: 713-960-0505 **Toll Free:** 800-44-CROWD
Email: crowd@bcm.tmc.edu
Web: www.bcm.tmc.edu/crowd/

CROWD is a research center that focuses on issues related to health, aging, civil rights, abuse, and independent living. CROWD's purpose is to promote, develop, and disseminate information to expand the life choices of women with disabilities so that they may fully participate in community life.

Department of Rehabilitation Medicine
University of Washington
Box 356490
Seattle, WA 98195-6490
Phone: 206-543-3600
Email: rehab@u.washington.edu
Web: http://depts.washington.edu/rehab/sci/forum-reports.shtml

The SCI Forum is an evening presentation and discussion series on topics of interest to persons with spinal cord injury and their friends, family members, and caregivers. They offer varying topics such as relationships, sexuality, dating, parenting, childbirth, fertility and more. They also post summary reports on past SCI Forums.

Health Promotion for Women w/Disabilities Project
Villanova University - College of Nursing
800 Lancaster Avenue
Villanova, PA 19085
Phone: 610-519-4922
Email: Vanessa.Zimmerman@Villanova.edu
Web: www.nursing.villanova.edu/WomenWithDisabilities/

The Project provides information for women with disabilities so they can be informed consumers of health care, can ask relevant questions of their health care providers, and can take measures to achieve a healthier life style and a better quality of life.

Parents with Disabilities Online!
Web: www.disabledparents.net/index.html

This is a great site if you are a parent with a disability, a person with a disability who is planning to become a parent, or a nondisabled partner of a disabled parent. It has accessible/independent parenting information on pregnancy, childbirth, and reproductive health issues; general issues of child care and child rearing.

Rehabilitation Institute of Chicago
345 East Superior Street
Chicago, IL 60611
Phone: 312-238-1051 **Toll Free:** 800-354-REHAB
Web: www.rehabchicago.org/community/hrcwd.php

RIC's Health Resource Center for Women with Disabilities provides accessible, comprehensive health services for women with disabilities. They develop and implement advocacy programs, clinical services, research, and resource networks that empower women with disabilities, and they educate professionals on health and cultural issues.

**** Spinal Cord Injury Information Network**
UAB - Dept of Physical Medicine & Rehabilitation
Office of Research Services
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
Phone: 205-934-3283
Email: RTC@uab.edu
Web: www.spinalcord.uab.edu

This site is maintained by the Rehabilitation Research and Training Center (RRTC) on Secondary Conditions of Spinal Cord Injury, which offers a poster on managing Autonomic Dysreflexia, a 5 part multimedia series, 2 videos, 3 newsletters and 20 **InfoSheets****. Some featured topics of information include women's sexuality and reproductive health. The site also offers links to other web sites with information on disability and spinal cord injury.

Through the Looking Glass
2198 Sixth Street, Suite 100
Berkeley, CA 94710-2204
Phone: 800-644-2666 or 510-848-1112
Email: TLG@lookingglass.org
Web: www.lookingglass.org

An excellent site for all women with disabilities. It provides a newsletter, books and other materials on available clinical and supportive services, training and research to families with either a parent or child with a disability. They also offer a Parent-to-Parent network where parents and those who are considering becoming parents can share their experiences.

WOMEN'S HEALTH RESOURCES

Canadian Women's Health Network
419 Graham Avenue - Suite 203
Winnipeg, Manitoba Canada R3C 0M3
Phone: 204-942-5500 **Toll free:** 888-818-9172
Email: cwhn@cwhn.ca
Web: www.cwhn.ca

CWHN is a Network of individuals, groups, organizations and institutions concerned with issues of women's health. The CWHN recognizes the importance of information sharing, education and advocacy for women's health and equality. It strives to build and strengthen the women's health movement in Canada and throughout the world.

Health Resources and Services Administration
US Department of Health and Human Services
Parklawn Building
5600 Fishers Lane
Rockville, Maryland 20857
Phone: 1-888-Ask HRSA (275-4772)
Web: www.ask.hrsa.gov

HRSA offers publications, resources, and referrals on health care services for low-income, uninsured individuals and those with special health care needs. Some topics of information include women's health and maternal and child health (also available en Español).

National Women's Health Information Center
8550 Arlington Blvd. - Suite 300
Fairfax, VA 22031
Phone: 800-994-WOMAN
Web site: www.4woman.gov

This web site and toll-free call center was created by the US Department of Health and Human Services to provide a FREE, reliable health information source for women everywhere. Browse the database for great resources or take a look through our Special Sections on topic areas like heart disease, disabilities and pregnancy.

