Model Systems Knowledge Translation Center
Spinal Cord Injury Resource Inventory

Model Systems Knowledge Translation Center

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About SCI Model Systems

• The Spinal Cord Injury (SCI) Model Systems program, sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, U.S. Department of Health and Human Services, supports innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational and other services to meet the needs of individuals with SCI.

• NIDILRR awards SCI Model Systems grants to institutions that are national leaders in medical research and patient care and provide the highest level of comprehensive specialty services, from the point of injury through rehabilitation and re-entry into full community life.

• There are 14 currently-funded SCI Model System Centers.

• Each SCI Model System Center contributes data to the National SCI Statistical Center, participates in independent and collaborative research, and provides information and resources to individuals with SCI, their family and caregivers, health care professionals, and the general public.
Current SCI Model System Centers

https://msktc.org/sci/model-system-centers
About SCI Model Systems Database

• The **National SCI Model Systems Database** – established in 1973 – captures data from an estimated 6% of new SCI cases in the U.S.

• 29 federally-funded SCI Model Systems have contributed data.

• As of September 2019, the database contained information on 34,130 persons with SCI.

• It is the world’s largest and longest active SCI research database.

• It is the world’s most extensive source of available information about the characteristics and life course of individuals with SCI.

• To assure comparability of data, rigid scientific criteria have been established for the collection, management, and analysis of information entered into the database.

• Visit the SCI Model Systems Database: [https://www.nscisc.uab.edu/](https://www.nscisc.uab.edu/).
Living with Spinal Cord Injury (SCI)

ALL TOPICS

- Adjusting to Life
- Aging and SCI
- Autonomic Dysreflexia
- Bladder Management
- Depression and SCI
- Driving after SCI
- Employment after SCI
- Exercise and Fitness after SCI
- Gait Training and SCI
- Managing Bowel Function
- Managing Pain after SCI

https://msktc.org/sci
Living with Spinal Cord Injury (SCI)

ALL TOPICS

- Personal Care Attendants
- Pregnancy and SCI
- Respiratory Health and SCI
- Safe Transfer Techniques
- Sexuality after SCI
- Skin Care and Pressure Sores
- Spasticity and SCI
- Surgical and Reconstructive Treatment of Pressure Injuries
- Understanding SCI
- Urinary Tract Infection and SCI
- Wheelchair Information

https://msktc.org/sci
Spinal Cord Injury Resources

- Factsheets
- Slideshows
- Hot Topics
- Quick Reviews
- Videos

https://msktc.org/sci/sci-resources
Adjusting to Life after SCI

What is adjustment?
Everyone experiences changes in their life. Adjustment is how you adapt to these new situations. Some examples of exciting changes include starting a new job, getting married, and having children. Losing a job, getting divorced, and losing a loved one are examples of changes that are not as positive. The SCI adjustment period may be brief, but most people adjust well in time. They continue to adjust to ongoing changes in life similar to those that everyone experiences.

What is it like when you first go home after injury?
Going home is a major step in adjusting to life after SCI. It can be exciting to get back to the comforts of home. You may experience a period of readjustment during the early weeks of your injury. For example, you may notice some of your daily routine before your injury, which may be different from your new routine. It's important to find a new “normal” routine that works for you and helps you manage your daily activities. Some tips for adjusting to life at home include:

1. Reassess your living situation. If your home is not set up for your new needs, you may need to make adjustments.
2. Stay positive. Focus on the things you can control and try to let go of what you cannot control.
3. Seek support. Talk to your family, friends, and caregivers about your experiences and how you are feeling.
4. Manage your stress. Find ways to cope with stress, such as exercise, meditation, or spending time with loved ones.
5. Plan your day. Create a daily schedule to help you stay organized and focused.

How people adjust to SCI
People have different expectations for life after injury. It may be exciting for some, while others may feel overwhelmed. It's important to remember that you are not alone in your experience.

What is SCI?
SCI refers to injuries to the spinal cord that result in some degree of permanent, partial, or complete loss of function in the part of the body served by the spinal cord. The degree of recovery after SCI varies widely depending on the location and severity of the injury. Some people may experience minimal symptoms, while others may have significant limitations in mobility, sensation, or function.

