





Resources Offered by the MSKTC to Support Individuals Living With

Spinal Cord Injury





Edition 1 November 2013



www.MSKTC.org/SCI



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About the Model Systems Knowledge Translation Center

The Model Systems Knowledge Translation Center (MSKTC) summarizes research, identifies health information needs, and develops information resources to support the Model Systems programs in meeting the needs of individuals with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury (Burn). The health information offered through the MSKTC is not meant to replace the advice from a medical professional. Users should consult their health care provider regarding specific medical concerns or treatment.

The current MSKTC cycle is operated by American Institutes for Research[®] (AIR[®]) in collaboration with the Center for Chronic Illness and Disability at George Mason University and BrainLine at WETA. The Center is funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) under grant number H133A110004.

https://www.msktc.org/

About the Model Systems Program

Model Systems are specialized programs of care in spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury (Burn). Model Systems conduct innovative and high-quality research, provide patient care, and offer other services to improve the health and overall quality of life for individuals with SCI, TBI, and burn injury. Model Systems are funded by the National Institute on Disability and Rehabilitation Research (NIDRR).

Spinal Cord Injury Model Systems

2011–2016 Funding Cycle

Kentucky Regional Model Spinal Cord Injury System Frazier Rehabilitation, Louisville, KY

Midwest Regional Spinal Cord Injury Care System Rehabilitation Institute of Chicago, Chicago, IL

New England Regional Spinal Cord Injury Center Network

Boston University Medical Center, Boston, MA Gaylord Hospital, Wallingford, CT Hospital for Special Care, New Britain, CT

Northern New Jersey Spinal Cord Injury System Kessler Foundation Research Center, West Orange, NJ

Northwest Regional Spinal Cord Injury System University of Washington, Seattle, WA

Regional Spinal Cord Injury Center of the Delaware Valley

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The Rocky Mountain Regional Spinal Injury System Craig Hospital, Englewood, CO Southeastern Regional Spinal Cord Injury Care System

Shepherd Center, Inc., Atlanta, GA

Southern California Spinal Cord Injury Model System

Rancho Los Amigos National Rehabilitation Center, Downey, CA

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Spaulding-Harvard Spinal Cord Injury System Spaulding Rehabilitation, Boston, MA

UAB Spinal Cord Injury Model System University of Alabama at Birmingham, Birmingham, AL

University of Michigan Spinal Cord Injury Model System University of Michigan, Ann Arbor, MI

University of Pittsburgh Model Center on Spinal Cord Injury UMPC Rehabilitation Institute, Pittsburgh, PA

About the National Spinal Cord Injury Statistical Center

The National Spinal Cord Injury Statistical Center (NSCISC) supports and directs the collection, management and analysis of the world's largest and longest spinal cord injury research database. Organizationally, NSCISC is currently at the hub of a network of 14 NIDRR-sponsored and 5 subcontract-funded Spinal Cord Injury Model Systems located at major medical centers throughout the United States. In addition to maintaining the national SCI database, NSCISC personnel conduct ongoing, database-oriented research. Many of the findings resulting from these investigative efforts have had significant impact on the delivery and nature of medical rehabilitation services provided to SCI patients.

The NCSISC for the 2011–2016 cycle is operated by the UAB Department of Physical Medicine and Rehabilitation and is funded by the National Institute on Disability and Rehabilitation Research.

https://www.nscisc.uab.edu/

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Overview of MSKTC Spinal Cord Injury Products Offered Through the MSKTC

The Model Systems Knowledge Translation Center (MSKTC) offers a variety of free resources on spinal cord injury (SCI) to support people with disabilities and their caregivers, researchers, practitioners and clinicians, and policy makers. The following resources are available at <u>www.MSKTC.org/SCI</u>.

SCI Factsheets

The MSKTC collaborates with SCI Model Systems to produce evidence-based and consumer-friendly factsheets.

SCI Slideshows

The MSKTC develops traditional and narrated slideshows based on information from select factsheets. These resources are developed for users who prefer a format with more images, less text, or an audio option.

SCI Hot Topic Module

The MSTKC developed a Hot Topic Module, which is a collection of resources such as videos, factsheets, and slideshows to support individuals who live with SCI.

SCI Quick Research Reviews

The MSKTC provides quick review of Model Systems research studies funded by the National Institute on Disability and Rehabilitation Research (NIDRR). Those reviews offer timely summaries of newly released model system research studies using lay language for easy access.

SCI Systematic Reviews

The MSKTC collaborates with Model System programs to conduct systematic reviews on high-priority health topics to inform clinical practice. Results of a systematic review provide the best information for making decisions about treatment, practice or behavior.

SCI Research Database

The MSKTC maintains a database of nearly 600 SCI citations and abstracts of studies funded by NIDRR.

Listing of MSKTC Spinal Cord Injury Products Offered Through the MSKTC

SCI Products Available on MSKTC.org/SCI as of August 2013

SCI Factsheets

- Depression and Spinal Cord Injury
- Employment after Spinal Cord Injury
- Spinal Cord Injury and Gait Training
- Pain after Spinal Cord Injury
- Safe Transfer Technique
- Skin Care and Pressure Sores (6 Part Series)
- Spasticity and Spinal Cord Injury
- The Wheelchair Series: What the SCI Consumer Needs to Know (3 Part Series)

SCI Research Database

 Nearly 600 studies conducted by SCI Model Systems researchers

SCI Slideshows

- Employment after Spinal Cord Injury
- Pain after Spinal Cord Injury

SCI Hot Topic Module

• Managing Pain after Spinal Cord Injury

SCI Systematic Review

• SCI and Measures of Major Depression

SCI Quick Research Reviews

- Manual Wheelchair Skills and Quality of Life
- Effects of Nicotine on Spinal Cord Injury Pain
- Walking Index for Spinal Cord Injury

Coming Soon to MSKTC.org/SCI

SCI Factsheets

- Spinal Cord Injury and Exercise
- Spinal Cord Injury and Bone Health
- Bladder and Bowel Problems and Spinal Cord
 Injury
- Aging and Spinal Cord Injury
- Obesity and Nutrition and Spinal Cord Injury
- Understanding SCI (2 Part Series)

SCI Slideshows

- Spasticity and Spinal Cord Injury
- Skin Care and Pressure Sores: Skin Care and Pressure Sores—How to do pressure reliefs (weight shifts)

SCI Systematic Reviews

- Spinal Cord Injury and UTI Surveillance
- Spinal Cord Injury and Measures for Predicting Outcomes of Employment
- Prevention and Treatment of Bone Loss in Spinal Cord Injury
- Spinal Cord Injury and Adverse Exercise Effects
- Women With SCI

Opportunities To Participate in MSKTC Activities

Involvement from the field plays a critical role in the success of the MSKTC. Periodically, we recruit individuals with spinal cord injury and their family members, caregivers, and clinicians to participate in MSKTC activities. We sometimes offer a small financial token of appreciation to participants. Examples of activities include:

- Providing feedback on factsheets
- Offering input on videos
- Participating in a conversation about the needs of caregivers

If you are interested in learning more about these activities or participating, please email **MSKTC@air.org** or call 202-403-5600.

Collection of SCI Factsheets Offered by the MSKTC

This section contains SCI factsheets offered by the MSKTC as of August, 2013. These and other resources are available at no charge on **MSKTC.org/SCI**.

- Depression and Spinal Cord Injury
- Employment after Spinal Cord Injury
- Spinal Cord Injury and Gait Training
- Pain after Spinal Cord Injury
- Safe Transfer Technique
- Skin Care and Pressure Sores (6 Part Series)
- Spasticity and Spinal Cord Injury
- The Wheelchair Series: What the SCI Consumer Needs to Know (3 Part Series)

Depression and Spinal Cord Injury



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

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.

Spinal Cord Injury Model System Consumer Information

Depression is common and can affect anyone. About 1 in 20 Americans (over 11 million people) get depressed every year. Depression is even more common in the spinal cord injury (SCI) population—about one in five people. Estimated rates of depression among people with SCI range from 11% to 37%.

What is depression?

Depression is not just "feeling blue" or "down in the dumps." It is a serious medical disorder (just like diabetes, in which both biology and behavior can help or hurt). Depression is closely linked to your thoughts, feelings, physical health and daily activities. Depression affects both men and women. Depression can cause some or all of the following physical and psychological symptoms:

- Changes in sleep (too much or too little)
- Feeling down or hopeless
- Loss of interest or pleasure in activities
- Changes in appetite
- Diminished energy or activity
- Difficulty concentrating or making decisions
- Feelings of worthlessness or self-blame
- Thoughts of death or suicide

Periods of sadness are normal after SCI. However, there is cause for concern when feeling depressed or losing interest in usual activities occurs almost daily and lasts for more than two weeks. Depression is not caused by personal weakness, laziness or lack of will power.

Causes of depression

Although we don't know for sure what causes depression, we do know that life stresses and medical problems can cause a change in certain brain chemicals, called neurotransmitters. This chemical imbalance is linked to changes in mood, enjoyment, sleep, energy, appetite and ability to concentrate.

Depression can and should be treated

The good news is that the symptoms of depression can almost always be treated with specific types of counseling or antidepressant medications. However, a combination of both counseling and antidepressant medication has been shown to have the best results. Regular exercise or physical activity can also

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improve mood, especially when used together with counseling or medications.

It is important to treat depression because it can have such a harmful effect on a person's ability to function in day-to-day life. Depression can make pain worse, make sleep difficult, sap your energy, take away your enjoyment and make it difficult for you to take good care of your health.

Untreated depression can last 6 to 12 months or more. Thoughts of death is a symptom of depression. The risk of suicide is higher while someone is depressed. Due to both brain chemistry and thought patterns, often people who have severe depression and suicidal thoughts have difficulty seeing a way out of their problems. Suicidal thinking goes away once depression is treated.

What counseling really is

Counseling or psychotherapy is often misunderstood. There are many different kinds of therapy, but one type that has been proven to help depression is called "cognitive-behavioral therapy." Cognitive-behavioral therapy is based on the idea that depression improves when people are more engaged in meaningful activities and when they regain their positive beliefs and attitudes about themselves, their world and their future. The therapist helps you find or resume activities that are meaningful or enjoyable to you. There will be barriers to overcome, so the therapist supports you like a coach to help resolve the problems you face. The therapist also helps you recognize how your thinking becomes more negative in depression and how, through experimentation and logic, you can improve your outlook and rebuild confidence.

How do antidepressants work?

Antidepressant medications seem to work by restoring a normal balance of important brain chemicals such as norepinephrine and serotonin. Rebalancing these chemicals leads to feeling better both emotionally and physically. Treating depression can also help you function better at home and at work. Antidepressants are not addictive. Some people get side effects, but they tend to lessen over time.

Depression Self-Test

For each of the nine items listed below, circle the number (0-3) that corresponds to how often you have been bothered by that problem over the past two weeks.