INTERNET RESOURCES

BabySite.org

Personal information about pregnancy and birth, as well as contributions from people around the world.

Childbirth.org

Professionals offering educational information to consumers on how to provide the best possible care are essential to a healthy pregnancy. Enjoy the many links of educational, informational, and personal nature.

FamilyCareIntl.org

Family Care International is dedicated to improving women's sexual and reproductive health and rights in developing countries, with a special emphasis on making pregnancy and childbirth safer.

iVillage.com

A women's network sharing solutions and advice on issues such as beauty, books, diet and fitness, entertainment, health, home and garden, money, parenting, pregnancy/babies, relationships and work.

ParentsPlace.com

A great part of iVillage offering information for women trying to conceive. Some topics include fertility, adoption, pregnancy, baby, breastfeeding, twins and multiples.

Pregnancy.org

A site built by parents for parents banded together to educate, empower, and connect parents and people trying to become parents.

PregnancyGuideOnline.com

For each of the 40 weeks of pregnancy, you'll find information about baby's development, the types of changes that occur within mom's pregnant body, tidbits for dads, specific info for pregnant moms of multiples and suggested readings.

Published by:
Office of Research Service
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Please check out our website at www.spinalcord.uab.edu

Date: **March, 2003**
Developed by: Phil Klebine, MA; Linda Lindsey, MEd
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This publication is funded by grant #476-00 from the Education and Training Foundation of the Paralyzed Veterans of American. Opinions expressed are not necessarily those of the granting agency.

Selecting a Wheelchair

INTRODUCTION

Most individuals with spinal cord injury (SCI) use a wheelchair for primary mobility. Although some individuals may have similar injuries and basic needs, every individual also has unique needs that should be address when selecting the proper wheelchair.

One of the biggest mistakes you can make is not learning how to select the proper wheelchair. You do not simply order off the Internet or from your local vendor. You need to do it right!

A TEAM APPROACH

Any time you need a wheelchair, selecting it should be a team effort with *you* as team captain. It is your wheelchair, so it is your responsibility to make choices.

A *doctor* is your second team member. Your doctor writes the prescription for your wheelchair. The prescription essentially justifies which specific type of wheelchair and options you need.

A *physical* or *occupational therapist* is another essential team member. Your therapist evaluates your unique needs, suggests the proper equipment to meet your needs, and provides your doctor with the justification for your equipment needs.

Finally, you and your therapist need to choose a *vendor*. A good wheelchair vendor should be able to show you a selection of wheelchairs and answer questions about each one's pros and cons. Plus, the vendor should be able to suggest wheelchair options and adjustments that best fit your needs.

THE SELECTION PROCESS

You need to be as informed as possible. You need to search the Internet, read wheelchair reviews, and get as much information as you can.

There are many aspects of your life to consider when selecting a wheelchair, and your therapist and vendor are there to advise you. Your goal is to select the wheelchair that best fits your needs based on your...

- goals. What wheelchair and options can help you best meet your goals?
- overall health. Consider your posture, body weight, pain type/severity, spasticity severity, bladder and bowel management, and pressure ulcer history.
- function: The proper equipment can often make your life easier and enhance your daily living activities despite limited communication, mobility, strength, range-of-motion, balance, ability to transfer, endurance, and energy level.
- environment: Consider a wheelchair that fits more easily into your environment instead of modifying your living space to fit your wheelchair.
- finances. Chances are you will have to pay at least some portion of the wheelchair costs. Always get the most "bang" for your money.
- transportation. Transferring and lifting the wheelchair into a car are issues for car owners. Power wheelchair usually own a van. People who fly often may prefer an easily collapsible manual wheelchair or a maintenance-free battery powered wheelchair.
- caregiver's role. Most people who need a caregiver use a power wheelchair. Power seat options can often make a caregiver's job easier.

After you make your wheelchair selection, your therapist and vendor will measure your body. This is important because any weight or posture changes can greatly impact how the equipment fits your body.

MANUAL WHEELCHAIR TYPES

Manual wheelchairs are self-propelled. This requires users to have good upper body balance with enough shoulder and arm strength to push hand rims to propel the rear drive wheels.

There are 8 types of manual wheelchair. The lower-end types are generally big, bulky and tend to be hard to push and maneuver. Low-end wheelchairs are temporarily used as "loaners" for patients during rehabilitation. People do not usually own low-end wheelchairs unless they are simply unable to afford a better choice. Higher-End types are typically preferred because they are more customized, highly adjustable, and offer a maximum ease of control as well as durability. The 8 types are:

1 *Standard* wheelchairs are a basic design that has been around for decades. It is not usually tailored to an individual. Instead, it is designed to fit multiple users with a simple sling seat and very limited adjustability.

