

Model Systems Knowledge Translation Center Spinal Cord Injury Resource Inventory

Model Systems Knowledge Translation Center

December 2020

A project funded by the National Institute on Disability,
Independent Living, and Rehabilitation Research
(NIDILRR grant number 90DP0082)



Model Systems
Knowledge Translation
Center

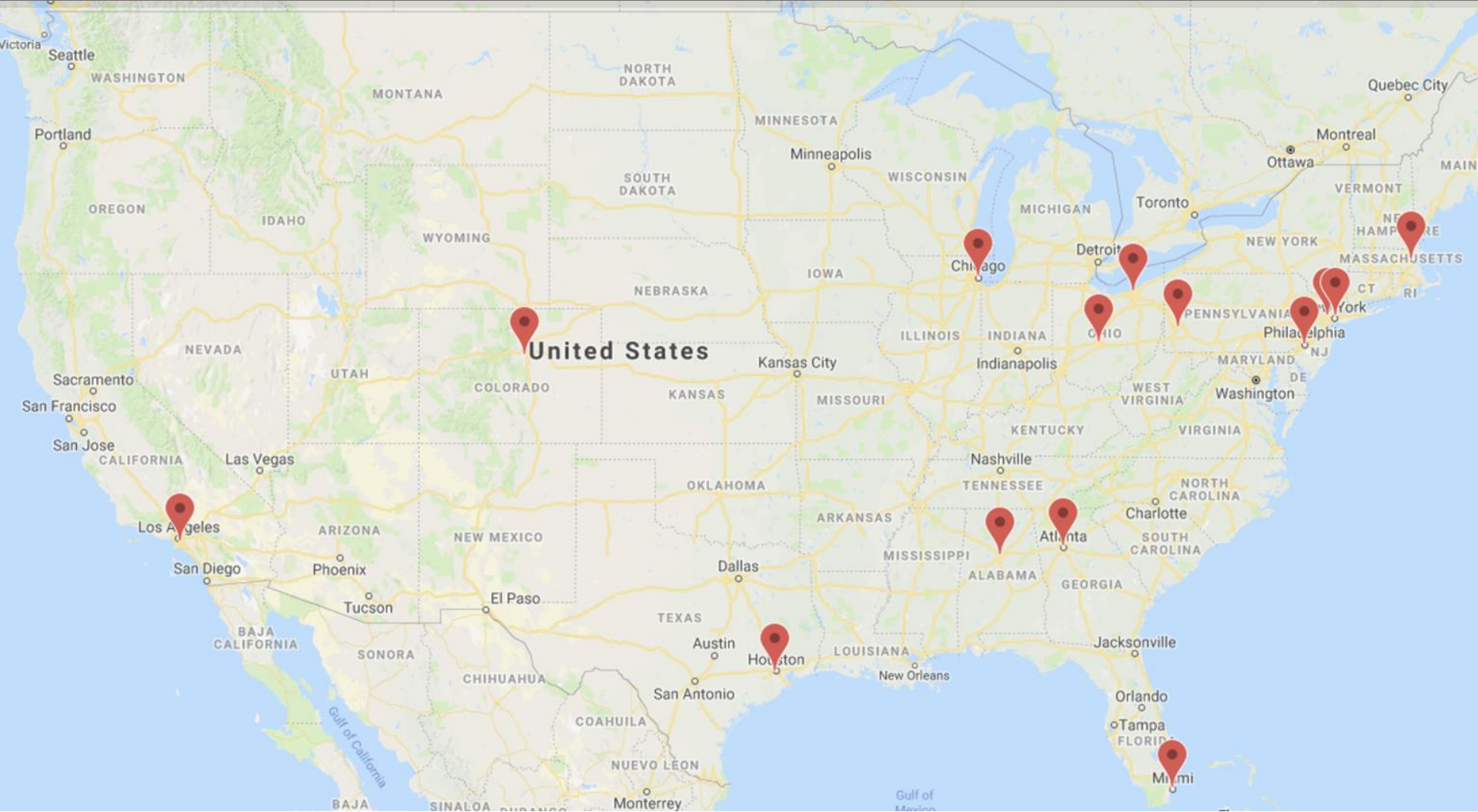
About SCI Model Systems

- **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>



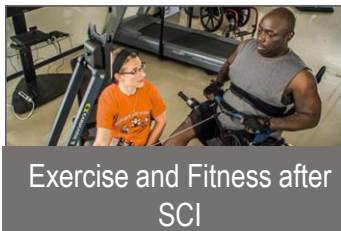
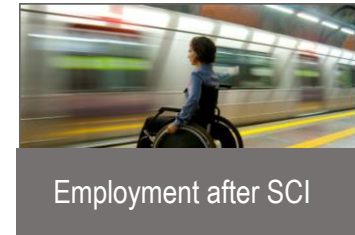
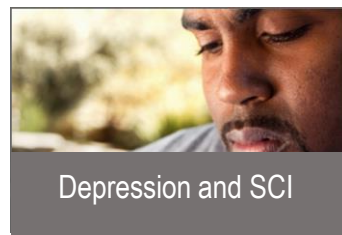
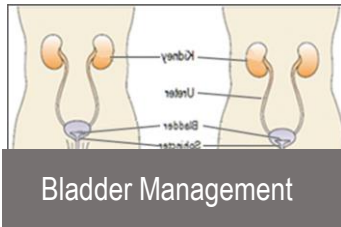
About SCI Model Systems Database

- 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/>

Living with Spinal Cord Injury (SCI)

<https://msktc.org/sci>

ALL TOPICS



Living with Spinal Cord Injury (SCI)

<https://msktc.org/sci>

ALL TOPICS



Personal Care Attendants



Pregnancy and SCI



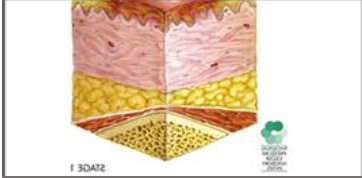
Respiratory Health and SCI



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

Spinal Cord Injury Resources

<https://msktc.org/sci/sci-resources>

Factsheets



Slideshows



Hot Topics



Quick Reviews



Videos



Factsheets



• Adjusting to Life after SCI

The screenshot shows the MSKTC website interface. At the top, there is a navigation bar with links for Home, Spinal Cord Injury, Traumatic Brain Injury, Burn Injury, Knowledge Translation, Model Systems, and About. Below this is a search bar and social media icons. The main content area features a blue header with the title 'Adjusting to Life after Spinal Cord Injury' and a sub-header 'SCI FACTSHEETS'. There are two language options: 'English PDF' and 'En Español PDF'. A 'On this page:' section lists various topics like 'What is adjustment?' and 'What is it like when you first go home after injury?'. The main text area contains the beginning of the factsheet, starting with 'Everyone experiences changes in their life. Adjustment is how you adapt to those new situations...'.



Adjusting to Life after Spinal Cord Injury

June 2016 www.msktc.org/sci/factsheets SCI Fact Sheet

It is important that rehabilitation to your main focus in the early weeks and months after injury. You can learn more about expectations for recovery, your role in rehabilitation, and find other suggestions to guide your recovery in "Understanding Spinal Cord Injury: Part 2—Recovery and Rehabilitation" at www.msktc.org/sci/factsheets/Understanding_SCI

What is adjustment?

Everyone experiences changes in their life. Adjustment is how you adapt to those new situations. A few examples of exciting changes in life are starting a new job, getting married, and having children. Losing a job, getting divorced, and losing a loved one are examples of changes that can be challenging.

Having a spinal cord injury (SCI) is without doubt a new and challenging situation. SCI affects almost every aspect of your life when it happens, and can be hard to put your life back in order and adjust to living with SCI. This initial adjustment period may be hard, but most people adjust well in time. Then 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. It can also be scary if you are unsure of what to expect once you get there.

Like most life-changing events, it takes time to adjust to a new "normal" after injury. For example, you were probably used to a daily routine before your injury. You may have gotten up each morning to go to school or work, taken care of your children, or had regular household chores. Whatever the routine was, the day seemed normal because you had some idea of what to expect.

After injury, you will establish a new "normal" routine. People who are newly injured often say it feels like they are doing things for the first time as they learn how to do activities differently. That feeling usually fades as you work through problems and learn how best to manage your daily routine.

- Chances are you will have outpatient rehabilitation for a while after inpatient rehabilitation. Your strength and stamina usually improves. Your ability to do daily activities usually improves. The time you spend out of bed and up in your wheelchair usually increases. At first, you may depend on medical equipment, such as a hospital bed or assistive devices, but not need them later.
- You usually learn to manage some of your activities during inpatient rehabilitation. However, you may change the way you manage things at home. For example, you may have showered or have done your bowel program at night during rehabilitation. You might find that doing these activities in the morning better fits your daily routine.