Over the <u>last 2 weeks</u> , how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or no pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or over- eating.	0	1	2	3
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking or slowly that other people could have noticed. Or the opposite: being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way.	0	1	2	3

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What you can do

- I. Take a "depression self-test" like the one above.
- 2. Answer all the questions honestly, add up your score and see where your score falls.
- 3. If your score is 10 or higher and you have been feeling this way for more than a week or two, contact your health care provider or

a psychologist, psychiatrist or counselor who has experience treating depression.

4. If you are having thoughts of death or suicide, contact your health care provider or a mental health specialist immediately. Also, inform those around you about how badly you are feeling so that they can support you and help keep you safe while you go through this difficult period.

If you are in danger of harming yourself now, please call 911, the 24-hour National Crisis Hotline at 800-273-8255, or your local Crisis Clinic right away.

Remember, depression is not a necessary or inevitable part of living with SCI. In fact, most people with SCI are not depressed. If you are struggling with depression or feeling low for more than two weeks, talk to your doctor. Depression is treatable and beatable.

How to find help

Many mental health professionals are qualified to treat depression. For example, psychiatrists have specialized training in medication management for depression and psychologists are trained to provide counseling for depression.

Other physicians, such as primary care physicians, neurologists and physiatrists, and nurse practitioners with experience in treating depression can often get treatment started and refer you to mental health professionals as needed.

When available, seek treatment from a comprehensive spinal cord injury rehabilitation program that can address all aspects of SCI recovery.

Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the SCI Model System directors.

Authorship

Depression and Spinal Cord Injury was developed by Charles H. Bombardier, PhD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

This document was adapted from materials developed by the Northwest Regional SCI System.

Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.



Employment after Spinal Cord Injury



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

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. Most people with spinal cord injuries (SCI) want to work yet need support, training and vocational rehabilitation services to help them obtain and keep a job. These sources of support may help to overcome many barriers that are outside the individual's control, such as financial and health care issues, accessibility, and employer attitudes.

Work is important to people not only because they can earn an income and receive health insurance and other benefits, but also because it gives them opportunities to interact with others and improved self-esteem and overall life satisfaction. And although there is no cause-effect relationship, there are consistent findings in the research that people who are employed after SCI live longer and report higher satisfaction with life and better health than people who are not working.

Although individuals with SCI can and do go on to have active work lives and successful careers, they have more barriers to overcome than those without disabilities. Federal and state laws and vocational rehabilitation services exist to help people with disabilities overcome these barriers.

The law protects you

Passed in 1990 and amended in 2008, the federal Americans with Disabilities Act (ADA) prohibits employers from discriminating against qualified individuals with disabilities who are able to perform the essential functions of the job with or without accommodation.

- To be protected under this law, you must have a disability that limits major life activities. Nearly all people with SCI are protected under ADA.
- An employer must make "reasonable accommodation" to your disability if it would not impose an undue hardship on the business. Whether an accommodation is considered a "hardship" depends on the business size, financial resources, nature of operation and other factors.
- When you apply for a job, an employer cannot ask you about the existence, nature or severity of your disability, even if you show up for your interview in a wheelchair. An employer can ask you about your ability to perform certain job functions.
- An employer can require you to pass a medical examination only if it is job-related and required of all employees in similar jobs.
- If you feel an employer has discriminated against you, contact the U.S. Equal Employment Opportunity Commission (EEOC). Call 800-669-4000 to find the office nearest you, or go to www.eeoc.gov. Many states have powerful disability rights laws as well.

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The Individuals with Disabilities Education Act (IDEA) is a law that helps young people who have not yet finished their K-12 education receive the services they need to meet their academic and vocational goals and to ensure a smooth transition into adult life. Students eligible under this law may remain in school until age 22 if the extra time is necessary to achieve their goals. For more information, contact the U.S. Department of Education (800-872-5327) or visit the IDEA 2004 website at *http://idea.ed.gov/.*

What is vocational rehabilitation?

Vocational rehabilitation programs can help individuals with disabilities obtain employment. Through these programs, a wide range of services are available to help people identify their career interests and skills; acquire the relevant education or training find and apply for jobs; and get work accommodations. For people who are covered under worker's compensation (because they were injured on the job), a similar set of vocational rehabilitation programs are often available.

Who pays?

- Some private health insurance companies pay for vocational rehabilitation services. Check with your insurer to find out what services are covered.
- State vocational rehabilitation programs are funded (through federal mandate) to provide free vocational rehabilitation services for anyone with a significant disability that limits their ability to work. Services include all the steps in the vocational rehabilitation process described in this factsheet.
- State workers' compensation programs provide free vocational rehabilitation services for individuals who have been injured on the job.
- The Veterans Administration (VA) provides vocational rehabilitation services to eligible beneficiaries with service related disabilities.

How does vocational rehabilitation work?

Vocational rehabilitation can take place at any time an individual with a disability needs help finding or keeping employment. If you are not working but are interested in finding employment, or if you are dissatisfied with your current job, you might try vocational rehabilitation.

Whenever the process begins, it includes the following steps:

Getting started

Your rehabilitation medicine physician can refer you to a vocational rehabilitation program, or you can find these services yourself by visiting *http:// askjan.org/cgi-win/TypeQuery.exe?902* for a listing of the State Vocational Rehabilitation offices.

In many settings, vocational rehabilitation services are provided by rehabilitation counselors with master's degrees who are specially trained to help people with disabilities find and keep employment.

Assessment

Finding satisfying employment means matching your interests and needs with the characteristics and demands of jobs. Being able to find and maintain employment will also depend on your abilities to meet the requirements of the jobs that are available in the job market or your current job.

Your rehabilitation counselor will begin by helping you to evaluate your interests, skills, limitations, health needs, work and education histories, and even personality style. The counselor gets this information through interviews, questionnaires, medical information from your physician, and sometimes tests of academic aptitude and skills. Your counselor may also set up real life opportunities for you to find out more about various jobs.

Real-life "tests"

Your rehabilitation counselor may be able to set up a "trial" work situation for you with a potential employer for a specified period of time to see if you are able to do the job, if you like the job, and what accommodations you might need. These situations may be paid or unpaid. After the trial period, both you and the employer can decide whether it will be a good long-term fit.

The job market

Part of the process may be assessing the job market related to various occupations. You may be interested in a specific job in a particular industry but if that industry is declining or does not have opportunities in your geographic area, you might need to look into something different. Your rehabilitation counselor can help you assess the job opportunities in your area, as well as the wages, tasks, education preparation and other characteristics of occupations you might be interested in. Setting goals The end-product of the rehabilitation counseling process is deciding on the specific career or occupation you want to pursue. This is your long-term goal. To get there, you may need to

long-term goal. To get there, you may need to complete several intermediate steps along the way. These steps should be described in as much detail as possible in a written plan that you and your rehabilitation counselor create together.

For example, you may need to finish high school or attend college to enter the occupation of your choice, or perhaps you can go right to work. To do either, you may need to increase your physical endurance, find reliable accessible transportation and accessible housing, and manage your medical needs so you can meet the demands of a job schedule.

Landing a job

After thorough preparation and planning, people with SCI often secure jobs on their own. Sometimes they need extra help, however. A rehabilitation counselor can help you determine whether a potential job would be a good match for you. He or she can conduct a job analysis to determine the actual kinds of tasks done in that particular job, the cognitive (thinking), social and physical demands of the job, and the need for accommodations. A job placement specialist can help you identify specific opportunities in your geographic area.

Discrimination in hiring is illegal even if it is not intentional. Employers with no experience interacting with people who have disabilities may assume someone with a disability cannot do the work or hold down a job. In these cases, a rehabilitation counselor can step in and work with the employer to overcome prejudices and suggest accommodations that improve the employer's comfort in hiring a person with a disability.

Getting support at work

You may need ongoing support and accommodations at work. Someone with high-level tetraplegia, for example, may need help with positioning or personal care assistance during the work day. These are typically not paid for by the employer, and a source of funding for this assistance must be identified in advance.

Types of accommodations

Job accommodations can include modifying work schedules, tasks or the work environment. Solutions can range from simple to high-tech. Examples:

- Removing a desk drawer or raising the height of a desk with four wood blocks so a wheelchair can fit underneath.
- Special software and hardware so a person with no hand function can work on a computer.
- A private changing area for someone who may have occasional bladder accidents.
- Shifting work hours to a later start and end to the work day to accommodate a worker's lengthy morning care needs.
- If a person has both SCI and a brain injury, he or she may need additional support in the form of extra supervision or job "coaching."

A rehabilitation counselor can help determine what kinds of accommodations might be helpful and whether they constitute "undue hardship" for the employer.

Work vs. benefits: finding a balance

Sometimes people are reluctant to start working because they don't want to lose their medical benefits under Social Security Disability Insurance (SSDI), Supplementary Security Income (SSI), or private or state long-term disability insurance (LTD).They may also be concerned about the extra costs of getting to or staying at work.

Federal work incentive programs under SSDI or SSI allow people with disabilities to receive benefits and federal health care (Medicare and/or Medicaid) while still keeping some of their earnings from employment. This can be a powerful incentive for someone with a high-level SCI who has a strong desire to work but needs personal care assistance on the job, must pay for a van, and needs other services in order to work. Some LTD policies include vocational rehabilitation benefits or incentives to return to work.

Work-incentive programs are complicated. and you may want to consult your vocational rehabilitation counselor, a resource specialist with an independent living center, or a social worker familiar with benefits systems. (Also see "Resources," below.)

If employment is not possible

Sometimes it is not possible for a person to obtain any kind of work after SCI. This includes people who cannot earn enough by working to pay for their own personal care assistance and other disability costs. People who live in rural areas may not have access to transportation or employment. Older workers may not be able to transfer their pre-injury skills to a new occupation. In these cases, the individual can apply for disability benefits with the help of the rehabilitation counselor or other health provider.

A person is eligible to receive disability payments from the Social Security Administration (SSA) if he or she is unable to perform any kind of work at a level of "substantial and gainful" activity and the disability is expected to last at least a year.

The SSA pays disability benefits under two programs:

- Social Security Disability Insurance (SSDI) is a long-term disability insurance program funded by payroll taxes. Eligibility is based on your past work history and income.
- Supplemental Security Income (SSI) is a federal welfare program for people with disabilities who are unable to work and are low income.

Newly injured individuals with SCI should apply for SSA benefits immediately if it seems likely that they will not return to work for at least a year. Sometimes there is a waiting period before starting to receive benefits. Once enrolled, a person is immediately eligible for either state Medicaid benefits or, after a waiting period, for federal Medicare benefits.

The case for volunteering

If paid employment is not possible, consider getting involved in a volunteer activity. Not only can volunteering provide enjoyment and a sense of accomplishment, it can give you the skills, confidence and professional contacts that might eventually lead to paid employment some day.

Reference

Johnson, K. (2009).Vocational Rehabilitation (pp. 715–722). In V. Lin (Ed.), *Spinal cord medicine: Principles and Practice*. New York: Demos.