2 A *standard hemi*-wheelchair is for users who require a lower seat height (17" to 18") because of short stature or to enable the user to place his/her feet on the ground for propulsion.

3 A *lightweight* wheelchair is for users who...
    ...cannot self-propel a standard wheelchair in the home; and
    ...can and does self-propel a lightweight wheelchair.

4 A *high strength lightweight* wheelchair is for users who...
    ...self-propel the wheelchair while engaging in frequent activities in the home that cannot be performed in a standard or lightweight wheelchair; and/or
    ...require a seat width, depth, or height that cannot be accommodated in a standard, lightweight or hemi-wheelchair, and spends at least two hours per day in the wheelchair.

5 An *ultralightweight* wheelchair is typically for persons with paraplegia and quadriplegia who need to adjust the rear axle to get a seat "dump" to improve balance or to propel the wheels.

6 A *heavy duty* wheelchair is for users who weigh more than 250 pounds or have severe spasticity.

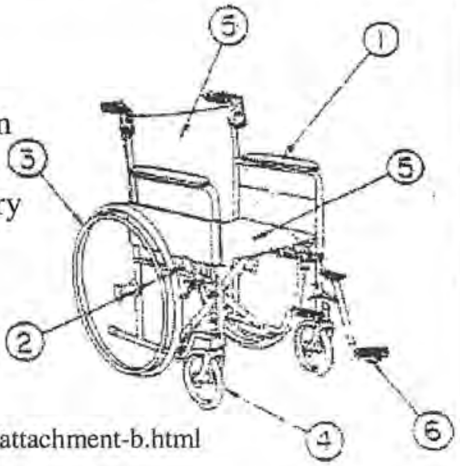
7 An *extra heavy duty* wheelchair is for users who weigh more than 300 pounds.

8 A *tilt-in-space* wheelchair can tilt the frame of the wheelchair greater than or equal to 45 degrees from horizontal while maintaining the same back to seat angle.

MANUAL WHEELCHAIR OPTIONS

Manual wheelchairs offer various options to help improve the independence of the user. Most of these features can be fixed or adjustable. Some basi~~c features~~ on most manual wheelchairs include:

1. Armrests
2. Wheel Locks
3. Wheel and Hand-rim
4. Casters
5. Seat/Back Upholstery
6. Foot plates



www.csus.edu/sswd/disaster/attachment-b.html

MANUAL WHEELCHAIR PUSH-ASSIST

Push-Assist technology bridges the gap between manual and power wheelchairs. It is intended for users who want to have a manual wheelchair but need assistance in pushing it.

There are currently two types of Push-Assist devices. One is a battery powered device attaches to the rear wheels. When the user pushes the wheelchair, a sensor monitors the force of the push and helps propel the wheel movement, which reduces the force needed by the user to propel the wheelchair. The second assistive device works very similar to a 2 speed bicycle. The standard rear wheels on the manual wheelchair are replaced by 2-geared, battery-free rear wheels. These wheels allow users to shift between gears to make it easier or harder to push the wheelchair depending on the terrain.

POWER WHEELCHAIR

Power (electric) wheelchairs are generally used by people who cannot push a manual wheelchair due to limited upper body strength. Battery powered motors propel front-, center-, or rear-wheel drive options. Each drive option has particular handling characteristics. For example, people who primarily use their power wheelchair indoors may prefer the tight turning radius of a center-wheel drive. A rear-wheel drive might be preferred for mostly outdoors use. A front-wheel drive might be preferred for equal amounts of indoor and outdoor use.

Power wheelchair components include a seat frame of some sort, armrests, footrests, seat and seat back. There are several control types for driving a power wheelchair. A joystick control is most common. A chin control, head control or mouthstick (the user sips/puffs into a tube located near the mouth) control can be used by people who are unable use a joystick due to limited hand or arm movement. Other customized control devices are available if needed.

The controller is also used to operate power seating systems. There are 4 options available that are intended to improve independence in self-care and daily activities:

1 A tilt seat frame tilts the user backward in the seated position at an angle to change pressure points to help prevent pressure ulcers. Tilting the seat can also improve sitting balance.
2 A reclining backrest opens the hip angle for users to lay back for pressure relief, resting, or self-catherization.
3 An elevating seat lifts a user while remaining in the seated position. Elevating can improve a user's reach and enhance the user's ability to socially interact on a more eye-to-eye level.
4 A standing frame lifts the user from a seated to standing position, offering the pressure relief of tilting and reclining along with the same functionality as the seat elevator. Standing may also improve a user's circulation, bladder function, digestion and respiration, but further research is needed to verify such benefits.