How people adjust to SCI

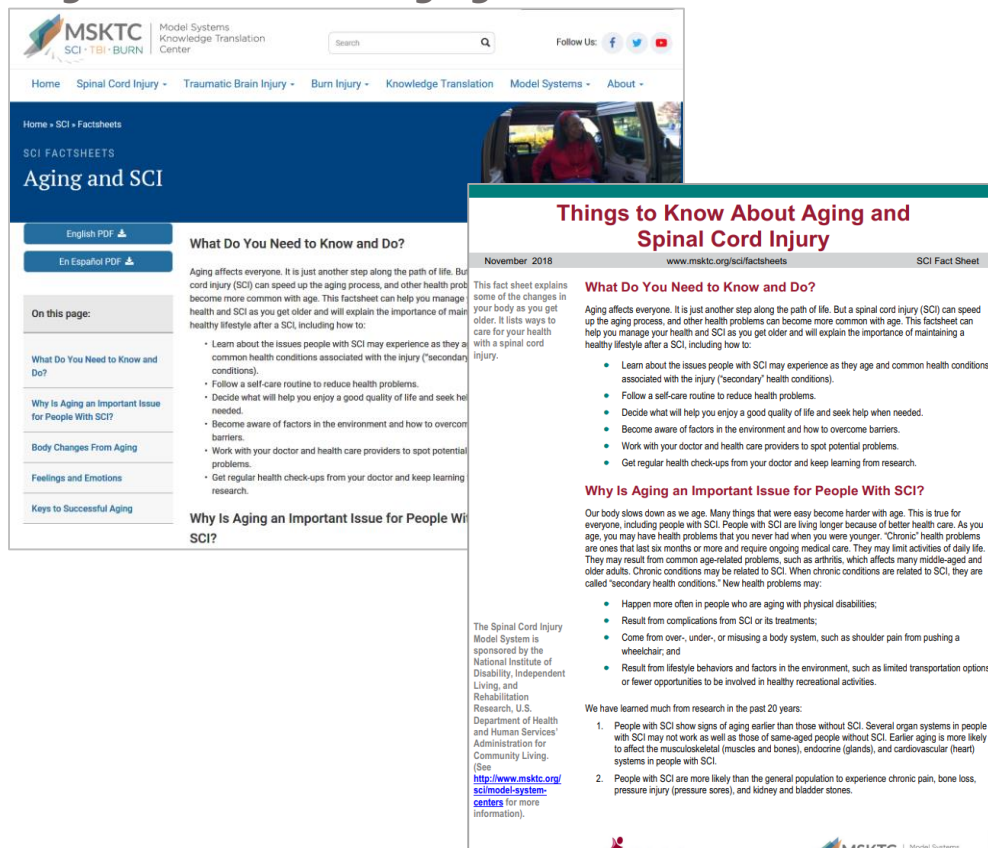
People have different expectations for life after injury. It may be feeling happy. It may be doing meaningful and enjoyable activities. It may be preventing stress, depression, or anxiety. It may be any or all of these things or something else, but most people adjust by setting and meeting their own expectations for life after injury.

- Your personality and the way that you adjust to changes in your life do not usually change after injury. Therefore, you will adjust to life after SCI in your own way and in your own timeframe.
- You may feel "different" in your body in the early weeks and months after injury. This feeling usually fades as you become comfortable with your self-image, learn to manage self-care, gain a better understanding of your body, and come to realize you are still the same person.
- You may re-think some of your personal values and what you think of as most important in your life after injury. For example, you may focus your attention more on your relationships with

The Model Systems Knowledge Translation Center provides useful health information that is based on research evidence and/or professional consensus and has been reviewed and approved by the SCI Model

Factsheets

• Things to Know About Aging and SCI





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Home | Spinal Cord Injury | Traumatic Brain Injury | Burn Injury | Knowledge Translation | Model Systems | About

Home » SCI » Factsheets

SCI FACTSHEETS

Aging and SCI

English PDF  | En Español PDF 

On this page:

- What Do You Need to Know and Do?
- Why Is Aging an Important Issue for People With SCI?
- Body Changes From Aging
- Feelings and Emotions
- Keys to Successful Aging

What Do You Need to Know and Do?

Aging affects everyone. It is just another step along the path of life. But cord injury (SCI) can speed up the aging process, and other health problems become more common with age. This factsheet can help you manage health and SCI as you get older and will explain the importance of maintaining a healthy lifestyle after a SCI, including how to:

- Learn about the issues people with SCI may experience as they age and common health conditions associated with the injury ("secondary" conditions).
- Follow a self-care routine to reduce health problems.
- Decide what will help you enjoy a good quality of life and seek help when needed.
- Become aware of factors in the environment and how to overcome barriers.
- Work with your doctor and health care providers to spot potential problems.
- Get regular health check-ups from your doctor and keep learning research.

Why Is Aging an Important Issue for People With SCI?

Our body slows down as we age. Many things that were easy become harder with age. This is true for everyone, including people with SCI. People with SCI are living longer because of better health care. As you age, you may have health problems that you never had when you were younger. "Chronic" health problems are ones that last six months or more and require ongoing medical care. They may limit activities of daily life. They may result from common age-related problems, such as arthritis, which affects many middle-aged and older adults. Chronic conditions may be related to SCI. When chronic conditions are related to SCI, they are called "secondary" health conditions. "New health problems may:

- Happen more often in people who are aging with physical disabilities;
- Result from complications from SCI or its treatments;
- Come from over-, under-, or misusing a body system, such as shoulder pain from pushing a wheelchair; and
- Result from lifestyle behaviors and factors in the environment, such as limited transportation options or fewer opportunities to be involved in healthy recreational activities.

We have learned much from research in the past 20 years:

- People with SCI show signs of aging earlier than those without SCI. Several organ systems in people with SCI may not work as well as those of same-aged people without SCI. Earlier aging is more likely to affect the musculoskeletal (muscles and bones), endocrine (glands), and cardiovascular (heart) systems in people with SCI.
- People with SCI are more likely than the general population to experience chronic pain, bone loss, pressure injury (pressure sores), and kidney and bladder stones.

The Spinal Cord Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/sci/model-system-centers> for more information).

November 2018 | www.msktc.org/sci/factsheets | SCI Fact Sheet

Things to Know About Aging and Spinal Cord Injury

What Do You Need to Know and Do?

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Factsheets



• Autonomic Dysreflexia

The screenshot shows the MSKTC website interface. At the top, there is a navigation bar with links for Home, Spinal Cord Injury, Traumatic Brain Injury, Burn Injury, Knowledge Translation, Model Systems, and About. Below this is a search bar and social media icons. The main content area is titled "SCI FACTSHEETS" and "Autonomic Dysreflexia". On the left, there are buttons for "English PDF" and "En Español PDF". Below these are several "On this page:" links: "What is Autonomic Dysreflexia?", "Am I at risk for AD?", "Why do people with SCI get AD?", "Why is AD life-threatening?", "What can trigger AD?", and "What are the symptoms of AD?". The main text area on the right contains the beginning of the factsheet, starting with "What is Autonomic Dysreflexia?" and "Autonomic Dysreflexia (AD), sometimes referred to as Autonomic Hyperreflexia, is a potentially life-threatening medical condition that can lead to serious stroke, seizure, organ damage, permanent brain injury, or even death if not treated immediately."

Autonomic Dysreflexia

November 2015 | www.msktc.org/sci/factsheets | SCI Fact Sheet

What is Autonomic Dysreflexia?

Autonomic Dysreflexia (AD), sometimes referred to as Autonomic Hyperreflexia, is a potentially life-threatening medical condition that can lead to serious stroke, seizure, organ damage, permanent brain injury, or even death if not treated immediately. This fact sheet will help you better understand AD and prepare you for what to do if you get it.

Am I at risk for AD?

- People with injury levels at or above T6
 - Read Understanding Spinal Cord Injury at www.msktc.org/lib/docs/Factsheets/AD_P111.pdf.
- People with injury levels below T6 may also be at risk for AD in some rare situations.

Why do people with SCI get AD?

AD happens because there is a change in the body's autonomic reflexes after injury.

Autonomic Reflexes before SCI

The autonomic nervous system controls body functions like blood pressure, heart rate, body temperature, sweating, digestion, sexual function, and dilation of your eyes' pupils through signals sent back and forth from the brain and body through the spinal cord nerves. These functions are largely automatic or involuntary, meaning they are controlled without you thinking about it.

There are two main systems within the autonomic nervous system.

- Sympathetic nervous system – this is the body's involuntary "fight or flight" response to prepare the body for action when there is some type of stress or threat. Pupils are dilated; the heart rate increases; the heart pumps with more force; and blood vessels get narrower causing blood pressure to rise.
- Parasympathetic nervous system – this is the "rest and digest" response. It causes digestion to improve, the heart to pump more slowly and with less force, and blood vessels get wider causing blood pressure to lower.

The body's first reaction to pain or discomfort is to go into the sympathetic, "fight or flight" mode. However, the brain usually reacts quickly and sends a parasympathetic, "rest and digest" response to counteract the sympathetic response. This normally creates the balance needed to prevent the body from overreacting to any pain or discomfort and staying in that "fight or flight" mode.