Resources

- Benefits for People with Disabilities, Social Security Administration: http://www.ssa.gov/disability/
- Find your local Vocational Rehabilitation Agency, Job Accommodation Network, U.S. Department of Labor: http://askjan.org/cgi-win/TypeQuery.exe?902
- The Red Book: A Guide to Work Incentives, Social Security Administration: http://www.socialsecurity.gov/redbook/
- Social Security Area Work Incentive Coordinators (AWIC) provide information about work incentive programs. You can find the AWIC in your area at http://www.ssa.gov/work//awiccontacts.html.

Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the SCI Model System directors and staff.

Authorship

Employment after Spinal Cord Injury was developed by Kurt Johnson, PhD and Jim Krause, PhD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

Spinal Cord Injury and Gait Training



For more information, contact your nearest SCI Model System. For a list of SCI Model Systems, visit <u>http://www.msktc.org/sci/</u> <u>model-system-center</u>

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Spinal Cord Injury Model Systems Consumer Information



Visit http://www.msktc.org/connect-with-us to sign up. Difficulty walking is very common following a spinal cord injury (SCI). People with an "incomplete" SCI have more potential to regain walking than those with a "complete" SCI, but people with both types of SCI may have gait training included in their therapy plans.

Gait training is practicing walking (also called ambulation) with assistive devices and braces as needed. The following categories are used by health professionals to describe the kind of walking you are able to do.

- Community: You are able to walk at home and in the community.
- Household: You can walk within the home and use a wheelchair as the primary way to get around in the community.
- Exercise: You use a wheelchair in the community and at home, and you walk with assistance once or twice a day for exercise.
- Non-ambulatory: You only use a wheelchair for mobility. You may also walk while doing gait training with the therapist in the therapy gym only.

Why is gait training needed?

A spinal cord injury damages nerve cells and can prevent movement signals from the brain to the muscles. It can also disrupt the signals that do reach the muscles, making the muscles "jump" on their own. Therefore, a SCI can create weakness and spasticity in the feet, legs, hips, and trunk, as well as in the hands and arms. The injury can also damage and disrupt nerve signals for sensation (feeling) so that parts of the body are without sensation or have abnormal sensations, such as burning or tingling. Each of these problems can lead to difficulty walking.

Is gait training right for you?

A physical therapist (PT) or other clinician will determine if gait training is right for you by using a variety of tests. He/she will test your strength, sensation, ability to stand up, balance while standing, spasticity or stiffness, and range of motion at your hips, knees, ankles, and trunk. If you are able to take some steps, the clinician will watch you walk to look for safety issues.

The clinician may also provide you assistive devices and/or braces to give you better balance, protect your joints, and ensure your safety as you walk. He/ she may then test your walking speed, endurance, and balance with these devices and braces to keep track of your therapy progress. Gait training can require a lot of work and be a long process, so it is important for your PT or other clinician to tell you what you can expect. Some people with SCI work on balance and other "pre-gait" activities many times a week for over 6 months before they start actual gait training (involving walking). Gait training may not be appropriate early in your recovery, but it may be at a later point when you are stronger and have better balance.

Gait training treatment options

Early Gait Training

You may take your first steps after the SCI using a variety of equipment including parallel bars, a pool, or a body-weight support device. A bodyweight support device lifts part of your weight through a harness you wear as you try to take some steps. Some of these devices roll on the ground and some are placed over a treadmill. Your therapist, a therapy team, or a roboticdevice may help with your balance and stepping movements. It is very beneficial to be upright and moving as soon as your doctor says it is OK.

Later Gait Training

Depending on your SCI, your therapist may begin to work with you on the ground without a bodyweight support device or parallel bars. You may also be given assistive devices and/or braces to improve your balance and help you walk safety. A device may be more or less appropriate depending on your strength and balance. It is helpful to experiment with different assistive devices and braces to find what is right for you.

Assistive devices may include:

- special walkers that have safety straps at your hips and trunk.
- a standard walker with no wheels on the legs.
- a rolling walker (walker with 2 wheels on front legs), if your balance is a little better.
- a rolling walker with forearm platforms, if you have weak arms.
- a rollator walker (walker with 4 wheels and a basket), if you have good enough balance to walk in the community.

- one or two forearm(or "Loftstrand") crutches, if you have better strength and balance, but a weak grip.
- one or two quad canes with four tips at the bottom, if you have pretty good strength and balance and at least a fair grip.
- one or two straight canes with a single tip at the bottom, if you only need a little help with your balance and have a good grip.

If you are able to use crutches and canes, you will likely start with two, using one in each hand. Sometimes you will train with a crutch or cane in only one hand to be able to use your other hand to carry things, open doors, etc. However, you should be careful when using only one crutch or cane. Many people who use a device in only one hand tend to lean on it too much and develop a limp to that side. Using a device in each hand helps to keep your posture straight and your steps even.

Braces

Braces can have many benefits such as the following:

- Protecting weak joints and preventing knee hyperextension by keeping your joints in the proper alignment as you put weight on them during walking.
- Reducing the risk of falling by helping to keep your knee straight and your toes up as you take a step.
- Increasing your walking speed and how long you are able to walk.

Types of braces:

ankle-foot-orthosis (AFO).

knee-ankle-foot-orthosis (KAFO).

hip-knee-ankle-foot-orthosis (HKAFO).

- floor reaction orthosis for people with knees that buckle.
- supra-malleolarorthosis (SMO) at just the ankle to keep you from "turning your ankle".

Spinal Cord Injury Model Systems Consumer Information

Braces may be made of plastic and metal, just plastic, or carbon fiber. They may be "off-theshelf" pre-made braces, or they may be custom made by an orthotist to fit you. Some newer ankle-foot-orthosis designs, such as the lateral strut braces, try to fit more people with a more versatile and open pre-made shape.

It is recommended that you get evaluated by your therapist or orthotist to determine the best brace for you, especially if you cannot feel where the brace will go.

Always be sure you check your skin before you put the brace on and after you take it off, looking for reddened areas on your skin or open wounds. If the brace has caused a pressure sore, do not wear it again until your therapist or orthotist can modify it for you.

Body-weight support device

If you are eventually able to walk with assistive devices or braces, you may still continue gait training on a body-weight support device to help increase your speed and improve your balance and the timing, coordination, and symmetry of your steps. This is performed without using walking devices or braces. You will receive verbal instructions and manual assistance from your therapist and team. All levels of gait training activities can be practiced safely in the harness of these devices, because you cannot fall.

Transferring what you have practiced in the harness to the ground is very important. Assistive devices and braces may still be required to protect your joints and prevent you from falling while transferring to the ground.

Continued gait training with your therapist will hopefully improve your balance and strength so that you can rely less on devices or braces.

Will gait training be effective for you?

The ultimate goal of gait training is to be able to walk in any community environment without assistive devices or braces, but many people will still need one or the other, or both.

Every individual makes progress in therapy at their own pace. Some people may learn to walk

well in a few months, and others may take years. Still others are unable to progress beyond just walking in therapy.

Safety

If you experience falls while walking with or without assistive devices, be sure to tell your health professional as you may need different walking supports and/or more training. People with SCI can have fragile bones due to lack of physical movement, so falling can cause broken bones. Preventing falls is a top priority during gait training and walking in the community.

Outcomes of Gait Training

The ability to walk after a spinal cord injury depends on many factors including your:

- level of injury
- severity of injury
- time since injury
- age
- level of fitness
- other injuries
- level of sensation
- other related problems such as spasticity and joint problems (contractures)
- level of pain

Therefore, it is difficult to predict if a person with SCI will regain walking abilities.

Looking at severity of injury as a factor, the following numbers show the percentage of people in a study who walked with some kind of assistive device and/or braces but no physical assistance from another person, at the time of discharge from inpatient rehabilitation. The ASIA Impairment Scale (AIS) classification level was made when patients were admitted to the hospital.

Proportion of people with SCI who walked at inpatient discharge with devices/braces and without physical assistance:

- ASIA B (motor complete, sensory incomplete): 23.5%
- ASIA C (motor and sensory incomplete, generally weaker legs): 51.4%
- ASIA D (motor and sensory incomplete, generally stronger legs): 88.9%

Those with the most severe, "complete" SCIs may experience that walking with their assistive devices and braces is very difficult and slow. They often decide to use a wheelchair to maneuver quickly and efficiently through their daily lives, and practice walking with devices and braces for exercise only. Regarding level of injury, those with a complete injury level below TII have greater potential to walk in the community while using devices and braces.

People with incomplete SCIs have greater potential than those with complete SCIs to regain function and walking. Those with the "incomplete" injuries Brown-Séquard Syndrome (left or right half of the spinal cord is injured) or with Central Cord Syndrome (the arms are more affected than the legs) have the greatest potential to regain walking. People with SCI who have more accurate sensation also have a better chance of walking.

Resources

Atrice MB, Morrison SA, McDowell SL, Ackerman PM, Foy TA. Traumatic spinal cord injury. In: Umphred DA. Neurological Rehabilitation. 5th ed. St. Louis, MO: Mosby; 2006: 605-657.

Field-Foté E. Spinal Cord Injury Rehabilitation (Contemporary Perspectives in Rehabilitation). Philadelphia, PA: F A Davis Co; 2009.

Sisto SA, Druin E, Macht Sliwinski MM. Spinal Cord Injuries: Management and Rehabilitation. St. Louis, MO: Mosby; 2008.

M Selzer, B Dobkin. Spinal Cord Injury: A Guide for Patients and Families (American Academy of Neurology). New York, NY: Demos Health; 2008. Gittler MS, McKinley WO, Stiens SA, Groah SL, Kirshblum SC. Spinal cord injury medicine. 3. Rehabilitation outcomes. Arch Phys Med Rehabil. 2002;83 Suppl 1: S65-71.

Morganti B, Scivoletto G, Ditunno P, Ditunno JF, Molinari M. Walking index for spinal cord injury (WISCI): criterion validation. Spinal Cord. 2005;43: 27-33.

Zörner B, Blanckenhorn WU, Dietz V, EM-SCI Study Group, Curt A. Clinical algorithm for improved predication of ambulation and patient stratification after incomplete spinal cord injury. J Neurotrauma. 2010;27:241-252.

Winchester P, Smith P, Foreman N, Mosby JM, Pacheco F, Querry R, Tansey K. A prediction model for determining over ground walking speed after locomotor training in persons with motor incomplete spinal cord injury. J Spinal Cord Med. 2009;32:63-71.

Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the SCI Model System directors.

Authorship

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Pain after Spinal Cord Injury



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

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.

Spinal Cord Injury Model System Consumer Information

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 your 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.

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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 spasmrelated 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.

Authorship

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Pain after Spinal Cord Injury SUPPLEMENT: Activity Modification for Musculoskeletal Pain



For more information,

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Exercise

- Almost everyone can benefit from a fitness program that includes resistance training of the muscles that stabilize the shoulder. This will help prevent shoulder pain from occurring as well as treat overuse pain. Strong muscles are much less likely to be injured. Talk with your doctor or therapist about starting a program of resistance exercises that emphasizes those muscles that are often neglected during everyday activities, such as during transfers and wheelchair propulsion.
- For cardiovascular exercise, use upper limb ergometry equipment, such as a stationary bicycle powered by the arms, or a hand-cranked sports wheelchair. You can also box with a speed-bag instead of pushing a manual wheelchair for exercise. Such equipment will reduce stress on the shoulders and wrists.
- Make sure your back and shoulder muscles are strong enough to support wheeling and transferring. It is especially important that there is a balance between your left and right sides. Ask your physical therapist to evaluate you and to prescribe strengthening exercises if you need them.