Other potential options include:

- swing away joystick mounts
- environmental control technology (inferred/ bluetooth operation through controller)
- flat free tires
- power leg rest elevation
- frame color
- high speed motors
- suspension

SPECIALIZED WHEELCHAIRS

Today, wheerlchair users are demanding wheelchairs that are tailor made for specific sports and recreational activities. You can purchase 4-wheel drive wheelchairs if you are an outdoorsman. There are wheelchairs designed for individualized sports such as basketball, tennis or racing. If you have a special interest, chances are you can find a wheelchair to maximize you performance.

WHEELCHAIR COSTS

Your "first" wheelchair is likely going to be paid for by private health insurance, Medicare, Medicaid, or an accident settlement. Some insurance will only pay for one chair in your lifetime. The insurance may pay for the full price of the chair or only a percentage of the cost. Medicare and Medicaid will only pay for a new wheelchair that will make you independent in your home. Some private insurers, Medicare, and Medicaid may purchase a new wheelchair every 5 years, but only if there is evidence that either your...

...current wheelchair is damaged beyond repair; or
...physical condition has changed such that you need a different wheelchair.

Even if you provide justification for all of your wheelchair needs, your insurance largely dictates the type of wheelchair and options you can get. Each insurance provider has quidelines for the type of wheelchair it will provide based on diagnosis, physical condition and functional abilities. For example, you may be able to justify a need for an elevating seat, but the payer may still decline to pay for it. This means you may need to pay out-of-pocket or get an external funding source such as vocational rehabilitation to pay any additional costs.

Insurance payment is made for only one wheelchair at a time. In general, costs for manual wheelchairs range from the low-end of $500 to the high-end of $4,000. Power wheelchairs normally range from $5000 to $30,000. Backup wheelchairs are denied as not medically necessary, but one month's rental of a wheelchair is covered if a patient-owned wheelchair is being repaired.

YOUR NEW WHEELCHAIR

Once your vendor has your new wheelchair, do not simply have it delivered to your home. Instead, you need to meet your vendor and therapist for your wheelchair fitting. This allows your therapist and vendor to "fine-tune" all of the adjustable aspects of your wheelchair to fit your needs. The fitting lets you make sure that everything is the way you want with your new wheelchair before you take it home.

It is essential that you get a seating evaluation as part of your fitting. Not only are there differences between your old and new wheelchairs, but your body is always changing in weight, shape and posture. Such changes can put you at higher risk for a pressure sore. If you get a seating evaluation each time you get a new wheelchair, you may be able to prevent problems.

Read all of the warranty information. Many wheelchairs have lifetime warranties on the frame. Do not try to fix something yourself until you check to see if it is covered by the manufacturer's warranty.

If you have problems with daily activities or discomfort, see your therapist for a re-evaluation. Minor seating adjustments may be needed.

Take care of your chair! Regular maintenance and care are important. Tightening loose screws can prevent major breakdowns later.

WHEELCHAIR LEMON LAWS

Many States have a law to protects consumers who buy a new wheelchair that turns out to be "lemon." If you purchase a wheelchair, you may be able to get a refund or have the wheelchair replaced if the..

... wheelchair does not conform to the terms of the written warranty; and

... the manufacturer or authorized dealer is unable to repair the wheelchair after a reasonable number of attempts during the first year.

CONCLUSION

Over the years, wheelchair technologies have advanced greatly. Today's wheelchairs have many options, parts and accessories to make the equipment more functional for you.

RESOURCES

United Spinal Association Tech Guide: A Web Guide To Wheelchair & Assistive Technology Choices
www.usatechguide.org/

wheelchair.ca: Medical Equipment Information & Resources
http://wheelchair.ca/

Fact Sheet on Manual Wheelchairs
www.abledata.com/abledata_docs/manwhch.htm

WheelchairNet
www.wheelchairnet.org

American Physical Therapy Association (APTA)
www.apta.org

American Occupational Therapy Association (AOTA)
www.aota.org/

Published by:
Office of Research Service
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
Please check out our website at www.spinalcord.uab.edu

Date: Updated 3/2009 (Created 1995)
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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