Autonomic Reflexes after SCI

Your body's first reaction to pain or discomfort below your injury level is still to go into the sympathetic, "fight or flight" mode. Your brain then tries to send the parasympathetic, "rest and digest" response to counteract the sympathetic response, but your SCI blocks the signals from reaching the spinal cord below your injury level. The "rest and digest" response only reaches those areas above your injury level, and this allows the "fight or flight" mode to continue out of control below your injury level.

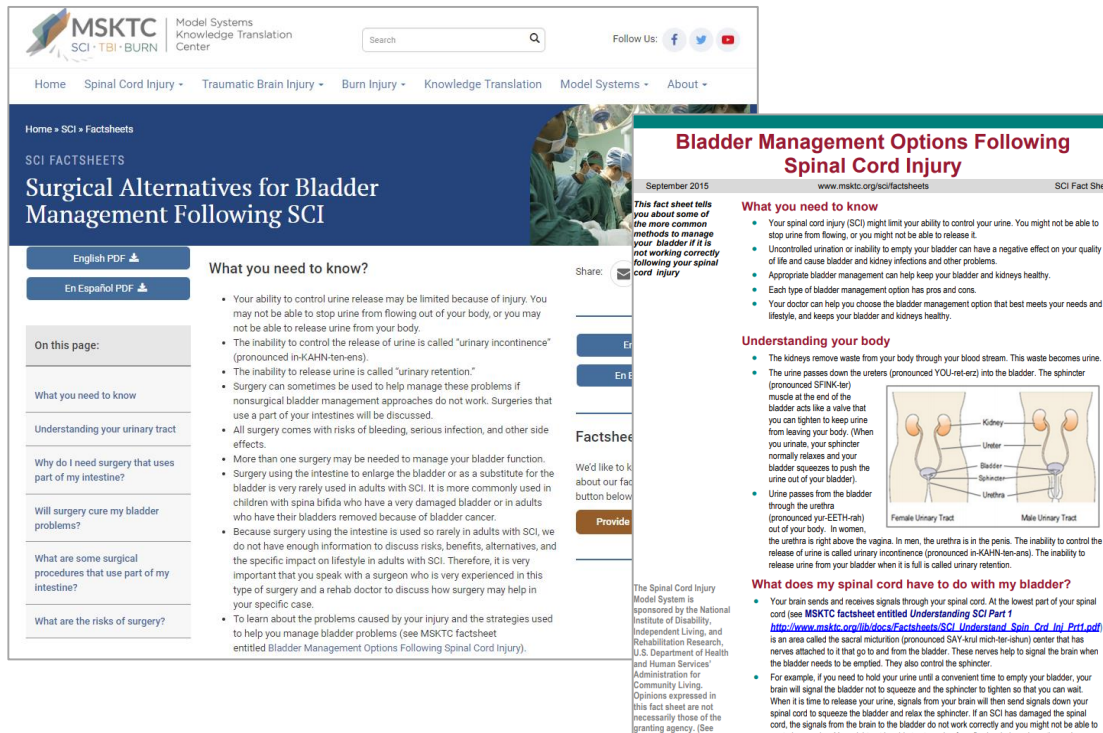
Why is AD life-threatening?

AD is life-threatening because blood pressure can rise to dangerous levels when your body stays in

The Spinal Cord Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/sci/model-system-centers> for more)

Factsheets

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



The screenshot displays the MSKTC website interface. At the top, there is a navigation bar with the MSKTC logo and the text 'Model Systems Knowledge Translation Center'. Below this is a search bar and social media links. The main content area features a blue header for the fact sheet titled 'Bladder Management Options Following Spinal Cord Injury', dated September 2015. The page is divided into several sections: 'What you need to know', 'Understanding your body', and 'What does my spinal cord have to do with my bladder?'. The 'What you need to know' section contains a list of bullet points regarding urinary control and surgical options. The 'Understanding your body' section includes a diagram of the urinary tract and text explaining the role of the kidneys, ureters, bladder, and urethra. The 'What does my spinal cord have to do with my bladder?' section discusses the neural pathways involved in bladder control and the impact of SCI. A sidebar on the left offers language options (English PDF, Spanish PDF) and a 'Factsheet' section with a 'Provide' button. The bottom of the page contains a small text block about the funding and support of the fact sheet.



Factsheets



• Depression and SCI

MSKTC Model Systems Knowledge Translation Center
SCI • TBI • BURN

Home • Spinal Cord Injury • Traumatic Brain Injury • Burn Injury • Knowledge Translation • Model Systems • About

Home » SCI » Factsheets

SCI FACTSHEETS

Depression and Spinal Cord Injury

English PDF

En Español PDF

On this page:

- What is depression?
- Causes of depression
- Depression can and should be treated
- What counseling really is?
- How do antidepressants work?
- What you can do

Depression is common and can affect anyone. About 11 million people get depressed every year. Depression in the spinal cord injury (SCI) population - about one in five people - has 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 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, when feeling depressed or losing interest in usual activities 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

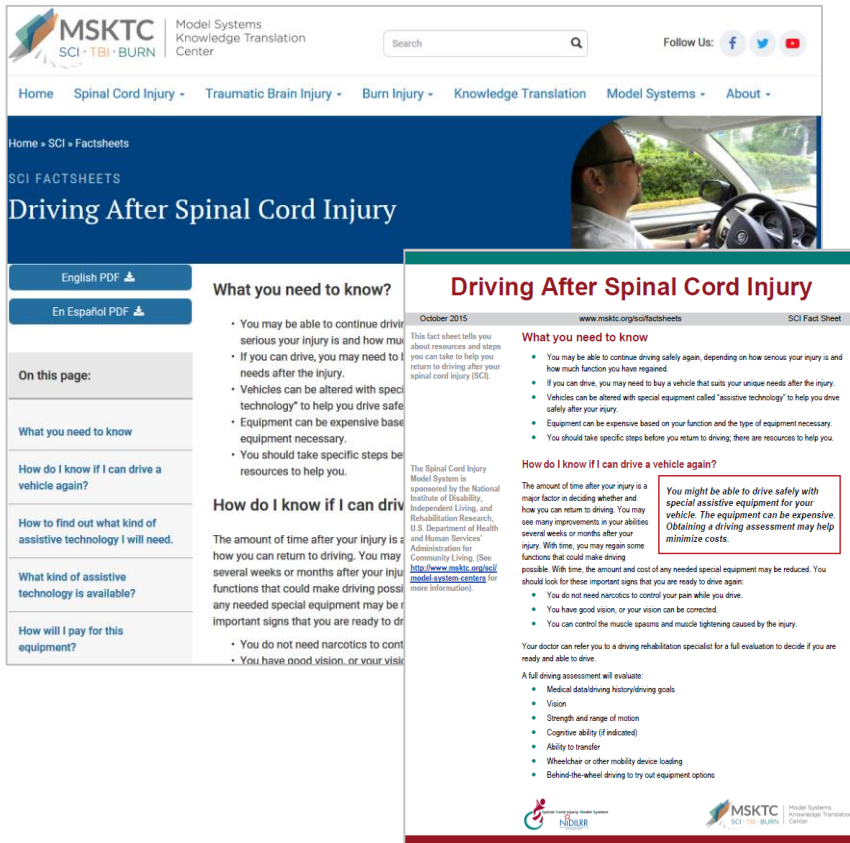
The good news is that the symptoms of depression can almost always be treated.

For more information, contact your nearest SCI Model System. For a list of SCI Model Systems go to <http://www.msksk.org/sci-topics/depression-sci>

This publication was produced by the SCI Model System 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. H131A06070.

Factsheets

• Driving after SCI




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SCI • TBI • BURN


Home Spinal Cord Injury Traumatic Brain Injury Burn Injury Knowledge Translation Model Systems About

Home » SCI » Factsheets

SCI FACTSHEETS

Driving After Spinal Cord Injury

English PDF 

En Español PDF 

On this page:

- What you need to know
- How do I know if I can drive a vehicle again?
- How to find out what kind of assistive technology I will need.
- What kind of assistive technology is available?
- How will I pay for this equipment?

What you need to know?

- You may be able to continue driving serious your injury is and how much you can take to help you return to driving after your spinal cord injury (SCI).
- If you can drive, you may need to take needs after the injury.
- Vehicles can be altered with special technology to help you drive safely.
- Equipment can be expensive based on your function and the type of equipment necessary.
- You should take specific steps before you return to driving; there are resources to help you.

How do I know if I can drive a vehicle again?

The amount of time after your injury is a major factor in deciding whether and how you can return to driving. You may see many improvements in your abilities several weeks or months after your injury. With time, you may regain some functions that could make driving possible. With time, the amount and cost of any needed special equipment may be reduced. You should look for these important signs that you are ready to drive again:

- You do not need narcotics to control your pain while you drive.
- You have good vision, or your vision can be corrected.
- You can control the muscle spasms and muscle tightening caused by the injury.

Your doctor can refer you to a driving rehabilitation specialist for a full evaluation to decide if you are ready and able to drive.