Using a Wheelchair

- Repetitive pushing of wheel rims is a major problem activity causing musculoskeletal pain. Consider obtaining a power or power-assist wheelchair if you:
 - Have significant upper limb (shoulder, elbow or hand) pain.
 - Have tetraplegia (quadriplegia).
 - Have a prior injury to an upper limb.
 - Are overweight.
 - Are elderly.
 - Live in a challenging environment such as on a steep hill or near very rough terrain.
- If you use a manual wheelchair, make sure it is the lightest model (made from aluminum or titanium) you can afford or your insurer will pay for. Lighter models give you less weight to push around and can often be customized to make it easier for you to propel the chair.
- If you do use a manual wheelchair, reduce the number of strokes you use per distance traveled. Rather than quick short pushes, use long smooth strokes.
- If you use a manual wheelchair, make sure it is in good repair and set up in a way that allows you to get around with minimal effort. Ask your

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therapist to check whether your seat is in the right position relative to your rear axle. Also have him/her check that the chair and cushion together give you good stability.

- Get your wheelchair seating, posture and pushing technique evaluated by a rehab professional periodically since your needs, habits or activities may change over time.
- Keep your tires well-inflated to minimize rolling resistance.
- Wheel your chair over concrete and linoleum rather than through sand, grass or heavy carpeting. The reduced resistance to your wheels lessens the load on your arms.

Shoulder Health

- Minimize the frequency of arm/hand tasks, especially tasks that involve lifting heavy loads higher than your shoulder. Let someone else get that book off a high shelf for you.
- If possible, do not do tasks repetitively that require you to bring your hand higher than your shoulder. This may require reorganizing your house. Talk with your occupational therapist about ways to do so.
- Minimize lifting heavy loads. If you cannot get someone else to do the heavy lifting, hold whatever you need close to your chest rather than at the end of an outstretched arm.
- Avoid doing push-up pressure reliefs (weight shifts), which can harm your shoulder joint. Instead, perform side-to-side or forward-lean pressure reliefs. Work with a therapist to learn proper technique for these methods or see the MSKTC fact sheet "How to do Pressure Reliefs (Weight Shifts)" before discontinuing push-ups.

Transfers

- The heaviest thing you lift generally will be yourself. Reduce the number of transfers you do each day, and do them in a way that minimizes risk of injury.
- Transferring from a high point to a lower one is not as hard on your wrists, elbows

and shoulders as transferring from a low to a higher point. It is better to make two level transfers rather than one downhill transfer followed by one uphill transfer.

- Use sliding boards and other assistive devices (such as lifts) in making transfers.
- When transferring, use a handgrip if available, rather than putting your hand on a flat surface.
- When transferring, don't spread your hand flat and rest on it. Make a fist, and rest on your knuckles.
- When transferring, position your hands as closely to your body as possible so that your arms are straight up and down and your weight hangs between them.
- Alternate which one of your arms is the lead arm in transferring. Different muscles are used by the lead and trailing arms during transfers, and alternating the arms keeps muscles balanced.
- Maintain your ideal weight. Being overweight is hard on your shoulders, arms and wrists when you do transfers or push your wheelchair.

Reference

Consortium for Spinal Cord Medicine. Preservation of upper limb function following spinal cord injury: a clinical practice guideline for health-care professionals. J Spinal Cord Med 2005; 28:433-70.

Authorship

Please see the Spinal Cord Injury Model Systems Consumer Information publication *Pain after Spinal Cord Injury* for information about authorship.



Safe Transfer Technique



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

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. Transferring in and out of your wheelchair puts higher stress on your arms and shoulders than anything else you do on a regular basis. Learning the correct way to transfer is extremely important in order to keep your arms functioning and pain-free.

Get proper transfer training

- Everyone needs individualized transfer training to preserve function and avoid injury. Work with a physical therapist to learn the best transfer technique for you and your body.
- Your transfer technique may need to be readjusted as years go by. If you develop any problems or if your living circumstances (e.g. pregnancy) or activities change, go back to your therapist for advice.

Safe transfer rules and technique

- Frequency Only transfer when necessary, keeping the number of transfers to a minimum.
- Transferring downhill is easier and, at modest height, safer than transferring uphill.
- Technique Steps (These are general steps. Work with your therapist to fine tune them for you.):
 - Positioning/setup
 - Get as close as possible to the surface you want to move to.
 - Lock your wheels if transferring from a wheelchair.
 - Put your feet on floor (unless your therapist tells you not to).
 - Scoot to the edge of your chair.
 - Get your arm rest out of the way on the side next to the surface you are transferring to.



continued on page 2

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- Lean your trunk forward.
 - When transferring, your head should move in the opposite direction of your hips. This is known as a head-hips relationship and can help with movement and clearing obstacles.
- To protect your shoulders, keep your arms as close to your body as possible (about 30–45 degrees away from your body) while you are lifting your weight.
- To protect your wrists, try to grip an edge or grab bar with your fingers rather than laying your hands flat. Keeping your hands flat and putting your weight on your palms is a dangerous position that can lead to wrist problems such as carpal tunnel syndrome down the road.
- Lift-off
 - Make sure you are clearing obstacles (not bumping or rubbing) to avoid shearing and pressure sores.
 - If you cannot perform the transfer in one smooth movement while keeping your arms close to your body, move in several small "steps" and/or use a transfer board.
 - Be careful sliding across the transfer board because the motion can damage your skin.
 Use a pad or towel on the board when bare skin may come in contact with the board during the transfer.
- Alternate leading arms and direction of transfers to keep your arm muscles balanced and reduce strain on one side.
- Maintain ideal body weight. The more you weigh, the more weight you have to transfer and the more stress you put on your shoulders and arms.
- If you are unable to perform a transfer safely or are at risk for developing arm pain, you should strongly consider using one of the many kinds of patient lifts available.

Resources

Consortium for Spinal Cord Medicine. Preservation of Upper Limb Function: What You Should Know. A Guide for People with Spinal Cord Injury, Paralyzed Veterans of America, 2008.

Source

Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the SCI Model System directors.

Authorship

Safe Transfer Technique was developed by Michael L. Boninger, MD, in collaboration with the University of Washington Model Systems Knowledge Translation Center.

Disclaimer

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.



Skin Care & Pressure Sores Part 1: Causes and Risks of Pressure Sores



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Spinal Cord Injury Model System Consumer Information

What do I need to know?

- Individuals with SCI are at high risk for developing pressure sores.
- Pressure sores can be life threatening.
- Possible complications:
 - Infections can develop and spread to the blood, heart and bone.
 - Amputations
 - Prolonged bed rest necessary for healing can keep you out of work, school and social activities for months.
 - Because you are less active when healing a pressure sore, you are at higher risk for respiratory problems and urinary tract infections.
 - Treatment can be very costly in lost wages or additional medical expenses.
- Up to 80% of individuals with SCI will have a pressure sore during their lifetime, and 30% will have more than one pressure sore.
- Most pressure sores are preventable.

What is a pressure sore?

A pressure sore (also called pressure ulcer, decubitus ulcer, decubiti (plural), bedsore or skin breakdown) is an area of the skin or underlying tissue (muscle, bone) that is damaged due to loss of blood flow to the area. Blood flow to the skin keeps it alive and healthy. If the skin does not get blood, it will die.

Why do pressure sores happen?

Normally the nerves send messages of pain or discomfort to your brain to let you know when to move to relieve pressure, stay away from hot surfaces, or shift your weight. After injury, messages from the sensory nerves may not normally reach the brain. With little or no feeling, you have no warning signs to tell you that you have been in one position too long and that something is pressing against your skin causing it harm.

How do pressure sores happen?

- Too much pressure on the skin for too long, as in sitting or lying too long in one position. Unrelieved pressure is the most common cause of pressure sores in SCI. The extended pressure cuts off the blood supply to the skin, leading to tissue damage, skin breakdown and a pressure sore. Common high-pressure situations:
 - Sitting too long without shifting weight.
 - Lying too long without turning.
 - Not enough padding in bed (to protect bony areas of the body, such as the heels).

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- Clothing and shoes that fit too tightly.
- Sitting or lying on hard objects, such as catheter connectors and clamps, bulky seams, or buttons on mattresses.
- Shearing occurs when the skin moves one way and the bone underneath it moves another way. This can result from slouching while sitting, sitting at a 45 angle (as in bed), or sliding during a transfer instead of lifting your body. Shearing can also happen during spasms.
- Trauma of any kind (cuts, bumps, burns, scrapes, rubbing)
 - Abrasion or friction: Cut or scratch; sliding across sheets or transfer board with bare skin.
 - Bump or fall: Bumping toes into doorways; bumping your buttocks off the tire during transfers; bumping knees under desks.

What puts me at risk of getting a pressure sore?

- Loss of muscle mass. With paralysis the muscles tend to shrink, become less bulky and get smaller (atrophy). Muscle mass or bulk serves as a natural cushion over the bony areas. A decrease in muscle mass leads to less protection over bony surfaces and more pressure on the thin skin layers.
- Being over- or underweight. When you are underweight, you have less natural padding to protect your body areas, so your skin can break down from even small amounts of pressure. But when you are overweight, it is harder to shift your weight and do pressure reliefs, and all that fat uses oxygen and nutrients that could be nourishing your skin.
- Decreased circulation.
 - Blood flow to the paralyzed limbs decreases due to the lack of muscle movement and results in less nutrients and oxygen getting to the skin. The skin does not heal well if there is poor circulation.
 - Edema or swelling is caused by fluid collecting in the tissues, usually in a part of the body that is not moved frequently and is below the level of the heart (feet, legs and hands). Skin over areas of edema becomes thin and pale and injures easily.

- Smoking is terrible for your circulation.
- Diabetes, high blood pressure and high cholesterol decrease circulation. If you have these diseases, pay particular attention to your feet and ankles. They are farthest away from the heart and are likely to be affected first or worst.
- Illness or poor overall health. This includes fevers, infections (such as UTIs), poor nutrition, and chronic diseases such as diabetes.
- **Moisture**. Wet skin (from urine, stool, sweat, water) is more likely to break down.
- **Dry, flaky skin** can crack and become inflamed and infected.
- Aging causes skin to become thinner, dryer, and more fragile. You may need to adjust your pressure relief schedule or switch to a different type of cushion when you get older.
- **Previous skin breakdown**. Scar tissue is more fragile than normal skin.
- Spasticity can cause your arms or legs to bump against an object and be injured, or rub against a surface (such as the sheets on your bed), which could produce an open sore.
- Extreme heat or cold.
- Alcohol (or drug) use often causes people to neglect their pressure reliefs and other personal care needs.
- Depression is also a risk factor for developing pressure sores.