The SCI Model System Knowledge and Translation Center (MSKTC) is a part of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at the Administration on Disability and Independent Living, U.S. Department of Health and Human Services, and is funded under the Rehabilitation Services Administration, U.S. Department of Education, to improve care and treatment for people with SCI through research, dissemination, and implementation.

https://msktc.org/sci-topics/adjusting-life
Aging and SCI

Factsheets

• Things to Know About Aging and SCI

[Link to more information]
Autonomic Dysreflexia

Autonomic Dysreflexia (AD), sometimes referred to as a potentially life-threatening medical condition that may occur after spinal cord injury (SCI) and can cause serious symptoms if not treated immediately. AD is associated with certain SCI injuries and can lead to severe consequences if not managed properly.

What is Autonomic Dysreflexia?
Autonomic Dysreflexia (AD) is a medical condition that can occur in people with spinal cord injuries. It happens when the spinal cord is damaged and the body’s autonomic nervous system, which controls functions like heart rate and blood pressure, is not able to function properly.

Am I at risk for AD?
People with SCI are at risk for AD. The risk increases with the severity of the SCI and the level of injury. AD can occur whenever there is a pressure sore, bowel or bladder problem, or any other condition that can lead to a rise in blood pressure.

Why do people with SCI get AD?
Pressure from the spinal cord injury can cause AD. The injury can damage the spinal cord, which sends signals from the brain to the body’s organs. When the spinal cord is damaged, the body’s organs can become overactive and cause an increase in blood pressure.

What are the symptoms of AD?
The symptoms of AD can include headache, dizziness, heart palpitations, flushing of the face and neck, sweating, and nausea. In severe cases, it can lead to a stroke, heart attack, or even death.

Why do people with SCI get AD?
AD is caused by a sudden increase in blood pressure. The pressure can cause the brain to become overly sensitive to changes in blood flow, leading to symptoms of AD.

Autonomic Dysreflexia: After SCI
Autonomic Dysreflexia is a medical condition that can occur in people with spinal cord injuries. It happens when the spinal cord is damaged and the body’s autonomic nervous system, which controls functions like heart rate and blood pressure, is not able to function properly.

1. Increased blood pressure: AD can cause the blood pressure to rise, which can lead to symptoms like headaches, dizziness, and flushing.
2. Nausea: AD can cause nausea and vomiting.
3. Vision changes: AD can cause blurred vision or double vision.
4. Speech difficulties: AD can cause difficulty speaking.
5. Pain: AD can cause pain in the face, neck, or chest.

How is AD treated?
AD is treated by reducing the blood pressure. This can be done by administering medication, such as nitroglycerin, or by removing the cause of the pressure rise, such as a catheter or a bowel impaction.

What can I do to prevent AD?
There are several things you can do to prevent AD. These include:
1. Keeping your blood pressure as low as possible.
2. Avoiding activities that can cause pressure sores, such as sitting or lying on your hands.
3. Eating a healthy diet.
4. Exercising regularly.
5. Keeping your blood pressure medication as prescribed.

Sources:

For more information, visit MSKTC.org/sci-topics/autonomic-dysreflexia.
Bladder Management

Factsheets

- Bladder Management Options Following SCI
- Surgical Alternatives for Bladder Management Following SCI

https://msktc.org/sci-topics/bladder-management
Depression and SCI

Depression is common and can affect anyone. About 1 in 10 million people get depressed every year. Depression in the spinal cord injury (SCI) population—about one in five—has more depressive symptoms among people with SCI.

What is depression?
Depression is not just “feeling blue” or “down in the dumps.” It is a serious medical disorder that affects how you think, feel, and act. Depression is 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, emotional, and psychological symptoms:

- Changes in sleep (too much or too little)
- Feelings of hopelessness
- Loss of interest or pleasure in activities
- Changes in appetite
- Decreased 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, when feeling depressed or losing interest in usual activities and lasts for more than two weeks, Depression is not normal.

Cues of depression

- Changes in sleep (too much or too little)
- Loss of interest or pleasure in activities
- Changes in appetite
- Decreased 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 or lack of willpower.

Depression can and should be treated

The good news is that the symptoms of depression can almost always be treated.
Driving after SCI

Driving After Spinal Cord Injury

What you need to know:
- You may be able to continue driving with your injury, but you need to know how much control you need to drive safely.
- If you can drive, you may need to change your driving habits to reduce your risk of injury to yourself and others.
- Equipment can be expensive and may require ongoing maintenance and repair.
- You should take specific steps to ensure your safety and the safety of others.