A full driving assessment will evaluate:

- Medical data/driving history/driving goals
- Vision
- Strength and range of motion
- Cognitive ability (if indicated)
- Ability to transfer
- Wheelchair or other mobility device loading
- Behind-the-wheel driving to try out equipment options

What you need to know

This fact sheet tells you about resources and steps you can take to help you return to driving after your spinal cord injury (SCI).

- You may be able to continue driving safely again, depending on how serious your injury is and how much function you have regained.
- If you can drive, you may need to buy a vehicle that suits your unique needs after the injury.
- Vehicles can be altered with special equipment called "assistive technology" to help you drive safely after your injury.
- Equipment can be expensive based on your function and the type of equipment necessary.
- You should take specific steps before you return to driving; there are resources to help you.

How do I know if I can drive a vehicle again?

You might be able to drive safely with special assistive equipment for your vehicle. The equipment can be expensive. Obtaining a driving assessment may help minimize costs.

The Spinal Cord Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msctc.org/> for more information).

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Employment after SCI

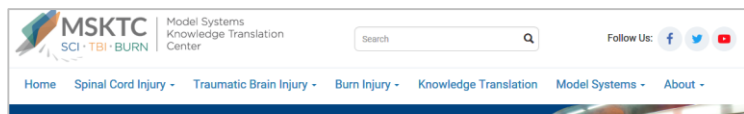
<https://msktc.org/sci-topics/employment-after-sci>

Factsheets

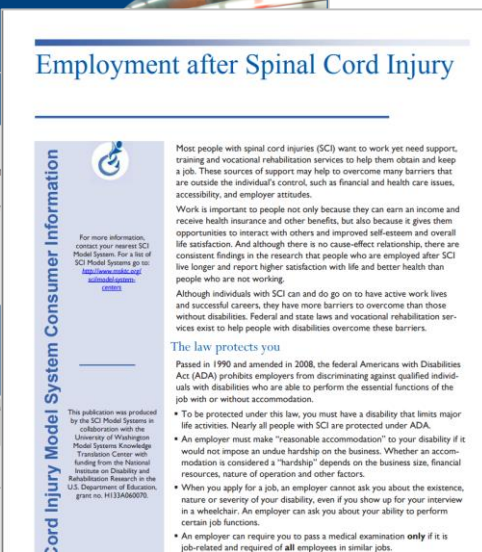
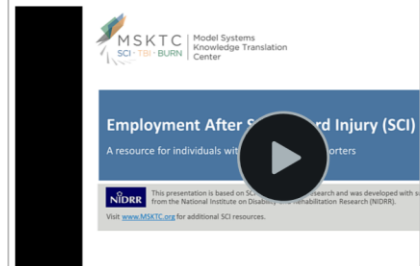
- Employment after SCI

Slideshows

- Employment after SCI



View our slide show on employment after a spinal cord injury.
To watch the slideshow in full screen mode, click the full screen button located at the far bottom. Once you click the button, the video will expand so that it covers the majority of your screen.
To exit full screen mode, simply press the Esc button on your keyboard or click the full-screen



Exercise and Fitness after SCI

<https://msktc.org/sci-topics/exercise-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

- The Therapeutic Feeling of Fitness
- Things to Watch Out for When Starting an Exercise Routine
- Thinking about Exercise in a New Way
- Troubleshooting for a Better Exercise Routine

Factsheets

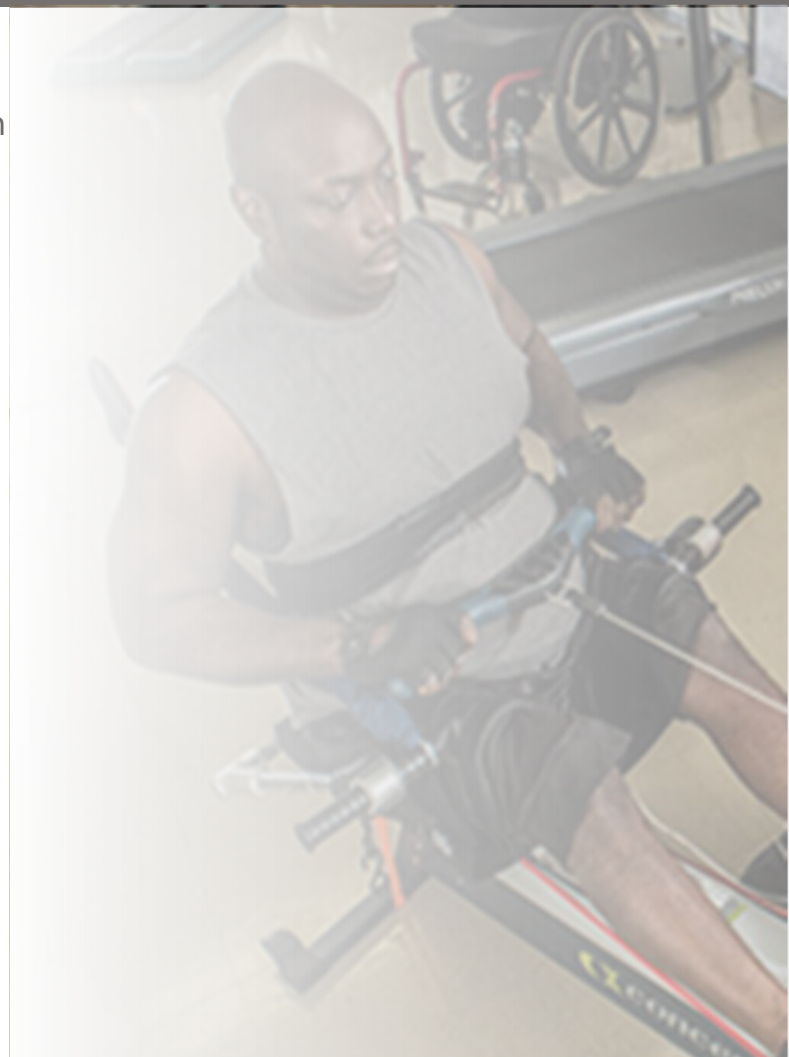
- Adaptive Sports & Recreation
- Exercise after SCI

Hot Topic

- Exercise & Fitness after SCI

Slideshow

- Gait Training after SCI



Gait Training and SCI

<https://msktc.org/sci/slideshows/gait-training-after-spinal-cord-injury>

Factsheets

- SCI and Gait Training

Slideshows

- SCI and Gait Training



The screenshot shows the MSKTC website interface. At the top, there is a navigation bar with links for Home, Spinal Cord Injury, Traumatic Brain Injury, Burn Injury, and Knowledge Translation. Below this, a search bar and social media icons are visible. The main content area features a blue header for 'SCI SLIDESHOWS' and a sub-header for 'Gait Training after Spinal Cord Injury'. A large play button icon is centered on the page, indicating a video or slideshow player. To the right of the play button, there is a sidebar with the title 'Spinal Cord Injury Model System Consumer Information'. The main text area contains a detailed article about gait training for SCI, including a list of categories for health professionals to describe walking ability and a section on why gait training is needed.

Spinal Cord Injury and Gait Training

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



Managing Bowel Function

<https://msktc.org/sci-topics/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

- The Challenges of Maintaining a Good Diet for a Bowel Program
- Travel Challenges
- Troubleshooting and Seeking Help