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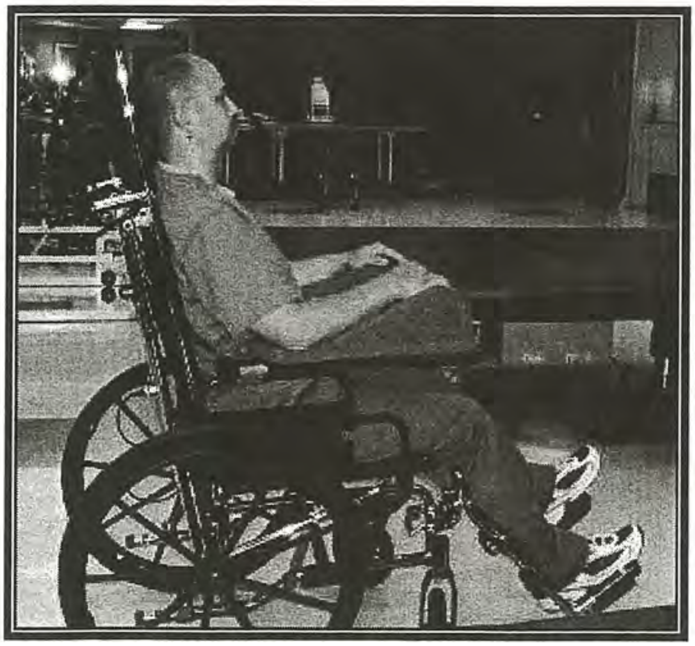
Rehab TIP SHEET #1

Wheelchair Positioning

Example of Bad Wheelchair Positioning →

Good Wheelchair Positioning is Important Because it:

1. allows for more comfort and less fatigue and greater ability to interact with the environment;
2. promotes good posture which decreases pain especially in the neck, shoulders and back;
3. allows a person to better perform activities of daily living such as eating and brushing hair;
4. distributes a person's weight to decrease the risk of skin breakdown/pressure ulcers, caused by bad posture and lack of movement;
5. decreases the risk of the patient falling out of the chair and being injured; and
6. improves a person's ability to see more of the surroundings, breathe and swallow better and have better digestion.



← Examples of Good Wheelchair Positioning

Note that the back is straight and hips are positioned all of the way back in the wheelchair. →

Steps to Safely Position a Patient in a Wheelchair

1. Lock the wheel locks of the wheelchair.
2. Stand in front of the patient and lean him/her forward and be sure to bend your knees and flatten your back like you are going to sit in a chair.
3. Place one hand under the patient's thigh and lift the leg while leaning the patient to the opposite side.
4. Push the buttock back into the chair and repeat the process for the other side until the patient is touching the back of the chair with his/her bottom.

Reminders

- Make sure the patient is sitting in the middle of the chair with space at both hips so neither thigh is touching the side of the chair.
- Make sure the patient is sitting up straight and resting on the back of the chair.
- The thighs should be parallel to the floor when the feet are on the footrests. Adjusting the level of the footrest will raise or lower the patient's knee level.
- If the patient needs arm support, the elbows should be slightly supported by the armrests with the hands resting in the patient's lap.
- When using a lap tray, the arms should be placed on the tray with the hands towards the center. If forearm support has been recommended, the forearm and hand should lie in the center of the cushion with the wrist straight and the hand lying palm down with the fingers lying flat against the cushion.

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Rehab TIP SHEET #2

Assisted Pressure Relief

Pressure relief is essential for preventing skin breakdown and keeping the skin tissue healthy. An important aspect of patient care is assisting with pressure relief.

- Steps for Assisting with Pressure Relief using a Wheelchair Tilt Method;

1. Park wheelchair on a solid non-moving surface.
2. Set the wheelchair locks.
3. Turn the wheelchair anti-tippers up. There is a button to release the anti-tippers underneath or on the side of the bar on the back of the wheelchair.
4. Set the wheelchair approximately 3 feet away from the non-moving surface.
5. Inform the patient that you are going to tilt him/her backwards for a pressure relief.

6. Place your foot underneath the wheelchair on part of the frame to get leverage while you tilt. Slowly tilt the wheelchair back until the back of the wheelchair is resting on your lap. Stay tilted for 2 minutes.
7. Return the person back to a sitting position monitoring the patient for dizziness or lightheadedness. If symptoms occur, slowly tilt the patient back again. After 1 or 2 minutes, slowly raise the patient back to a sitting position stopping in 1/3 increments on the way up for 1-2 minutes.
8. Place the anti-tipper bars back down and unlock the wheel locks on the wheelchair.
9. Repeat these steps every 20-30 minutes unless otherwise instructed by a therapist or doctor.

How to position a person in bed

Many materials may be used for positioning on a bed, but the two most common materials used for positioning are pillows and towel rolls. Only dry, clean pillows, pillowcases, and towels should be used. To make a towel roll, simply flatten a towel on a clean surface and roll to form a cylinder. Towels can be stacked or folded and then rolled if a larger roll is desired.