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More in the Skin Care & Pressure Sores series:

- Part 2: Preventing Pressure Sores Supplements:
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 - Stages of Pressure Sores: Illustrations

Skin Care & Pressure Sores Part 2: Preventing Pressure Sores



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What do I need to know?

- Ninety-five percent of all pressure sores are preventable!
- After spinal cord injury, your skin requires daily care and a lot of attention.
- You will need to spend time daily cleaning the skin, keeping it dry (from incontinence or perspiration), checking the skin for problems or changes, moving yourself so the skin will get proper blood supply, and drinking and eating properly so the skin can stay healthy.

How can I avoid getting a pressure sore?

Do regular pressure reliefs (also called weight shifting, pressure redistribution and pressure reduction)

- Pressure relief is moving or lifting yourself to take the pressure off areas that have been under pressure, usually from sitting or lying in one position, so blood can circulate.
- When sitting in your wheelchair you should do pressure reliefs every 15 to 30 minutes for a duration of at least 30 to 90 seconds. Continue to perform pressure reliefs when sitting in a car or on other surfaces (such as on sports equipment). [For more information, read the fact sheet on "How to do Pressure Reliefs (Weight Shifts)."]
- If you are unable to perform a pressure relief independently, instruct the person who helps you with your daily care (family, attendant) to consistently, routinely move you and reduce pressure over areas at risk for pressure sores.
- Your therapist or nurse will teach you how to do pressure reliefs before you leave the hospital. The methods and timing of pressure reliefs will vary somewhat according to your injury and skin tolerance.
- Each person's skin tolerance is different. Some people may need to relieve pressure very often, others may not need to do it very often—but they still need to do it! Building skin tolerance is a gradual process. [For more information, read the fact sheet on "Building Skin Tolerance for Pressure."]
- For pressure relief at night, see the recommendations described in "Padding, positioning and turning in bed," below.

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Skin inspection

- Check your skin, or have your attendant or caregiver check your skin, a minimum of twice a day (morning and bedtime).
- Look for changes in skin color (redness or darkening), blisters, bruises, cracked, scraped or dry skin.
- Feel for hardness, swelling or warmth that may signal skin breakdown.
- Closely inspect areas that are at especially high risk for pressure sores because in some areas of the body the bones are close to the surface of the skin; the skin that is directly over bone is at highest risk. [For more information, read the fact sheet on "Areas at High Risk for Developing Pressure Sores."]:
 - sacrum (lower back)
 - coccyx (tailbone)
 - heel of the foot
 - ischium (the base of the buttocks, "seat bones")
 - trochanter (hip, from lying on side, something rubbing, or tight clothes)
 - elbow (from leaning on it)
 - knee (from spasms or side-lying with one knee on top of other)
 - ankle (from lying on side)
 - toes and bony areas of foot (from tight-fitting shoes)
 - back of the head
- Inspect areas of skin that are in contact with casts or braces twice daily.
- Use a mirror to inspect skin in hard-to-see areas. Train the person who helps you to carefully and regularly check your skin.
- Pay attention to fingernails and toenails: an ingrown toenail or cut along your nail bed may lead to a sore which can easily be infected.
- As soon as you notice a discolored area, stay off the area until it returns to normal skin color.
- If you suspect skin damage of any kind, read the fact sheet "Skin Care & Pressure Sores, Part 3: Recognizing and Treating Pressure Sores."

Padding, positioning and turning in bed

- Use a regular schedule of turning at night. Depending on weight and skin tolerance, your turning schedule may vary from every 2 to every 6 hours. Ask your health care provider for advice about a turning schedule. When turning and moving in bed, lift rather than slide across sheets.
- Use pillows and foam pads (not folded towels or blankets) to protect bony areas. No two skin surfaces should rest against each other!
- Unless your doctor tells you to do it, avoid elevating the head of your bed, which can put too much pressure on your buttocks and lower back areas.
- For individuals at the highest risk for pressure sores, your health care provider may prescribe a special mattress, mattress overlay or bed for long-term use.

Keep skin clean and dry

- Bathe daily with mild soap and warm water and rinse and dry thoroughly. Pay particular attention to keeping the genital area and skin folds clean and dry.
- Immediately wash and dry skin and change clothing after any leakage of stool or urine.
- Avoid harsh soaps, skin agents with alcohol, and antibacterial or antimicrobial soaps. Do not use powders. Use a moisturizer that has been approved by your health care provider.

Get a proper seating evaluation at least every two years or sooner if your health or skin condition changes.

- Make sure you have the proper cushion for your wheelchair and your seating tolerance.
- Make sure you have the appropriate wheelchair, one that has been measured specifically for you and is compatible with your level of mobility, activities, work and associated equipment.
- The therapist doing the seating evaluation should place a pressure map above your cushion and under your buttocks to see where

your pressure-sensitive areas are. If at-risk areas on the pressure map are found, then the therapist may try a different cushion; alter the wheelchair seat, back or foot rest; or show you how to relieve pressure on the vulnerable areas by repositioning your body.

- Pressure mapping is an excellent way to visually demonstrate the effectiveness of weight shifts.
- If pressure mapping is unavailable, work with a seating professional and try several different cushions to see what works best for you.

Positioning and transferring

- Sit as erect as possible in your wheelchair.
 Slouching can damage skin.
- Perform safe transfers. Do not drag or scrape your bottom when moving in and out of your wheelchair.
- If you need help during transfers, make sure the person who is helping you is very well trained to assist.

Clothing, shoes

- Wear properly fitted clothing; avoid thick seams, rivets or bulky pockets and check for folds and wrinkles in areas of pressure.
- Shoes should be 1-2 sizes longer and wider than your pre-injury shoe size to allow for swelling of feet during the day.
- Use shoes with stiffer toes for protection when you bump into objects with your feet.
- Do not carry anything (comb, wallet, etc.) in your back pockets.

Hydration (fluid intake)

- Drink enough water every day to give your body the fluids it needs. Water intake may vary according to your bladder management routine— consult your health care provider for advice about how much water to drink.
- Avoid caffeinated drinks like coffee, tea and soft drinks, which are dehydrating and may trigger bladder spasms.

Nutrition

- Eat a balanced diet that includes adequate protein, fruits and vegetables (fresh if possible).
 Poor nutrition prevents the body tissue from rebuilding, staying healthy and fighting infection.
- If there is any question about your nutritional status you may ask your doctor to order a blood test to check your protein, albumen, prealbumen, lymphocyte or hemoglobin levels.
- If you have any conditions that may be affected by your nutrition (such as diabetes or hypertension), please consult with your health care provider who may recommend a consultation with a dietician.
- More information about nutrition and spinal cord injury:
 - "Nutritional Guidelines for Individuals with Spinal Cord Injury." Northwest Regional Spinal Cord Injury System. (2006) http://sci. washington.edu/info/forums/reports/nutrition. asp.
 - "Weight Management Following SCI SCI InfoSheet #8." Discusses the role of nutrition in an overall weight management program. Spinal Cord Injury Information Network (2005). http://www.spinalcord.uab. edu/show.asp?durki=21481

Sun exposure

 Avoid getting sunburned. Some medicines make your skin more sensitive and may cause it to burn more easily. Use sunscreen and limit your time in the sun, or seek shade.

Equipment

- Use prescribed, individualized equipment when seated or lying down. Have a doctor or quailfied professional recommend what specialized equipment (seat cushion, mattress, pillows) you need to protect your skin.
- Check wheelchair, mattress, cushions and transfer boards daily for problems. Maintain, at a minimum, the manufacturer's recommendations for maintenance of all equipment.

Temperature

- Compared to before your injury, you are more susceptible to frostbite in cold weather due to changes in circulation and lack of sensation.
- You are also more susceptible to burns. Avoid contact with hot objects (metal pipes, fireplaces, heater in your home or car, hot water in the shower, microwaved dishes or food items you might want to place on your lap).

Circulation

- Quit smoking!
- Keep as active as possible.

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Skin Care & Pressure Sores Part 2: Preventing Pressure Sores Supplement: Areas at high risk of developing pressure sores





skin-to-skin contact and increase air circulation between your legs.

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Skin Care & Pressure Sores Part 2: Preventing Pressure Sores Supplement: Building skin tolerance for pressure



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Spinal Cord Injury Model System Consumer Information

What is skin tolerance?

Skin tolerance is how much time your skin can stand to be under pressure before damage starts to occur. Each person's skin tolerance is different. Some people may need to relieve pressure very often, others may not have to do it as often, but they still need to do it!

Skin tolerance changes if you are sick, not eating well, have changes in posture or you change the surface you sit or lie on. Inspect your skin more frequently under these circumstances.

How do I know what my skin can tolerate?

When you were in the hospital, the staff worked with you daily to help you build skin tolerance and know what limits your skin can handle. Discuss skin tolerance with your physician or seating specialist if you have questions.

The increase in redness of your skin after applying pressure (the first sign of a pressure sore) and the amount of time it takes for the redness to fade will tell you what your skin can tolerate and whether to increase your time between pressure reliefs.

Remember, no matter how many hours you sit in a wheelchair, you need to move yourself every 15 to 30 minutes.

How do I know if I can increase sitting time or time in one position?

- Building up skin tolerance is a gradual process. You can build skin tolerance for any position, lying down or sitting, by following these steps:
 - Lie in one position for the amount of time advised by your doctor.
 - Look at your skin. Test if the pink areas of you skin turn white when touched.
 - Stay off the area until the redness or pinkness clears completely.
 - If redness or pinkness clears in 15-30 minutes, you may increase your time between pressure reliefs or turning by 30 minutes.
 - If redness or pinkness does not clear in 15-30 minutes, do not increase your time between pressure reliefs or turning.

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Skin Care & Pressure Sores Part 2: Preventing Pressure Sores Supplement: How to do pressure reliefs (weight shifts)



The pressure relief technique you use will depend on your level of injury, the type of wheelchair you use and how much movement and strength you have in your arms and shoulders.

Tilting or reclining

- If you are unable to perform independent pressure reliefs, you can use a power tilt wheelchair for regular pressure relief.
- Tilt, recline and elevating leg rests are features that can be used to change body position in a manner that provides pressure relief.
- It is very important that you receive training from your health care provider in how to use any of these features in order to make sure you are getting enough pressure relief. Improper use of these features can also lead to injury.
- Note that tilt and recline features provide the most pressure relief when used in combination. (RESNA, 2008)
- Tilt systems maintain the seat to back angle but change the angle orientation to the ground. Tilt angle of between 25 and 65 degrees has been shown to provide pressure relief, but 15 degrees or less does not provide adequate pressure relief. Figure 1 shows a 65 degree tilt.

• **Recline systems** (Figure 2) provide a change in

- - Figure 1:Tilt System

seat-to-back angle while maintaining a constant seat angle with respect to the ground. The use of recline affects the vertical (downward) pressure and horizontal pressure on your skin and needs to be evaluated individually.

• Elevating leg rests allow change in the angle of legs and/or footrests in relation to the seat, extending the knee. This feature can help reduce pressure when using the recline feature.



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Leaning from side to side

This technique relieves pressure over one buttock at a time.