Factsheets

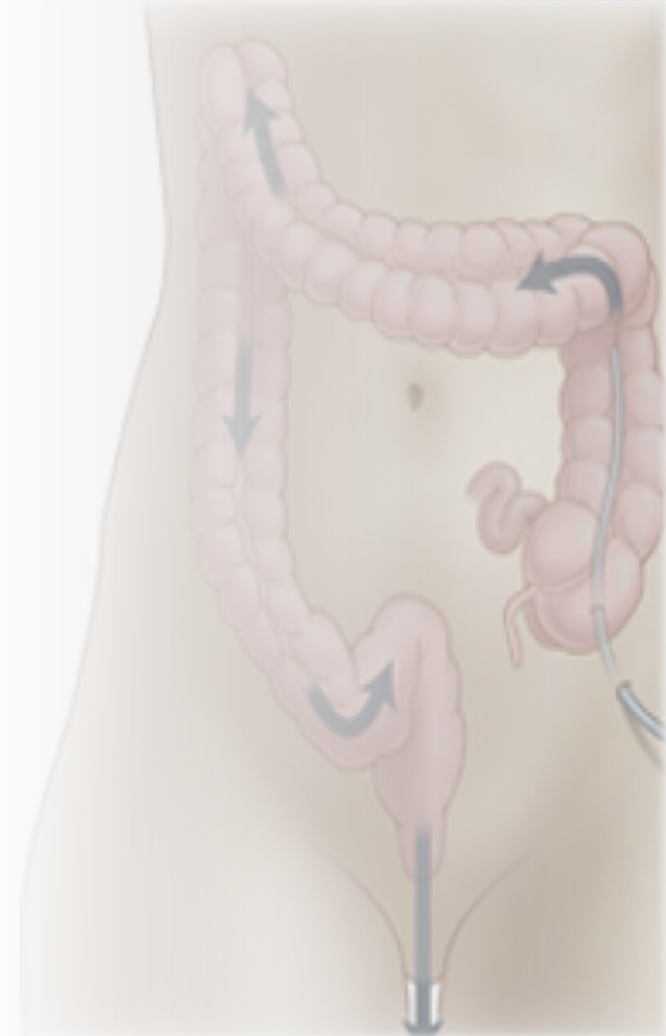
- Bowel Function after SCI

Hot Topic

- Managing Bowel Function after SCI

Slideshow

- Bowel Function after SCI



Managing Pain after SCI

<https://msktc.org/sci-topics/managing-pain-after-spinal-cord-injury>

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

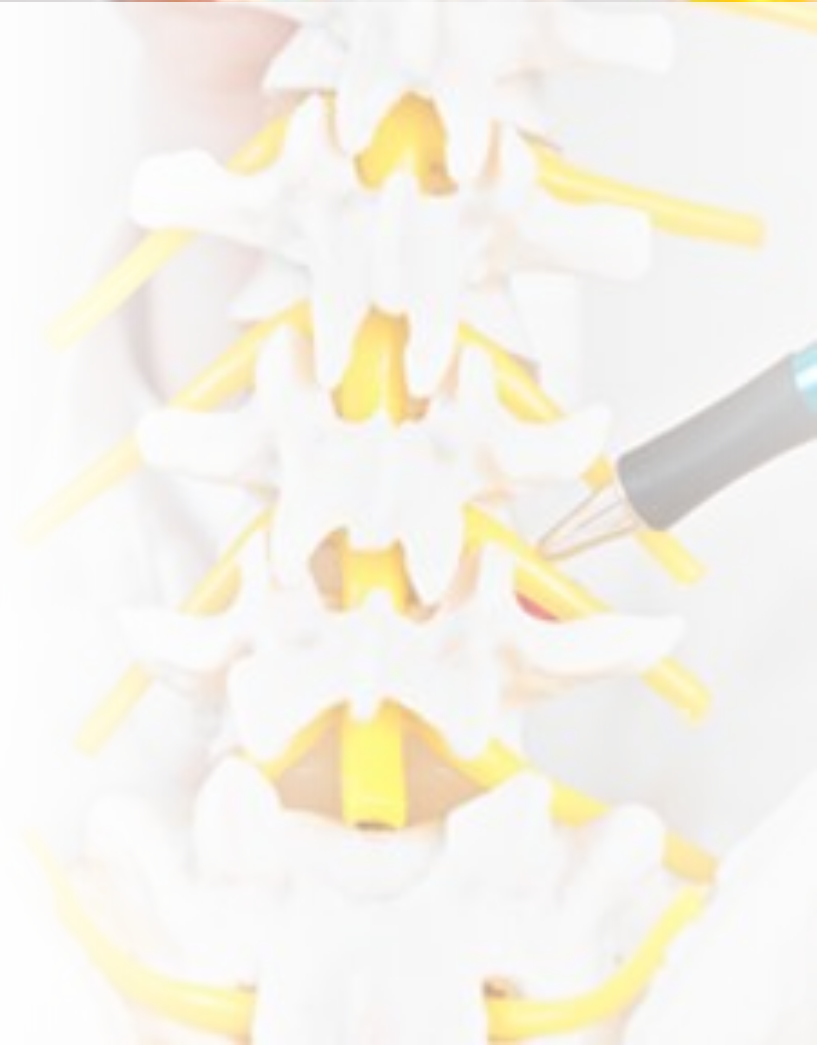
- Pain after SCI

Hot Topic

- Managing Pain after SCI

Slideshow

- Pain after SCI







Personal Care Attendants and SCI

<https://msktc.org/sci/factsheets/personal-care-attendants-and-spinal-cord-injury>

Factsheets

• Personal Care Attendants and SCI



MSKTC Model Systems Knowledge Translation Center
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Home • SCI • Factsheets

SCI FACTSHEETS

Personal Care Attendants and Spinal Cord Injury

August 2020 www.msktc.org/sci/factsheets SCI Factsheet

This fact sheet offers suggestions on finding, interviewing, funding, and managing a personal care attendant.

What is a personal care attendant?

A personal care attendant, or PCA, is someone paid to help you with some or all of your self-care and other activities that you need for your spinal cord injury (SCI).

- "Personal Assistant" and "Personal Assistant Service" are other terms that refer to similar personal care services.

Do I need a PCA?

You may benefit from a PCA if you need help with daily needs. A few ways a PCA might help you include:

- Meeting basic daily care needs.
- Making the best use of your time and energy to get through a full day of activities. For many people with higher levels of SCI, a PCA can make it easier to work or go to school.
- Helping to minimize pain or fatigue that you have when doing daily activities without help.
- Adapting to any decline in your abilities to do daily activities as you age.

What help does a PCA provide?

- Self-care. This often includes help with feeding, and bladder and bowel management. It may also include help with other tasks, like keeping your lungs clear of secretions.
- Mobility. This may include help with transfers, pressure relief movements, using a wheelchair, and driving.
- Set-up. This may include help with setting up assistive devices or other items around you, such as a computer, so that you can do activities by yourself.
- Light housework. This may include help with tasks like preparing food, washing dishes, doing laundry, and cleaning.



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.

- Some states pay a family member if you prefer a family member to a PCA.

Getting help from family for some or all of your daily needs can have benefits, but there may also be downsides. It is important to consider your needs as well as the needs of your family members when making a plan for your care.

The Spinal Cord Injury Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. See <http://www.msktc.org/sci/model-system-centers> for more information).

Pregnancy after SCI

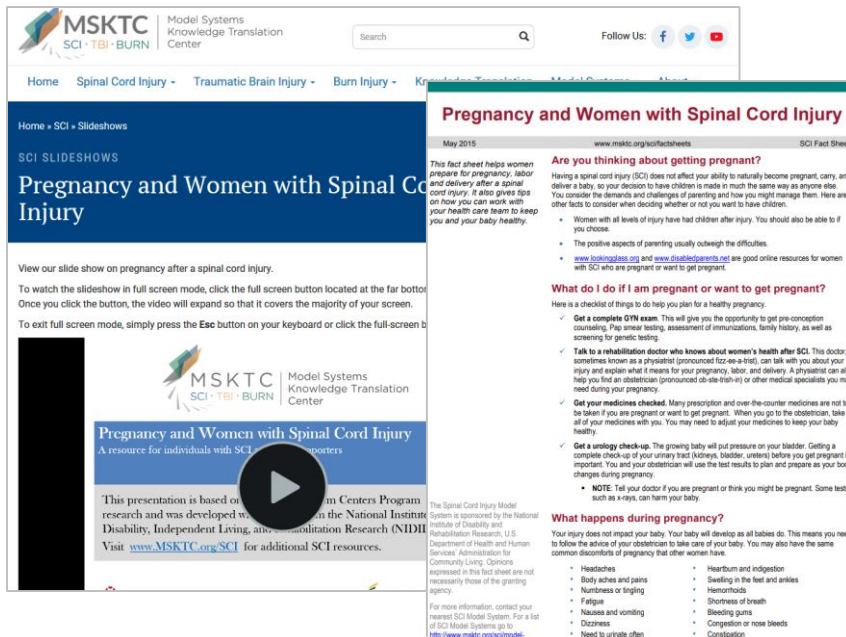
<https://msktc.org/sci-topics/pregnancy-sci>

Factsheets

- Pregnancy and Women with SCI

Slideshows

- Pregnancy and Women with SCI



The screenshot shows the MSKTC website with a navigation menu and a search bar. The main content area features a blue header for 'Pregnancy and Women with Spinal Cord Injury' and a play button icon. Below the header, there is a text box with a play button and a description of the slideshow. To the right, there is a preview of the slideshow content, which includes a title, a date (May 2015), and several sections of text and bullet points.

MSKTC Model Systems Knowledge Translation Center
SCI • TBI • BURN

Home Spinal Cord Injury - Traumatic Brain Injury - Burn Injury - Knowledge Translation Model Questions - About

Home » SCI » Slideshows

SCI SLIDESHOWS

Pregnancy and Women with Spinal Cord Injury

View our slide show on pregnancy after a spinal cord injury.

To watch the slideshow in full screen mode, click the full screen button located at the far bottom. Once you click the button, the video will expand so that it covers the majority of your screen.

To exit full screen mode, simply press the **Esc** button on your keyboard or click the full-screen button.

MSKTC Model Systems Knowledge Translation Center

Pregnancy and Women with Spinal Cord Injury

A resource for individuals with SCI and their supporters

This presentation is based on research from the National Institute of Disability, Independent Living, and Rehabilitation Research (NIDILRR). Visit www.MSKTC.org/SCI for additional SCI resources.

The Spinal Cord Injury Model System is sponsored by the National Institute of Disability and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. Opinions expressed in this fact sheet are not necessarily those of the granting agency.

For more information, contact your nearest SCI Model System. For a list of SCI Model Systems go to <http://www.msktc.org/scimodel>.