Side-Lying

1. If the patient is not mobile, reach across the patient by bending at the knees and hips to grasp the draw sheet on the opposite side. Pull the sheet close to your stomach and stand up using your legs. If the patient can move, ask him/her to bend knees, push with foot, and reach across with the opposite arm until they are on their side.

2. When not using a draw sheet, reach over the patient's knees with one arm and bend the patient's legs to about 45°, or until they can lie unsupported. Make sure that the patient is lying on their shoulder blade and **NOT** on their arm or shoulder.
3. The arm on the bottom should be perpendicular to the body, with the forearm bent or straight.

4. Make sure that the patient's head is in the middle of a pillow and that his/her head is even with the center of their body.
5. Place a pillow between the patient's knees so that the hip and knee are evenly aligned to prevent pressure areas between the knees.
6. Gently lift the arm on top, being careful to not pull on the shoulder. Place a pillow folded in half underneath the forearm. The upper arm should be supported by the patient's torso.

Reminder

- Lift with your legs by bending at your knees and hips. Keep your spine straight.
- Keep the patient as close to your body as possible while lifting to avoid muscle strain.
- A "draw" sheet can be folded in half and placed underneath the patient to help move up, down, left, right, or roll in the bed.

A Circle of Supports

Caring for Caregivers

INTRODUCTION

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

PCA VS CAREGIVER

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

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

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

ADJUSTMENT TO SCI

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

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

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

MANAGING SELF-HEALTH

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

Recognizing Stress

Stress is a physical, chemical, or emotional factor that causes tension in your body or mind. Most everyone has some type of stress in their life. Stress is common because it is almost impossible to escape.

Stress can quickly become a problem for people who have learned to ignore signs and symptoms of stress until it gets out of control. Continued stress puts people at higher risk for serious health problems including illness, addiction, and depression.

There are several signs and symptoms of stress that you can learn to recognize when stress might be getting out of control. When you are under a lot of stress, you may experience one or more of the following:

Mood (Emotional) Symptoms of Stress

Anxious
Scared
Irritable
Moody

Thought Symptoms of Stress

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

Behavioral Symptoms of Stress

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

Bodily Symptoms of Stress

Perspiration /sweaty hands
Increased heart beat
Trembling
Nervous ticks
Dryness of throat and mouth
Tiring easily
Sleeping problems
Diarrhea / indigestion / vomiting
Butterflies in stomach
Headaches
Premenstrual tension
Pain in the neck and or lower back
Weight loss or gain

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

Adopting a Healthy Lifestyle

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

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

Getting Help

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

Asking for help is a sign of strength - not weakness. It may not be easy at times to ask for and receive assistance. This difficulty usually stems from two notions of thought.

First, some people may not ask for help because they do not want to "burden" others, especially family members. If you feel this way, ask yourself if it would be a burden on you to help a loved one in need. We are part of a family; we are part of a society; and we all need each other. We all need help at times, and we rely on each other in many ways, and most people gladly help family and friends if needed.

A person's impression of "independence" is the second problem notion of thought. Some people may not seek assistance or refuse it if offered because they believe that being independent means doing things without the help from others. The reality is that there is no shame in asking for and receiving help when you need it. And you will probably make your everyday life more of a burden on you if you do not get assistance when you need it.

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

Learning to Solve Problems

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

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

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

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

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

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

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

Learning to Relax

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

Self-Guided Imagery:

- Close your eyes. Focus on your breathing and take slow, deep breaths.
- Imagine that you are in a peaceful setting such as relaxing on a beach, meadow, or mountain top.
- Focus on the peaceful setting that you are imagining and pay close attention to all the details. Notice the sounds (any birds, wind rustling the leaves, waves crashing on the shore?). Pay attention to what you feel (warm sun on your skin, hot sand on your feet, cool grass beneath you). Attend to any smells and tastes you may imagine having. Spend some time focusing on all the sensations you are experiencing while imagining your peaceful place.
- After a few minutes return your attention on your breathing. Notice how you are breathing deeply in and out and focus on what is going on around you

(the pressure of the seat against your legs, the ticking of a clock, etc.).

- Ask yourself how relaxed you are at the moment using a scale from 0 - 10 with zero indicating not relaxed at all and 10 reflecting the most relaxed you have ever been.

Abdominal Breathing:

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

Progressive Muscle Relaxation:

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

PARTNER OR SPOUSE CAREGIVING

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

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

Problem Issues

Most couples face obstacles early after injury. For most adults, pre-injury life is routine, familiar, and comfortable. People usually have established views of what they consider "normal," and they generally have defined notions of their relationship.

In most cases, pre- and post-injury routines are very different for caregivers and their spouses or partners. Like many other aspects of life post-injury, changes in views and established routines are usually necessary in adapting to life after injury.