1. Lock your wheels, and swing away one armrest from your wheelchair.



- 2. Hold onto the remaining armrest and lean your body to the opposite side, taking the weight off one buttock for 30-90 seconds (Figure 3). If you cannot grasp the armrest with your hand, you may be able to hook your wrist behind the wheelchair push handle or back rest (Figure 4).
- 3. To regain the upright position, you may need to use the wheelchair push handle or armrest for assistance. Some also find that pushing up on the push rims of the wheels helps in regaining upright position.
- 4. You may use a table or other stationary object to lean against for assistance (Figure 5). Just be sure the weight is completely off the opposite buttock, and hold the position for 30-90 seconds.
- 5. Repeat on the other side.

Leaning forward

This technique can be done independently or with assistance.

- 1. Move your wheelchair so that **the front casters are turned forward**, then **lock the wheels** of your wheelchair.
- 2. Bend forward and bring your chest to your knees (Figure 6). This lifts the weight of your bottom from the wheelchair. Stay in this position for 30-90 seconds.
- 3. Return your body to the upright position. There are several techniques to regain upright position depending on your equipment and the strength in your arms and trunk. You may:
- Place your hand on your knees and push up.
- Keep your hand on push handles and pull up.
- Place your hand against the front of the armrest and push up.

Independent push-ups

This technique can be used by individuals who can extend their elbows and lift their body weight (people with an injury at C7 and below). Grip your arm rests with your hands and lift up completely off your seat for 60 seconds. Since this method could harm the rotator cuff (part of the shoulder joint), it should only be used if you are unable to complete the other techniques.



Figure 6

Progression of Training

Early in your training, you may find that it is difficult to shift your weight away from the center of your chair. It may also be difficult for you to regain upright position after shifting your weight. You may try the following techniques.

- Position and lock your chair next to a stationary object. Perform the side lean as instructed above, but use the object to push up as you regain the upright position.
- Position and lock your chair in front of a table. Lean forward onto the table and use it to push back up.

Alternate Techniques

If you are looking for less obvious pressure relief techniques when you are out in the community, the following suggestions can be done without attracting attention.

- Cross one leg over the other and lean back to one side while holding your knee in position, lifting the weight off one buttock (Figure 7). Repeat using the other leg.
- Cross your leg by putting one ankle over the other knee and lean forward, lifting the weight off your buttock (Figure 8). Repeat using the other leg.
- Spend some time "fixing" your shoe laces, your feet, or the hem of your pants to achieve the same position as the forward lean technique (Figure 6).
- Lean against tables as you speak to friends.





References

Resna Position on the Application of Tilt, Recline and Elevating Legrests, Rehabilitation Engineering & Assistive Technology Society of North America. Arlington, VA. April 2008.

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Skin Care & Pressure Sores Part 3: Recognizing and Treating Pressure Sores





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How can I tell if I have a pressure sore?

- First signs. One of the first signs of a possible skin sore is a reddened, discolored or darkened area (an African American's skin may look purple, bluish or shiny). It may feel hard and warm to the touch.
- A pressure sore has begun if you remove pressure from the reddened area for 10 to 30 minutes and the skin color does not return to normal after that time. Stay off the area and follow instructions under Stage 1, below. Find and correct the cause immediately.
- Test your skin with the blanching test: Press on the red, pink or darkened area with your finger. The area should go white; remove the pressure and the area should return to red, pink or darkened color within a few seconds, indicating good blood flow. If the area stays white, then blood flow has been impaired and damage has begun.
- Dark skin may not have visible blanching even when healthy, so it is important to look for other signs of damage like color changes or hardness compared to surrounding areas.
- Warning: What you see at the skin's surface is often the smallest part of the sore, and this can fool you into thinking you only have a little problem. But skin damage from pressure doesn't start at the skin surface. Pressure usually results from the blood vessels being squeezed between the skin surface and bone, so the muscles and the tissues under the skin near the bone suffer the greatest damage. Every pressure sore seen on the skin, no matter how small, should be regarded as serious because of the probable damage below the skin surface.

Stages of pressure sores

[Also see "Stages of Pressure Sores: Illustrations."]

STAGE 1

- Signs: Skin is not broken but is red or discolored or may show changes in hardness or temperature compared to surrounding areas. When you press on it, it stays red and does not lighten or turn white (blanch). The redness or change in color does not fade within 30 minutes after pressure is removed.
- What to do: Stay off the area and remove all pressure; keep the area clean and dry; eat adequate calories high in protein, vitamins (especially A and C) and minerals (especially iron and zinc); drink more water; find and remove the cause; inspect the area at least twice a day; call your health care provider if it has not gone away in 2-3 days.
- Healing time: A pressure sore at this stage can be reversed in about three days if all pressure is taken off the site.

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STAGE 2

- Signs: The topmost layer of skin (epidermis) is broken, creating a shallow open sore. The second layer of skin (dermis) may also be broken. Drainage (pus) or fluid leakage may or may not be present.
- What to do: Get the pressure off, follow steps in Stage I, and see your health care provider right away.
- Healing time: Three days to three weeks.

STAGE 3

- Signs: The wound extends through the dermis (second layer of skin) into the fatty subcutaneous (below the skin) tissue. Bone, tendon and muscle are not visible. Look for signs of infection (redness around the edge of the sore, pus, odor, fever, or greenish drainage from the sore) and possible necrosis (black, dead tissue).
- What to do: If you have not already done so, get the pressure off and see your health care provider right away. Wounds in this stage frequently need special wound care. You may also qualify for a special bed or pressure-relieving mattress that can be ordered by your health care provider.
- Healing time: One to four months.

STAGE 4

- Signs: The wound extends into the muscle and can extend as far down as the bone. Usually lots of dead tissue and drainage are present. There is a high possibility of infection.
- What to do: Always consult your health care provider right away. Surgery is frequently required for this type of wound.
- Healing time: Anywhere from three months to two years.

SUSPECTED DEEP TISSUE INJURY *

- Purple or maroon localized area of discolored intact skin or blood-filled blister due to damage of underlying soft tissue from pressure and/or shear. The area may be surrounded by tissue that is painful, firm, mushy, boggy, warmer or cooler as compared to nearby tissue.
- Deep tissue injury may be difficult to detect in individuals with dark skin tones. Progression may include a thin blister over a dark wound

bed. The wound may further evolve and become covered by thin eschar (scab). Progression may be rapid exposing additional layers of tissue even with optimal treatment.

UNSTAGEABLE *

 Full thickness tissue loss in which the base of the ulcer is covered by slough (dead tissue separated from living tissue) of yellow, tan, gray, green or brown color, and/or eschar (scab) of tan, brown or black color in the wound bed.

* From: Pressure Ulcer Stages Revised by National Pressure Ulcer Advisory Panel (2007). http://www.npuap.org>.

Possible complications of pressure sores:

• Can be life threatening.

- Infection can spread to the blood, heart and bone.
- Amputations.
- Prolonged bed rest that can keep you out of work, school and social activities for months.
- Autonomic dysreflexia.
- Because you are less active when healing a pressure sore, you are at higher risk for respiratory problems or urinary tract infections (UTIs).
- Treatment can be very costly in lost wages or additional medical expenses.

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NORMAL SKIN



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STAGE 1

Skin is not broken but is red or discolored. When you press it, it stays red and does not lighten or turn white (blanch). The redness or change in color does not fade within 30 minutes after pressure is removed.



STAGE 2

The topmost layer of skin (epidermis) is broken, creating a shallow open sore. The second layer of skin (dermis) may also be broken. Drainage may or may not be present.



For more information, contact your nearest SCI

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STAGE 3

The wound extends through the dermis (second layer of skin) into the subcutaneous (below the skin) fat tissue. Bone, tendon and muscle are not visible. Look for signs of infection (pus, drainage) and possible necrosis (black, dead tissue).

STAGE 3

STAGE 4

The wound extends into the muscle and can extend as far down as the bone. Usually lots of dead tissue and drainage are present. There is a high possibility of infection.

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Illustrations are from the National Pressure Ulcer Advisory Panel (http://www.npuap.org/).

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Spasticity and Spinal Cord Injury



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Spinal Cord Injury Model System Consumer Information

What is spasticity?

Spasticity is the uncontrolled tightening or contracting of the muscles that is common in individuals with spinal cord injuries. About 65%–78% of the SCI population have some amount of spasticity, and it is more common in cervical (neck) than thoracic (chest) and lumbar (lower back) injuries.

Symptoms and severity of spasticity vary from person to person and can include:

- Sudden, involuntary flexing (bending) or extending (straightening) of a limb, or jerking of muscle groups such as in the trunk (chest, back, and abdomen), bladder, or rectum.
- Hyperactive (overactive) reflexes, such as a muscle spasm when you are lightly touched.
- Stiff or tight muscles at rest, so that it is difficult to relax or stretch your muscles.
- Muscle tightness during activity, making it difficult for you to control your movement.

What causes spasticity?

The nerves of the spinal cord and brain form a complex communication circuit that controls our body movements. Information on sensations or processes such as touch, movement or muscle stretch is sent up the spinal cord to the brain. In response, the brain interprets the signal and sends the necessary commands back down the spinal cord to tell your body how to react. The reaction of the body, such as jerking away from a hot object, is a reflex and happens quickly and automatically.

After a spinal cord injury, the normal flow of signals is disrupted, and the message does not reach the brain. Instead, the signals are sent back to the motor cells in the spinal cord and cause a reflex muscle spasm. This can result in a twitch, jerk or stiffening of the muscle.

Just about any touch, movement or irritation can trigger and sustain spasms.

Common triggers are:

- Stretching your muscles.
- Moving your arm or leg.
- Any irritation to the skin, such as rubbing, chafing, a rash, in-grown toenails, or anything that would normally be very hot or cold or cause pain.
- Pressure sores.
- A urinary tract infection or full bladder.

- Constipation or large hemorrhoids.
- Fracture or other injury to the muscles, tendons or bone below the level of spinal cord injury.
- Tight clothing, wraps or binders.

Spasticity can be irritating, inconvenient or even limit your ability to go through your day.

What are the benefits of spasticity in SCI?

Spasticity is not always harmful or bothersome and does not always need to be treated. Sometimes spasticity can help with functional activities such as standing or transferring. Spasticity that causes your fingers to bend can help you grip objects. Spasticity can also be a signal that you have a medical problem that you might not know about otherwise, such as a urinary tract infection, fracture, or pressure sore.

What problems are caused by spasticity?

- Spasticity can be painful.
- Spasticity can result in loss of range of motion in your joints (contractures).
- Severe spasms can make it difficult for you to drive or transfer safely, or to stay properly seated in your wheelchair.
- Spasticity in your chest muscles may make it difficult to take a deep breath.
- Strong spasms in the trunk or legs can cause you to fall out of your wheelchair when you change position, transfer, or ride over uneven surfaces.
- Repeated muscle spasms at night can cause you to sleep poorly and be tired during the day.
- Spasms can cause rubbing that leads to skin breakdown.
- Spasticity can make movement harder to control, so that activities such as feeding yourself may be more difficult.