Pregnancy and Women with Spinal Cord Injury

May 2015 www.msktc.org/scifactsheets SCI Fact Sheet

This fact sheet helps women prepare for pregnancy, labor and delivery after a spinal cord injury. It also gives tips on how you can work with your health care team to keep you and your baby healthy.

Are you thinking about getting pregnant?

Having a spinal cord injury (SCI) does not affect your ability to naturally become pregnant, carry, and deliver a baby, so your decision to have children is made in much the same way as anyone else. You consider the demands and challenges of parenting and how you might manage them. There are other factors to consider when deciding whether or not you want to have children.

- Women with all levels of injury have had children after injury. You should also be able to if you choose.
- The positive aspects of parenting usually outweigh the difficulties.
- www.talkinggirls.org and www.disabledparents.net are good online resources for women with SCI who are pregnant or want to get pregnant.

What do I do if I am pregnant or want to get pregnant?

Here is a checklist of things to do help you plan for a healthy pregnancy.

- ✓ **Get a complete GYN exam.** This will give you the opportunity to get pre-conception counseling, Pap smear testing, assessment of immunizations, family history, as well as screening for genetic testing.
- ✓ **Talk to a rehabilitation doctor who knows about women's health after SCI.** This doctor, sometimes known as a physiatrist (pronounced fiz-ee-ah-trist), can talk with you about your injury and explain what it means for your pregnancy, labor, and delivery. A physiatrist can also help you find an obstetrician (pronounced ob-stee-trish-ee) or other medical specialists you may need during your pregnancy.
- ✓ **Get your medicines checked.** Many prescription and over-the-counter medicines are not to be taken if you are pregnant or want to get pregnant. When you go to the obstetrician, take all of your medicines with you. You may need to adjust your medicines to keep your baby healthy.
- ✓ **Get a urology check-up.** The growing baby will put pressure on your bladder. Getting a complete check-up of your urinary tract (kidneys, bladder, ureters) before you get pregnant is important. You and your obstetrician will use the test results to plan and prepare as your body changes during pregnancy.
 - **NOTE:** Tell your doctor if you are pregnant or think you might be pregnant. Some tests, such as x-rays, can harm your baby.

What happens during pregnancy?

Your injury does not impact your baby. Your baby will develop as all babies do. This means you need to follow the advice of your obstetrician to take care of your baby. You may also have the same common discomforts of pregnancy that other women have.

- Headaches
- Body aches and pains
- Numbness or tingling
- Fatigue
- Nausea and vomiting
- Dizziness
- Need to urinate often
- Heartburn and indigestion
- Swelling in the feet and ankles
- Hemorrhoids
- Shortness of breath
- Bleeding gums
- Congestion or nose bleeds
- Constipation

Factsheets



• Respiratory Health and SCI



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Home > SCI > Factsheets

SCI FACTSHEETS

Respiratory Health and Spinal Cord Injury

English PDF

En Español PDF

On this page:

What does the respiratory system do?

How does the respiratory system work?

How does spinal cord injury impact the respiratory system?

How does loss of muscle function affect my health?

What health problems are

What does the respiratory system do?

Your respiratory system (or this system enables you to take in oxygen and remove carbon dioxide. Your body needs to remove carbon dioxide to avoid the build-up of acid in your body.

How does the respiratory system work?

You normally breathe with your diaphragm contracting and relaxing. Your brain sends signals down your spinal cord to the phrenic nerves which start at the 3rd, 4th, and 5th cervical spinal levels to contract the diaphragm.

- You can learn more about spinal nerve function in the fact sheet, "Understanding Spinal Cord Injury, Part 1 – The Body Before and After Injury."



The Spinal Cord Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. Opinions expressed in this fact sheet are not necessarily those of the granting agency. (See <https://www.msktc.org/sci-model-system> for more information).

August 2015

www.msktc.org/scifactsheets

SCI Fact Sheet

Respiratory Health and Spinal Cord Injury

What does the respiratory system do?

Your respiratory system (or pulmonary system) is responsible for breathing. This system enables you to inhale oxygen into your blood and exhale carbon dioxide. Your body needs the oxygen to survive, and carbon dioxide must be removed to avoid the build-up of acid in your body.

How does the respiratory system work?

You normally breathe without thinking about it, but your brain is carefully coordinating this activity. Your brain sends signals down your spinal cord to the phrenic nerves which start at the 3rd, 4th, and 5th cervical spinal levels to contract the diaphragm.

- You can learn more about spinal nerve function in the fact sheet, "Understanding Spinal Cord Injury, Part 1 – The Body Before and After Injury."



Your diaphragm is the dome-shaped muscle located under each lung (at the bottom of your chest) and is the primary muscle used for inhaling. The diaphragm moves down as it contracts. Your lungs, rib cage and abdomen (belly) expand as air is drawn into (inhaling) your lungs through your nose and mouth. Air travels through the main airway (the trachea) and smaller airways (a series of tubes) that lead to the air sacs. Air sacs in your lungs transfer oxygen from the air to your blood. Your diaphragm moves up to where it started as it relaxes after inhalation. Your lungs, rib cage and abdomen (belly) get smaller as the muscles of inhalation relax, pushing carbon dioxide out (exhaling) through your nose and mouth.

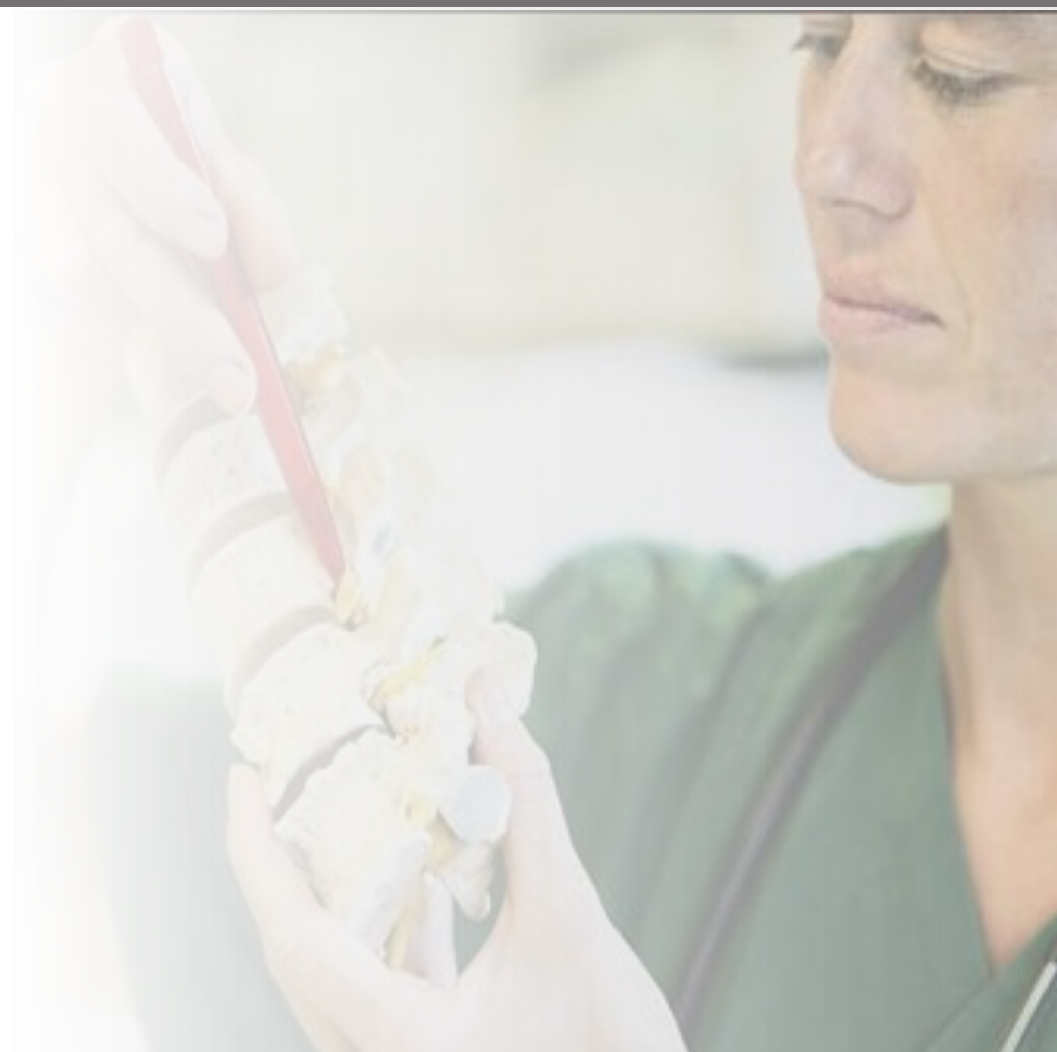
You normally need more muscle strength, or force, to help with breathing when you exercise or cough. To provide this added assistance, particularly to help with exhaling forcefully during a cough, your brain sends signals down your spinal cord and out through the nerves coming from the thoracic portion of the spinal cord to direct your abdominal muscles (over your belly) and intercostal muscles (between the ribs).