Again, each family is different, so every family will not necessarily experience the same problem issues. As a caregiver, however, you will likely experience many of the same issues as others. Research has shown that caregivers generally report problem issues with:

1. the negative attitude of the person with SCI;
2. personal feelings of guilt;
3. lack of appreciation for being a caregiver;
4. not enough time for personal activities;
5. having to say "no" to the person with SCI; and
6. feeling overwhelmed.

Individuals with SCI expressed problem issues with:

1. wanting to walk;
2. sexual function;
3. pain;
4. bowel and bladder function;
5. lack of money;
6. not being able to do simple tasks; and
7. being anxious.

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

It is essential to talk about problem issues and openly discuss how these issues are affecting your relationship.

In time, hopefully, the two of you can reach a mutual understanding of how, together, you can overcome the situation, resolve problem issues if possible and strengthen the relationship.

Resolving Conflict

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

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

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

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

Basic Conflict Resolution Guidelines:

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

STEP 2 - State the Problem: you cannot resolve issues unless everyone knows exactly what the issue is. You are more likely to have success in resolving the problem if you are respectful when stating the issue. For example, state the problem in the form of a self-expression, not a personal attack.

Examples of Request:

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

Example of Attacking Statement:

- "You make me mad when you do not give me a break."

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

Examples of Request:

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

Examples of Demand Statement:

- "You have to start acting like a father."
- "You are going to do (something) my way."

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

It is tough being a good listener. If you find it difficult, you might try to "repeat" in your head what is being said as another person talks. That way, you stay focused on hearing what is said. There may be times when you hear what is said but do not really understand the other persons meaning. When someone talks to you, it is natural to imply your own reasoning to what is being said. However, people often mean to express themselves differently than you might think. If you are not clear about another person's meaning, you can easily repeat what they said and ask for more information. If you are open minded, listen and understand; it is easier to suggest possible solutions that both parties can agree.

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

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

However, there may be issues that cannot be resolved. If the conflict is a matter of opinion, recognize that it is impossible to control the thoughts of anyone else. You may not change another person's mind even with your best efforts and intentions. Likewise, you cannot change other people's behaviors.
When there is no mutual resolution, you have to resolve the issue for yourself. You might agree to disagree on matters of opinion, or "let go" of a matter that you simply have no control over. These concepts may be hard to do at times, but they can be the best thing that you can do for your overall health.

CONCLUSION

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

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

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

REFERENCES & RESOURCES

Accepting New Help
A brochure from Craig Hospital
303-789-8202
www.craighospital.org/SCI/METS/acceptingNewHelp.asp
Caregiver's Guide to Self-Health: Solving Problems and Reducing Stress
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=117376
Caregiving
A brochure from Craig Hospital
303-789-8202
http://www.craighospital.org/SCI/METS/caregiving.asp
Healthy Living: Relationships
An article from the Pushin' On, Vol 19[1], 2001.
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=36069

Long-term Care Givers
A brochure from Craig Hospital
303-789-8202
http://www.craighospital.org/SCI/METS/longtermCareGivers.asp

Personal Care Attendant - SCI InfoSheet #6
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=22411

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Revised: June, 2008
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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Personal Care Attendant

Spinal Cord Injury InfoSheet 6

Level - All Audience

INTRODUCTION

Between 40 and 45 percent of individuals with spinal cord injuries (SCI) need personal assistance with some daily activities [1]. It is understandable that the majority of persons needing assistance have higher levels of injury. They may need personal care assistance with getting in or out of bed, managing bowel and bladder issues, bathing, and dressing. Some individuals may need someone to drive, shop, and clean for them too. However, there is also a growing percentage of persons with lower levels of injury needing assistance as they get older. They may need assistance with household activities as they grow older and experience increased pain or fatigue.

ASKING AND RECEIVING

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

First, some people may not ask for help because they do not want to "burden" others, especially family members. If you feel this way following SCI, ask yourself if it would be a burden on you to help a loved one in need. Probably not. However, many people with SCI still do not ask for the help they need.

We are part of a family; we are part of a society; and we all need each other. We all need help at times, and we rely on each other in many ways, and most people gladly help family and friends if needed . Children are dependent on their parents and rely on them for care, and children commonly assist their parents as they age and become increasingly dependent. It is a natural state. Likewise, we function as a society helping each other throughout life. Health care professionals help us when we are sick; teachers help educate us; and police officers and fire fighters help protect us from danger. In fact, most jobs provide some type of service for people. The reality is that there is no shame in asking for and receiving help when you need it. And you will probably make your everyday life more of a burden on you if you do not get assistance when you need it.