How do I know if I can drive again?

The amount of time after your injury that you can return to driving depends on your injury and how much control you need to drive safely. You may be able to return to driving if you can:
- Perform routine driving tasks
- Control the vehicle and make appropriate lane changes
- Make sudden stops and starts
- Perform emergency braking

What do I need to know about driving after SCI?

You might be able to drive safely with specific assistive equipment based on your injury. The equipment can be expensive and may require ongoing maintenance and repair. You should take specific steps to ensure your safety and the safety of others.

To learn more about driving after SCI, visit the following link:
https://msktc.org/sci-topics/driving
Employment after SCI

Factsheets

- Employment after SCI

Slideshows

- Employment after SCI

Employment After Spinal Cord Injury

For more information, contact your local SCI Program or visit www.msmtc.org.

More people with spinal cord injuries (SCI) want to work and need support, training, and vocational rehabilitation services to help them choose and keep a job. These services of support may help to overcome many barriers that are outside the individual’s control, such as financial and health-care issues, accountability, 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 well-being. And although there is no cause and 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.

Many people with SCI want to work but have limited work skills and vocational training. Although they are often required to go through strenuous and successful courses, 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.

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” in your disability if it would not impose an undue hardship on the business. Whether or not accommodation is considered “reasonable” depends on the business size, financial resources, nature of operations and other factors.

When you apply for a job, an employer cannot ask you about the existence, reason or severity of your disability, even if you show up for your interview in a wheelchair. An employer can ask 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 consistent with all other employees in similar jobs.
Exercise and Fitness after SCI

Videos
- Exercise & Fitness after SCI
- A Range of Fitness Activities
- About Hand Cycling
- About Wheelchair Rugby
- Accessing Adaptive Equipment
- Any Exercise is Better than No Exercise
- Breaking Down Barriers
- Collaborating on Accessibility
- Components of a Good Exercise Routine
- Exercise for People with High Levels of SCI
- Exercise, Health, & Happiness
- Exercising & Independence
- Horseback Riding with SCI
- Peer Support & Exercise
- Meeting Other People with SCI through Sports
- Peer Support & Exercise
- Strengthening & Protecting the Shoulders
- The Benefits of Team Sports

Factsheets
- Adaptive Sports & Recreation
- Exercise after SCI

Hot Topic
- Exercise & Fitness after SCI

Slideshow
- Gait Training after SCI

https://msktc.org/sci-topics/exercise-fitness-after-sci
Gait Training and SCI

Factsheets

- SCI and Gait Training

Slideshows

- SCI and Gait Training


Spinal Cord Injury and Gait Training

Difficulty walking is very common following a spinal cord injury (SCI). People with an "complete" SCI have more potential to walk safely 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 a balance training (also called ambulatory) with assistive devices and braces as needed. The following categories are used by health professionals to describe the level 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 at home and in the community.
- Nonambulatory: You use a wheelchair for mobility. You may also walk while doing gait training with the therapists in the therapy gym.

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 change the signals that do reach the muscles, making the muscles "jumpy" on their own. Therefore, a SCI can create weakness and spasticity in the feet, legs, trunk, and arms, as well as in the hands and arms. The injury can also damage and disrupt some signals for normal movements of the body, including balance and coordination. 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, stability or stiffness, and range of motion in your hips, knees, ankles, and toes. 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 improve your walking ability.
Managing Bowel Function

Videos
- A Typical Bowel Program
- Analyzing Your Bowel Movements
- Barriers to Following a Bowel Program
- Colostomy as a Last Resort
- Dating and Sex
- Different Types of Independence
- Digital Stimulation and Evacuation by a Caregiver
- Don’t Let Your Bowels Control You
- Family Dynamics and Resilience
- Fecal Incontinence
- Fiber and Fluids
- Managing Bowel Function after SCI
- Medication, Techniques, and More
- Mental Challenges of a SCI
- Overcoming Embarrassment
- Research on the Causes of Constipation
- Technological Advanced Needed

https://msktc.org/sci-topics/managing-bowel-function

Factsheets
- Bowel Function after SCI

Hot Topic
- Managing Bowel Function after SCI

Slideshow
- Bowel Function after SCI
Managing Pain after SCI

Videos
- A New Standard of Care
- Asking About Pain
- Assessing Pain in People with SCI
- Coming to Terms with SCI
- Does Exercise Prevent or Reduce Pain in SCI patients
- Finding the Right Doctor
- Predicting Pain to Head It Off
- Shoulder Exercises for People with SCI
- Shoulder Pain and SCI
- The Impact of Pain