- Coughing is important because you produce small amounts of mucus in your lungs every day. Coughing helps to remove the mucus and prevent mucus build-up that can block the airways leading to the air sacs in your lungs that absorb the oxygen from the air. When you cough, the muscles responsible for most of the force are the abdominal muscles.

How does spinal cord injury impact the respiratory system?

Signals sent from your brain can no longer pass beyond the damage to the spinal cord, so your brain can no longer control the muscles that you would normally use for inhaling and exhaling. The extent of your muscle control loss depends on your level of injury and if there is complete or incomplete spinal cord damage.

If you have a complete high cervical injury that involves the spinal cord at or above the cervical 3rd, 4th, and 5th spinal nerves, you may have a loss of or weakness in diaphragm function depending on the extent of damage. You may even need a tracheostomy (an opening through the neck into the



Safe Transfer Techniques

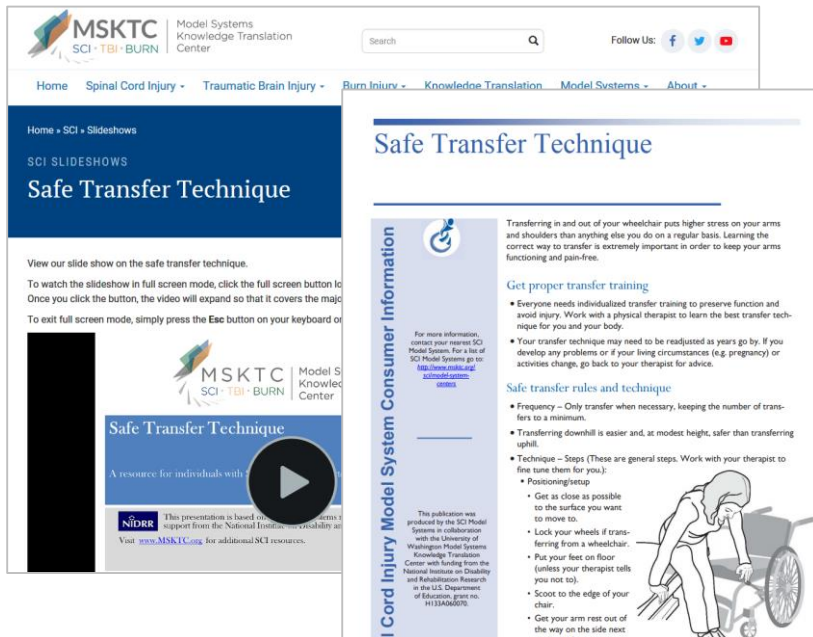
<https://msktc.org/sci-topics/safe-transfer-techniques>

Factsheets

- Safe Transfer Technique

Slideshows

- Safe Transfer Technique



The screenshot shows the MSKTC website interface. At the top, there is a navigation bar with the MSKTC logo (SCI • TBI • BURN) and the text 'Model Systems Knowledge Translation Center'. A search bar and social media links (Facebook, Twitter, YouTube) are also present. The main content area is titled 'Safe Transfer Technique' and includes a 'Safe Transfer Technique' slideshow player. Below the player, there is a 'Safe Transfer Technique' factsheet. The factsheet contains the following text:

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 moving to.

For more information, contact your nearest SCI Model System. For a list of SCI Model Systems go to <http://www.msctc.org/about-us/locations>.

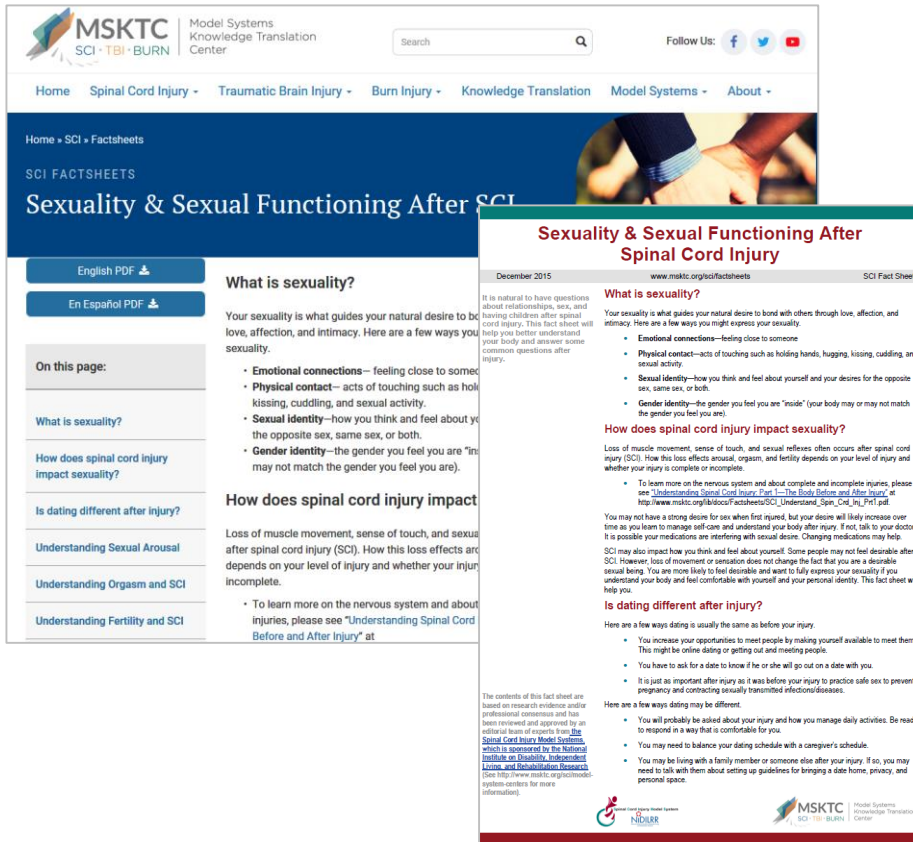
This publication was produced by the SCI Model Systems in collaboration with the University of Washington Model Systems Knowledge Translation Center with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education, grant no. H113AM66076.

Sexuality and Sexual Functioning After SCI

<https://msktc.org/sci-topics/sexuality>

Factsheets

• Sexuality and Sexual Functioning After SCI

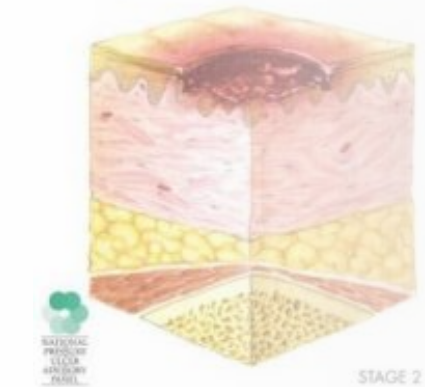
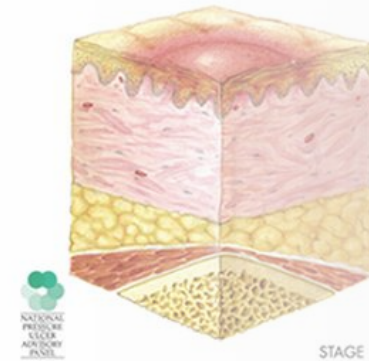


The screenshot shows the MSKTC website interface. At the top, there is a navigation bar with 'Home', 'Spinal Cord Injury', 'Traumatic Brain Injury', 'Burn Injury', 'Knowledge Translation', 'Model Systems', and 'About'. Below this is a search bar and social media links. The main content area features a blue header with 'SCI FACTSHEETS' and the title 'Sexuality & Sexual Functioning After SCI'. On the left, there are buttons for 'English PDF' and 'En Español PDF'. The main text area is titled 'What is sexuality?' and includes a list of bullet points: 'Emotional connections', 'Physical contact', 'Sexual identity', and 'Gender identity'. Below this, it asks 'How does spinal cord injury impact sexuality?' and 'Is dating different after injury?'. At the bottom, there are logos for NIDILRR and MSKTC.



Factsheets

- 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



The screenshot shows the MSKTC website interface. The main heading is "Skin Care & Pressure Sores Part I: Causes and Risks of Pressure Sores". The page includes a table of contents with sections like "Causes and Risks", "Preventing Pressure Sores", and "How to do Pressure Reliefs (Weight Shifts)". A sidebar on the left lists "On this page:" with links to various sections. The main content area starts with "What do I need to know?" and lists key facts for individuals with SCI.

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), bed sore 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.

Factsheets

• Spasticity and SCI



MSKTC Model Systems Knowledge Translation Center
SCI • TBI • BURN


Home Spinal Cord Injury - Traumatic Brain Injury - Burn Injury - Knowledge Translation Model Systems - About -

Home » SCI » Factsheets

SCI FACTSHEETS

Spasticity and Spinal Cord Injury

English PDF 

En Español PDF 

On this page:

- What is spasticity?
- What causes spasticity?
- What are the benefits of spasticity in SCI?
- What problems are caused by spasticity?
- Managing spasticity after SCI

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 signs 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.