Managing spasticity after SCI

First, practice healthy behaviors and good self-care that will help you avoid problems that can increase spasticity, such as urinary tract infections and skin breakdown. Check to see if any of the common triggers listed above may be causing the problem.

Physical treatments

The following treatments will help to maintain flexibility and therefore reduce spasticity and the risk for permanent joint contracture:

- Regular stretching (range-of-motion) exercises twice daily will help maintain flexibility and temporarily reduce muscle tightness.
- Weight-bearing or standing with support, such as using a standing frame or other supportive devices, will help stretch muscles.
- Splints, braces, or progressive casting into the desired position provides continuous muscle stretching that helps to maintain flexibility and a position that does not trigger a spasm.
- Careful use of hot or cold packs. When used in body areas that have partial sensation, check skin tolerance frequently as it may result in a burn if too hot and frostbite if too cold. Avoid the use of hot packs over areas without sensation.

Medications

When physical measures are not enough to control spasticity, medications may be needed.

Oral medications

If spasticity involves large areas of your body, your doctor may prescribe one or more of the following medications:

- Baclofen
- Benzodiazepines (muscle relaxants) such as diazepam, clonazepam
- Dantrolene
- Tizanidine

The effectiveness of these medications varies with each person. Because these medications can have side effects such as fatigue or drowsiness, weakness, nausea, or sometimes low blood pressure, your provider needs to monitor you closely.

Nerve or motor point blocks

If only part of your body has spasticity, anesthetic medications, alcohol, phenol or neurotoxins (such as strains of botulinum toxin) can be injected into the muscles that have spasticity. The medications rarely cause widespread side-effects. The benefits of the injections are only temporary, however, so injections must be repeated a few times a year. These injections can be used alone or in combination with oral spasticity medications.

Surgery

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Intrathecal medication therapy (also called a "pump" or "baclofen pump")

Intrathecal drug therapy uses a surgically placed, battery-powered pump and an attached catheter to deliver medication directly into the spinal canal, around the spinal cord (called the "intrathecal" space).The most commonly used intrathecal drug for spasticity is baclofen. Intrathecal baclofen can be used in conjunction with the other treatments listed above.This treatment is generally not recommended until other treatments have been tried and failed to provide relief or if oral medications cause unacceptable side effects.

Advantages of intrathecal baclofen:

- The drug is delivered directly around the spinal cord, so lower doses of medication are needed.
- Fewer negative side effects because the drug does not enter the bloodstream.
- The amount and dosing schedule of drug throughout the day can be precisely set and adjusted by the health care provider to meet each individual patient's needs.
- The pump can be stopped or removed, if necessary.

Disadvantages of intrathecal baclofen:

- You will need surgery to implant the pump and catheter system. Any surgery has risks, such as infection.
- The pump has a limited battery life and will need to be replaced about every 5-7 years.
- You will need to go to your provider periodically for pump refills (done by injecting baclofen through the skin into the pump reservoir).

Mechanical problems with the device may occur and could result in a baclofen overdose or underdose. For this reason, it is important for you to understand the risks, monitor yourself carefully, and get regular follow-up from your provider.

Other Surgery

Other surgical treatments for spasticity are far less commonly performed because they are not reversible. These include cutting a section of the spinal cord (myelotomy) or nerve roots (rhizotomy), or lengthening and transposing a tendon. Your doctor will discuss these surgical options with you if necessary.

Which treatment is best for me?

Discuss your specific needs and treatment options with your health care provider or team. You may need to try different methods, medications, or combinations of treatments before you feel your spasticity is under control. Consider the following questions and discuss them with your provider:

- What are your goals for treatment of your spasticity?
- How important is it that the treatment can be reversed or stopped?
- What are the possible short-term and long-term side-effects of each treatment?
- Are there other health conditions that would influence the treatment choice?
- If you are considering intrathecal baclofen: Will you be able to follow the maintenance requirements? Do you have a good understanding of the possible risks and benefits?

Whatever treatment you choose, you will need to work closely with your treatment provider or team to get the best possible outcome.

What happens to spasticity over time?

In general, spasticity appears to become less bothersome over time. Possibly this happens because people learn to avoid things that trigger spasticity. Changes that naturally go on in the body as you age, such as a slowing down of nerve conduction, may also decrease spasticity. However, an unexplained, sudden or dramatic change in your spasticity level may sometimes signal a problem, so let your health care provider know immediately.

Source

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Getting the Right Wheelchair: What the SCI Consumer Needs to Know

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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. Your wheelchair is an important part of your life, so you want to make sure you end up with the right wheelchair that fits your body, preferences, activities and lifestyle.

Wheelchair seating technology is a complex and rapidly changing industry, with new types of wheelchairs and components coming on the market all the time. The days of "one size fits all" are long gone. With all the different choices, how do you pick the right one? Many different factors must be considered when making the decision.

The Clinic

Selecting the right clinic is a critical first step. The clinic you select should have a process and the key players in place to assist you with making the right choice. You can call in advance to find out who is part of the team, if they have certification, and how long the process takes. It may be necessary for you to travel to get the best team to work with you on your chair. You would not hesitate to drive a long distance for the right surgeon; your wheelchair selection is equally important.

The Team

The right clinic will have a team of individuals to help with wheelchair selection, each of whom has different expertise.

- You: The most important member of the team is you, the wheelchair user. Even if this is your first wheelchair, your opinions and desires are essential in order to make the best selection.
- Family members or caregivers: Individuals you live with or who care for you will also be affected by the wheelchair selection and should provide input.
- Rehabilitation professionals:
 - **Rehabilitation medicine doctor** (called a **physiatrist**) who understands your overall health situation. The doctor is the one who writes the prescription needed for your insurance to pay for the wheelchair and has ultimate responsibility for determination of medical necessity.
 - Occupational or physical therapist who is experienced in wheelchair evaluation and training.
 - **Qualified wheelchair supplier** who works with the therapy and medical team to trial, order and maintain equipment.
 - **Certification**: Many occupational and physical therapists and wheelchair suppliers will have Assistive Technology Practitioner (ATP) certification from RESNA (Rehabilitation Engineering and Assistive Technol-

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ogy Society of North America) indicating they have passed a national examination and credentials check in their specialty. If Medicare is the payer, they require the wheelchair vendor to have at least one ATP-credentialed specialist.

Medical and Physical Considerations

The team needs to consider many factors to ensure that you get the right wheelchair for your body, your health and your care needs.

- Time since injury
 - Newly injured individuals: If this is your first wheelchair, you will likely need more advice on the technology that will best suit your needs. In addition, you may continue to have physical changes or recovery over the next several months, in which case this first chair may only be temporary. As a result, the team may recommend a rental chair or more frequent follow-ups.
 - Long-time injuries: If you have been using a wheelchair for a long time and have developed new problems, such as weakness or pain, you may need to make changes to your current wheelchair seating system.
- Age affects endurance and strength and may be a deciding factor between a manual or power wheelchair.
- Strength and range of motion will determine whether or how much you can push your wheelchair, transfer in and out of your wheelchair, lift and fold your wheelchair, etc.
- Height and weight will affect what size wheelchair you will need.
- Trunk stability: The higher your level of injury, the more unstable you are likely to be, and this requires extra attention to seating and position to enhance stability.
- Functional abilities: Your level and completeness of spinal cord injury will affect how much function you have in your arms and hands and whether you will need a power or manual wheelchair.
- Medical conditions or risks: Conditions such as spasticity, previous pressure sores, or urinary

leakage can also affect wheelchair selection and should be discussed with your team.

Caregiver Considerations

It is important for the people who care for you to be able to work with your wheelchair, which may include pushing it occasionally or lifting, folding, fixing, cleaning or adjusting the wheelchair.

Environment and Lifestyle Considerations

Your wheelchair is a tool that enables you to do more of what you want in life.

- Home: Is your home carpeted? Are entrances to your home steep? Are there difficult surface conditions that a wheelchair might need to push over, such as gravel or grass? While you may make changes to your home to accommodate a chair, it is also possible that chairs exist that can help you when changes to the home environment are not possible or desired.
- Work: What will you be doing for work, and how does your wheelchair need to fit into that environment? For example, will your wheelchair fit under the conference room table where you meet twice a week?
- Transportation: Will you be driving your own vehicle? Van or car? Will you be taking public transportation? Will someone else be driving you around?
- Leisure activities: Will you spend time outdoors on grass or hiking on trials? Will the wheelchair also be used for sports?
- Personal taste/preferences: For example, some people may prefer a sportier-looking chair or a specific color (but note that something other than the standard color may cost more).

Financial Considerations

- Insurance coverage: This is often a major consideration when choosing a wheelchair and may limit your choices. However, it is best to choose the optimal chair first, then consider your financing.
- Other financial resources: Local resources to assist in purchasing your chair may be available

through organizations such as United Cerebral Palsy or the Multiple Sclerosis Society. Despite their names, these organizations often help people with any disability. Some individuals have fund-raisers through their church or temple.

Steps in the Process of Getting a Wheelchair

- **I.History and physical exam** by physician, OT, and/or PT, who will use this information to justify (to the insurance company) the wheelchair and seating system you need and to ensure that medical issues are properly addressed.
- **2.Test Drive**: You should always test drive the device. Ideally this will occur at the clinic during your visit and later during the home assessment. A good wheelchair clinic should have the ability to get devices for you to test drive during your visit.
- **3.Home assessment**: It is best to have a supplier or therapist assess your home to recommend appropriate equipment. Some insurance plans (including Medicare) require this step, and others do not.
- **4.Submission of prescription and documentation** The clinical team will likely need to submit a Letter of Medical Necessity (LMN).
- **5.Delivery, final fitting and wheelchair driving skills training**: Ideally the wheelchair will be delivered to the clinic, where the team will make sure that the wheelchair that was ordered is, in fact, what was delivered. In addition, the chair will likely need to be adjusted for the best fit. Finally, the team will train you on how to use the chair properly to avoid injury.

Plan Ahead

It is important to plan for the possibility that your wheel chair will break down and need repairs. If possible, keep a spare wheelchair on hand. If not, have a plan in place to insure timely repair and the use of a loaner.

Pressure Mapping Technology

Pressure mapping technology is a way of measuring seating pressure and can help a clinician decide which cushion provides the best pressure distribution for a particular individual. A pressure-mapping evaluation of a cushion and seating system can help make sure your skin is protected.

Resources

Choosing A Wheelchair: A Guide for Optimal Independence by Gary Karp (Cambridge, Mass: O'Reilly, 1998).

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The Manual Wheelchair What the SCI Consumer Needs to Know





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Introduction

The wheelchair is a complex piece of equipment that has been extensively engineered and studied. Most individuals with SCI become wheelchair experts because doing so increases their chances of getting a wheelchair that truly meets their needs. However, there are numerous options when considering a manual wheelchair, so it is critical to get help (see the SCI Model System Consumer Information guide *Getting the Right Wheelchair: What the SCI Consumer Needs to Know*). While it is not possible to teach you all there is to know in a single handout, this factsheet includes some of the most important information.

Why Choose a Manual Wheelchair?