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

FINDING A PCA

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

INTERVIEWING FOR A PCA

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

You can save time by preparing a list of questions to ask each candidate. A few examples might be:

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

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

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

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

EDUCATION AND TRAINING

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

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

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

PARTNER OR SPOUSE VS. PCA

A spouse or partner is often the first to provide personal care following injury. Although this arrangement is initially common for couples, the partner/caregiver role can be unhealthy if it continues long following injury. They may feel it is their "duty". Some family members do not want an outsider caring

TOP 10 REASONS PCAs QUIT THEIR JOBS

1 Their initial job description was incomplete or keeps changing.
2 The method and order in which they must perform their duties are illogical, inefficient and waste time.
3 Their working environment is messy, unpleasant, disorganized, etc.
4 They're not paid enough, don't get appropriate raises or don't feel their work is appreciated.
5 They feel another PCA is favored over them.
6 The employer (YOU) is either too passive or too aggressive in his/her style of interaction.
7 The employer is dishonest about the hours worked, the salary owed, or has inappropriate expectations such as monetary loans or sexual favors.
8 There are unreasonable duties–those the employer is able to perform alone, those which cannot be performed in the allotted time or those which are too tightly supervised.
9 The employer is intolerant of honest mistakes, the need for sick time, etc.
10 The employer doesn't respect PCA's personal life and expects that his or her needs should take priority over all else in the PCA's life.

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

for their loved one. However, it is the individual with SCI who needs to decide what help he/she needs and who will provide it.

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

Unfortunately, some couples have no option other than for a partner or spouse to be the primary caregiver. In this instance, it is very important to keep the partner/spouse role separate from the caregiver role. One way to do this is to have a routine that keeps the caregiving activities separate from those of a partner. Couples also need to have occasional time apart. Keeping the partner/caregiver roles as distinct and separate as possible will help you to avoid confusing and blurring of the partner role with the caregiver role, which is healthier for a couple's personal relationship [2].

FUNDING

The US Department of Labor's Wage and Hour Division administers and enforces the federal minimum wage law. The federal minimum wage for employees is currently $5.85 per hour, and the minimum wage will increase over time to $6.55 per hour effective July 24, 2008 and to $7.25 per hour effective July 24, 2009 [3]. Many states also have minimum wage laws. In cases where an employee is subject to both the state and federal minimum wage laws, the employee is entitled to the higher of the two minimum wages.

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

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

Finally, you should probably talk with an accountant about any possible issues related to the Internal Revenue Service [4]. Before you can know how to treat payments you make for services, you must first know the business relationship that exists between you and the person performing the services. If you have an employee, you may be responsible for Federal Income Tax Withholding, Social Security and other taxes as an employer. You may also need an accountant to help you with what you can and cannot claim on your personal income tax returns.

WORKING WITH AN PCA

A PCA is often your friend and employee. It is up to you to balance the two roles. The first step is to make clear that a PCA's role is helping you with daily activities that you cannot do for yourself, and it is you who decides what assistance is needed.

There are times when you need to be assertive, and you need to also be flexible sometimes. If there is a specific way that your care needs to be done, give the PCA clear directions on what needs to be done and the proper techniques involved. However, a PCA is a person, too. Although you are in charge of your care, your PCA may have a different approach to providing the same quality care. So you need to be reasonable in listening and accepting different ideas and opinions. It is also nice to express your appreciation to your PCA for the help he/she is providing for you. Finally, it is important that you are understanding if your PCA has a "bad" day or makes a mistake. Hopefully, you will find that you can be flexible but still keep a professional relationship.

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

CONCLUSION

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

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A brochure from Craig Hospital
303-789-8202
www.craighospital.org/SCI/METS/acceptingNewHelp.asp

2 Healthy Living: Relationships
An article from the Pushin' On, Vol 19[1], 2001.
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=36069

3 U.S. Department of Labor
1-866-4-USWAGE
www.dol.gov/esa/whd/flsa/

4 The Internal Revenue Service
800-829-1040
www.irs.gov/

OTHER RESOURCES

Center for Personal Assistance Services
1-866-PAS-9577 (free call)
www.pascenter.org

State Rehabilitation Providers
1-800-772-1213 (free call)
www.ssa.gov/work/ServiceProviders/rehabproviders.html

Published by: Office of Research Services
619 19th Street South - SRC 529
Birmingham, AL 35249-7330
(205) 934-3283 or (205) 934-4642 (TTD only)
www.spinalcord.uab.edu
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Revised: September, 2007
Developed by: Linda Lindsey, MEd
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This publication is supported by grant #H133N060021 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.