Factsheets
- Pain after SCI

Hot Topic
- Managing Pain after SCI

Slideshow
- Pain after SCI

https://msktc.org/sci-topics/managing-pain-after-spinal-cord-injury
Personal Care Attendants and SCI

Factsheets

• Personal Care Attendants and SCI

Personal Care Attendants and Spinal Cord Injury

What is a personal care attendant?
A personal care attendant, or PCA, is someone who helps you with some of your self-care and other activities that are part of your spinal cord injury (SCI).

Do I need a PCA?
You may benefit from a PCA if you need help with daily activities.

What help does a PCA provide?
- Self-care. This includes help with bathing, grooming, dressing, feeding, and bladder and bowel management.
- Mobility. This may include help with using a wheelchair, getting in and out of bed, and getting dressed.
- Housework. This may include help with tasks like preparing food, washing dishes, and doing laundry.

Is it better to rely on care from a PCA or a family member?
Each person’s situation is different. It is common to get help from family members. You may also prefer to have family help with ongoing daily needs because it works best for your situation or you simply feel more comfortable getting help from someone in your family.

What is the SCI Model System?

The SCI Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research. For more information, visit http://www.nidilrr.gov/model-system-center.

Reference:
Pregnancy after SCI

- Factsheets
- Slideshows

Pregnancy and Women with SCI

https://msktc.org/sci-topics/pregnancy-sci
Respiratory Health and SCI

Factsheets

- Respiratory Health and SCI

https://msktc.org/sci-topics/respiratory-health
Safe Transfer Techniques

Factsheets

- Safe Transfer Technique

Slideshows

- Safe Transfer Technique

https://msktc.org/sci-topics/safe-transfer-techniques

Safe Transfer Technique

Transferring is one of the activities that require a higher level of comfort, control, and safety. Learning the correct way to transfer is extremely important to keep your joints functioning and pain-free.

Get proper transfer training:
- Everyone needs individualized transfer training to preserve function and avoid injury. There is a great advantage to learn the basic transfer techniques.
- Your transfer techniques may need to be revised or adjusted. If you develop any problems or if your living environment (e.g., programs or activities change), go back to your therapist for advice.

Safe-transfer rules and techniques:
- Frequency: Daily transfers are necessary to maintain flexibility and muscle tone.
- Transferring should be easier and safer than transferring without a chair.
- Technique: (Steps)
  1. Position yourself.
  2. Get as close as possible to the chair you want to move.
  3. Lock your wheelchair, transferring from a wheelchair.
  4. Put your feet on your seat (if you are tall).
  5. Slide the edge of your chair.
  6. Get your arms out on the chair.

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Skin Care and Pressure Sores

- Areas at High Risk for Developing Pressure Sores
- Building Skin Tolerance for Pressure
- Causes and Risks
- Preventing Pressure Sores
- Recognizing and Treating Pressure Sores
- Skin Care and Pressure Sores in SCI

https://msktc.org/sci-topics/skin-care-pressure-sores
Spasticity and SCI

Factsheets

• Spasticity and SCI

What is spasticity?
Spasticity is the increased tightening or contracting of the muscles that is common in individuals with spinal cord injuries. About 65%-76% of the SCI population have some amount of spasticity, and it is more common in cervical (neck) than thoracic (upper back) injuries. Symptoms and severity of spasticity vary from person to person and can include:
- Sudden, involuntary flexing or extending (stretching) of a limb, or pulling of muscle groups such as the trunk (hips, back, and abdomen), bladder, or rectum.
- Hyperactive (uncontrolled) 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 movements.

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 to the spinal cord from the brain. In response, the brain transmits the signal and sends the necessary commands back down the spinal cord to tell your body how to react. The message travels throughout the body, causing muscles to be relaxed or contracted, or a reflex and movement to occur.