If you have enough function to propel a manual wheelchair, it is probably the best form of mobility. Manual wheelchairs are easy to transport, need fewer repairs, and provide a form of exercise. However, they are not for everyone; you need to have the ability to propel. Most people with an injury level below C6 can propel a manual chair and some individuals with a C6 level can as well; this will be dependent on your weight, fitness, strength, level of pain, and the environment in which you need to push. While manual wheelchair propulsion can be a form of exercise, it can also lead to arm injuries from repetitive use. This risk makes it critical to get the right chair, to set it up correctly and to learn how to effectively propel.

Features and Components

Weight

Wheelchairs are generally classified by Medicare (which sets the industry standards) as *lightweight* (less than 34 lbs.) and *ultralight* (less than 30 lbs.). (These weights do not include footrests or armrests.)

Lightweight chairs are often not adjustable and are not recommended for SCI. Ultralight chairs are more expensive than the lightweight chairs, are highly adjustable, and incorporate many design features that improve mobility and comfort. Adjustability allows the wheelchair to be set up for optimal propulsion efficiency, which can reduce the risk of injury. It is harder to get insurance companies to pay for this type of wheelchair. Clinical practice guidelines recommend the lightest chair possible. Titanium and aluminum chairs can weigh under 20 lbs.

Frames

Frames may be folding or rigid. Rigid frames tend to perform better when maneuvering. Folding frames are often easier to transport, although many

rigid chairs can get to a very small size by removing the wheels and folding down the backrest.

Components

Many components (Figure 1) are imortant for wheelchair function. These components come in a variety of styles, and selection depends on your needs, preferences and lifestyle.

- Footrests support your feet and lower legs. They can be fixed, folding or swing-away and come in many different styles.
- Armrests are places to rest your arms when you're not moving. They can be wraparound, full-length or desk-length; fixed or height-adjustable; removable or flipback. Fit is important because armrest position can alter the way you propel your wheelchair. Many individuals choose not to have armrests because they don't like the way they look or they get in the way of propulsion.
- Wheel locks act as parking brakes to stabilize your wheelchair when you transfer to other seats or want to remain in a particular spot. They may be push-to-lock or pull-to-lock, positioned low or high on the wheelchair, and retractable or not, depending on what the user finds easier.Wheel locks can get in the way during propulsion and add weight to the wheelchair. For this reason many individuals choose not to have wheel locks, relying on their hands to keep their chair still. Not having wheel locks can increase the risk of the chair moving during a transfer, however, which you should consider when making this decision.
- Tires are most commonly air-filled (pneumatic) and therefore lightweight. They also require maintenance and can puncture. If you maintain them, this is usually the best choice. Pneumatic tires may instead be filled with solid foam inserts; these won't puncture but are slightly heavier and don't perform as well. Solid tires are low-cost and no-maintenance, but make for an uncomfortable ride and are not usually recommended.





- Backrest: Sling backrests are the most common, but provide little postural support. Adjustable tension backrests can provide more support and can be adjusted over time. Rigid backrests provide the best support, but may make it more difficult to collapse the chair. The weight and height of the backrest are important. In general, the lighter the better, with carbon fiber backrests being a nice option. If support is not needed, a lower backrest is better as it does not get in the way of pushing.
- Cushions come in a huge and ever-changing array of different types and materials and comprise a major topic unto itself. While pressure relief is an important consideration when selecting a cushion, you should also keep in mind that you want a firm base and a light-weight cushion. A firm base refers to feeling stable, not sliding on the cushion when reaching for an object or propelling your chair.
- Pushrims: There are a variety of pushrims with different friction coatings and shapes that may assist with propulsion and reduce the risk of injury to the hand.
- Additional features include anti-tippers, wheels and caster wheels of various styles, push handles and grade-aids (which keep the chair from rolling backward).

Set-up and Fit

Set-up and fit of your wheelchair is critical to good performance.

- Seat height and width: If the fit is too tight, it can cause pressure sores; too wide, and it may cause problems with stability, posture and fitting through doorways. The seat height should make it easy to access the pushrim as well as transfer surfaces. To test this, let your hands dangle at your side when sitting in the chair: your fingertips should extend just past the chair's axle.
- Seat slope is the difference between the front seat-to-floor height and the rear seat-to-floor

height. It is common to have a slight seat slope (so buttocks are lower than your knees) to keep your body stable in your wheelchair.

- Rear axle position is important as it impacts how easy it is to push and tip your chair. In general you want the rear axle as far forward as possible (this will make it easier to push) without making the chair too easy to tip over backwards.
- Camber is the angle of the wheel with respect to the chair (Figure 2). A little camber is a good thing as it will protect your hands and increase your base of support. Too much camber will make it hard to fit through doorways.

Figure 2. Camber

P

Propulsion

Your therapist will train you on the best way to propel your wheelchair to be efficient and avoid injury. Long smooth strokes are better than short strokes, and the hand should drop below the push rim during the recovery (non-pushing) part of the stroke.

The Wheelie

Ask your physician for a referral to a therapist who can teach you how to "pop" and hold a wheelie. This skill can help you get through uneven terrain and over curbs. It can give you greater awareness of your balance point, which may decrease your chances of tipping over. When performing a wheelie, if your front wheels are more than two or three inches off the ground, your rear axle is probably too far back and could be adjusted forward.

References

Boninger ML, Cooper RA, Fay B, Koontz A, Musculoskeletal Pain and Overuse Injuries in Spinal Cord Medicine: Principles and Practices, Demos Medical Publishing, NY, 2003.

Resources

ABLEDATA is a non-commercial information center for assistive technology, including wheelchairs. Go to www. *abledata.com* (select *Products*, then *Wheeled Mobility*) or call 800-227-0216.

Consortium for Spinal Cord Medicine, Preservation of Upper Limb Function Following Spinal Cord Injury: What You Should Know (Paralyzed Veterans of America, 2005).

Gary Karp, Choosing A Wheelchair: A Guide for Optimal Independence (Cambridge, Mass: O'Reilly, 1998).

Cooper RA, Olson J, Cooper RM, Manual Wheelchair Lingo, *Paraplegia News*, pp. 17-24, Vol. 63, No. 11, November 2009.

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Introduction

The wheelchair is a complex piece of equipment that has been extensively engineered and studied. Most individuals with SCI become wheelchair experts because doing so increases their chances of getting a wheelchair that truly meets their needs. However, power wheelchairs are technologically advanced and have many components, so it is critical to get help when purchasing a new chair (see the SCI Model Systems Consumer Information guide *Getting the Right Wheelchair: What the SCI Consumer Needs to Know*). While it is not possible to teach you all there is to know in a single handout, this factsheet includes some of the most important information.

Why Choose a Power Wheelchair?

A power wheelchair is appropriate if you are unable to propel a manual wheelchair or if you need to reduce the strain on your shoulders and arms so you can continue to perform transfers safely. The choice of power chair will depend on many factors, including the kind of surface conditions the chair will be driven over, the need to negotiate thresholds and curbs, and clearance widths in your usual environment.

Power Wheelchair Components

The Base

The power wheelchair base is the lower portion of a power wheelchair that houses the motors, batteries, drive wheels, casters and electronics to which a seating system is attached. It is classified according to drive wheel location relative to the system's center of gravity.

Rear-Wheel Drive

The drive wheels are behind the user's center of gravity, and the casters are in the front. It has predictable drive characteristics and stability but can be difficult to maneuver in tight places because of its larger turning radius.

Figure 1. Rear-wheel drive power wheelchair



Front-Wheel Drive

The drive wheels are in front of the user's center of gravity, and the rear wheels are casters. This setup tends to be quite stable and provides a tight turning radius. However, it may have a tendency to fishtail and be difficult to drive in a straight line, especially when traveling fast on uneven surfaces.



Figure 2. Front-wheel drive power wheelchair with recline capability.

Midwheel Drive

The drive wheels are directly below the user's center of gravity. It has a smaller turning radius, making it more effective for indoor mobility, but not as good outdoors.



Figure 3. Midwheel drive power wheelchair with tilt-in-space capability.

Controls

The device used to control a power wheelchair is called an *access device* or *drive control*. It can also be used with environmental control systems and computer access. These controls are usually programmable and can be operated using various kinds of joysticks or switches (such as sip-and-puff).

Seating and Positioning

Seating and positioning are a critical part of your wheelchair and have an important role in your comfort, function, safety and health. Your seating system should be prescribed and designed specific to your medical, functional and personal preference needs, including protecting your skin from too much pressure.

Seating Systems

Seating systems fall into three general categories: off-the-shelf, modular and custom. In general, custom seating is only needed when musculoskeletal deformities are present such as scoliosis, or after a flap surgery for a pressure sore. The basic components of the seating system are the cushion and backrest.

Cushions and Backrests

Cushions and backrests are made out of a variety of materials, including contoured foam, air-filled bladders, combinations of air and foam, and gels. They vary in how well they address pressure distribution, postural stability, airflow, insulation or conduction of heat. Choice of style and material will depend on your individual needs and activities.

If all the needed features cannot be found in one cushion, trade-offs are necessary. Unlike with manual wheelchairs, the weight of the cushion and back support is generally not a consideration.

Research evidence suggests that a properly fitted pressure-reducing cushion, in contrast to a lowcost foam cushion, reduces the chances of getting a pressure sore.

Recline and Tilt-in-Space

Recline and tilt-in-space technologies relieve pressure, manage posture, provide comfort and help with personal care activities.

Recline (Figure 2), which changes the angle between the seat and backrest, helps to stretch hip flexors and makes attending to catheters, toileting and transfers more convenient for caregivers.

The addition of tilt-in-space (Figure 3), which tilts the seat and backrest together, keeps the hip and

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knee angles constant when tilting back. This reduces the possibility of shear when in the recline position.

People who cannot independently shift weight or transfer should have a tilt-in-space and recline system on their wheelchair.

Seat Elevation & Standing Chairs

Power wheelchairs can also have elevating seats or mechanisms that stand the user upright while in the chair. Elevating seats can help with transfers, as it is easier to transfer downhill. In addition, elevating seats and standing chairs can make it easier and more functional to perform activities that are above shoulder height when sitting. Because performing activities above shoulder height puts you at risk of injuring your arms, recent guidelines



Figure 4. Power-elevating seat.

recommend that all individuals with SCI who use power wheelchairs and have good arm function be provided with seat elevation.

Power-Assisted Wheelchairs

Power-assisted wheelchairs are essentially manual wheelchairs with a motor that provides propulsion assistance when desired. This allows a user to propel the wheelchair more quickly and easily, and helps with obstacles such as steep ramps.

For individuals with shoulder pain or tetraplegia (quadriplegia), this can be a good compromise between a manual and power wheelchair.

Power-assisted wheelchairs are bulkier and less maneuverable than manual chairs, but they are less bulky, easier to transport and more maneuverable than power wheelchairs.

References

Boninger ML, Cooper RA, Fay B, Koontz A, Musculoskeletal Pain and Overuse Injuries in Spinal Cord Medicine: Principles and Practices, Demos Medical Publishing, NY, 2003.

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