After a spinal cord injury, the normal flow of signals is disrupted, and the message does not reach the brain. Instead, the signal goes back to the inner cells in the spinal cord and causes a reflex muscle spasm. This can result in a muscle spasm, or stiffening of the muscle. Just about any stretch, movement or irritation can trigger and sustain these spasms.

Common triggers are:
- Stretching your muscles.
- Moving your arm or leg.
- Any pressure to the skin, such as rubbing, scratching, or contact, immediate or sustained, on anything that would normally be very hot or cold or painful.

Spasticity and Spinal Cord Injury Model System Consumer Information

For more information on the Model System Consumer Information Program, please visit NIDILRR/SCS at

https://msktc.org/sci-topics/spasticity-sci
Surgical and Reconstructive Treatment of Pressure Injuries

What is a pressure injury?

Pressure injury is a newer term for what people might know as a pressure sore, pressure ulcer, decubitus ulcer, bed sore or skin breakdown. The term change because not all stages of injuries caused by pressure are actually open "wors" or "ulcers." However, the meaning is similar. A pressure injury is an area of the skin or underlying tissue (muscle, bone) that is damaged when prolonged pressure cuts off blood flow to the area for too long.

To learn more about skin care, visit https://msktc.org/sci/factsheets/skincares.

What is Surgical and Reconstructive Treatment?

Stage 3 and 4 pressure injuries are wounds that most often need surgical and reconstructive treatment to promote healing:

- Stage 3 is a wound that extends from the first layer of the skin (epidermis), through the second layer (dermis), and into the fatty tissue below (subcutaneous tissue).

Surgical Treatment

During surgery, the wound is cleaned (debrided) to remove any dead or infected tissue. The surgeon will sometimes include removing some bone. This process creates a larger wound, but the remaining tissue is healthy and more likely to heal.

Reconstructive Treatment

Reconstructive treatment is most often done in one of two ways using a section of healthy skin and tissue known as a "flap."

1. A flap of healthy skin and tissue near the wound is partly detached and pulled over the wound. This allows part of the flap to stay attached to the blood vessels connected to healthy skin and tissue. That blood supply helps nourish the skin and tissue pulled over the wound.
Understanding SCI

- Understanding SCI: Part 1—The Body Before and After Injury
- Understanding SCI: Part 2—Recovery and Rehabilitation

https://msktc.org/sci-topics/understanding-sci
Urinary Tract Infection and SCI

Factsheets

- Urinary Tract Infection and SCI

https://msktc.org/sci-topics/urinary-tract-infection
Wheelchair Information

Factsheets

- Getting the Right Wheelchair: What the SCI Consumer Needs to Know
- The Manual Wheelchair: What the SCI Consumer Needs to Know
- The Power Wheelchair: What the SCI Consumer Needs to Know

https://msktc.org/sci-topics/wheelchair-information
Maintenance Guide

Introduction
Wheelchair breakdowns can impair wheelchair participation. Poor wheelchair maintenance can increase the risk of breakdowns and personal injury or death, and it can also significantly reduce the lifespan of the equipment and its cost. The number of users injured from wheelchair breakdowns has been declining in recent years, but it is still a concern.

It is important to maintain a wheelchair properly to ensure its safe and efficient operation. By following the guidelines provided in this guide, you can help prevent breakdowns and ensure that your wheelchair is in good working order.

Importance of maintaining a wheelchair
- Regular maintenance can help prevent breakdowns and reduce the risk of injury.
- Proper maintenance can extend the lifespan of your wheelchair.
- Regular checks can help you identify potential problems before they become critical.

When to perform maintenance
- At least once a month
- After any major use

Tools and parts
- Allen wrench
- Ampersand wrench
- Locking pliers
- Hex wrench
- Key wrench
- Screwdriver
- Battery

Checklist for maintenance
- Check the tires for air pressure
- Check the brakes for proper function
- Check the seating system for any wear or damage
- Check the suspension for any leaks or damage
- Check the upholstery for any tears or damage


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www.msktc.org/sci/factsheets

SCI FACT SHEETS


On this page:

Introduction
Importance of maintaining a wheelchair
When to perform maintenance and what to look for

Manual wheelchair: Areas for maintenance

Power wheelchair: Areas for maintenance