For more information, contact your nearest SCI Model System. For a list of SCI Model Systems go to: <http://www.msktc.org/about-us/contact>

Spasticity and Spinal Cord Injury

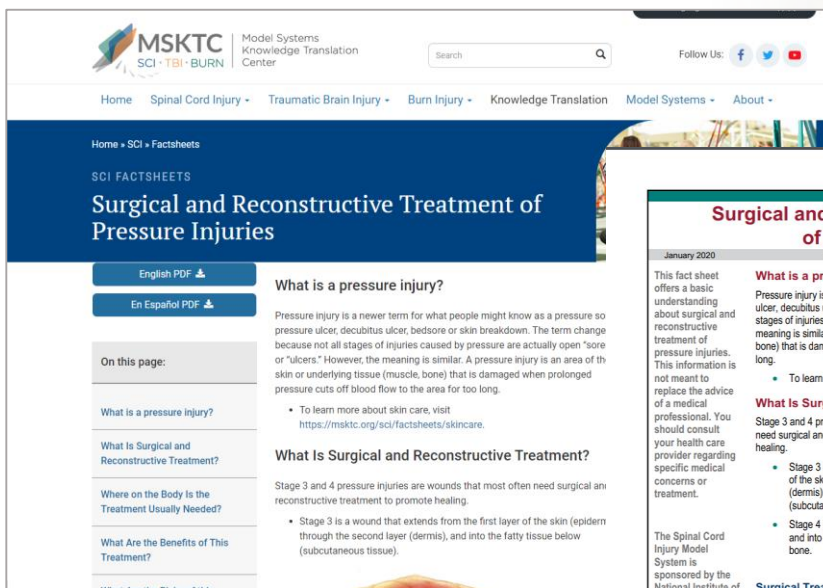
Spinal Cord Injury Model System Consumer Information

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. H111AN0070.

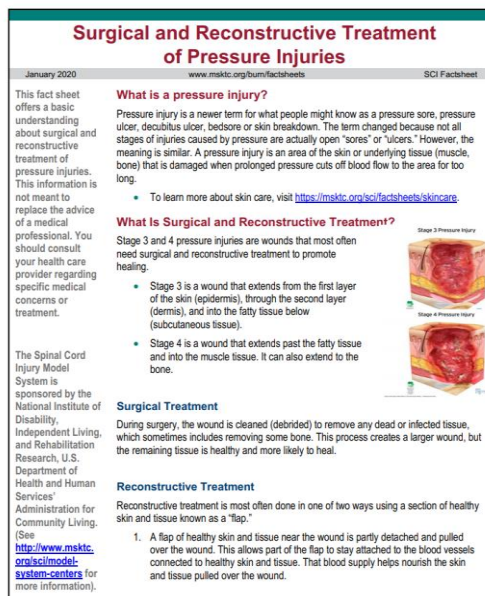


Factsheets

• Surgical and Reconstructive Treatment of Pressure Injuries



The screenshot shows the MSKTC website interface. At the top, there is a search bar and social media links. The main navigation includes Home, Spinal Cord Injury, Traumatic Brain Injury, Burn Injury, Knowledge Translation, Model Systems, and About. The page title is "Surgical and Reconstructive Treatment of Pressure Injuries". There are buttons for "English PDF" and "En Español PDF". A sidebar on the left lists related topics: "What is a pressure injury?", "What is Surgical and Reconstructive Treatment?", "Where on the Body is the Treatment Usually Needed?", "What Are the Benefits of This Treatment?", and "What Are the Risks of this".



Surgical and Reconstructive Treatment of Pressure Injuries
 January 2020 | www.msktc.org/burnfactsheets | SCI Factsheet

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 "sores" 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/scifactsheets/skincare>.

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).
- Stage 4 is a wound that extends past the fatty tissue and into the muscle tissue. It can also extend to the bone.

Surgical Treatment
 During surgery, the wound is cleaned (debrided) to remove any dead or infected tissue, which sometimes includes 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."

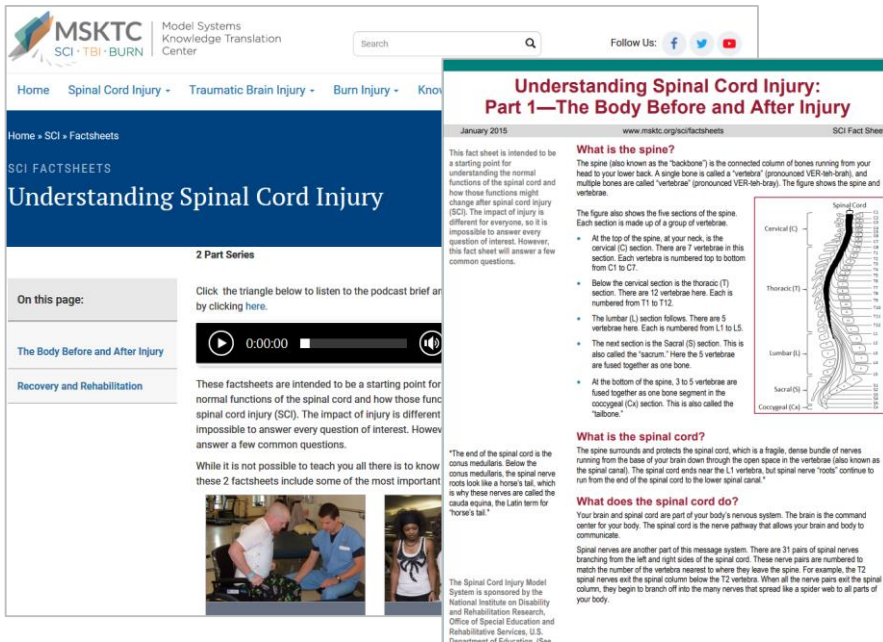
- A flap of healthy skin and tissue near the wound is partly detached and pulled over the wound. This allows part of the flap to stay attached to the blood vessels connected to healthy skin and tissue. That blood supply helps nourish the skin and tissue pulled over the wound.

The Spinal Cord Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/sci-model-system-centers> for more information).




Factsheets

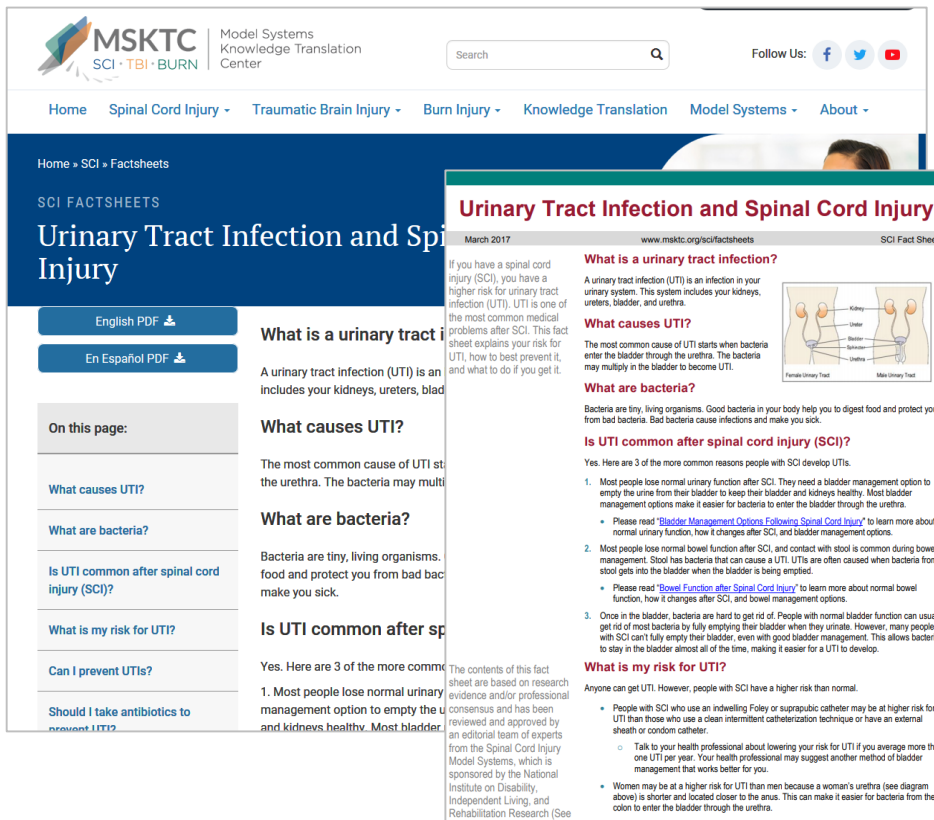
- Understanding SCI: Part 1—The Body Before and After Injury
- Understanding SCI: Part 2—Recovery and Rehabilitation



The screenshot shows the MSKTC website interface. The top navigation bar includes 'Home', 'Spinal Cord Injury', 'Traumatic Brain Injury', and 'Burn Injury'. The main content area is titled 'Understanding Spinal Cord Injury' and features a '2 Part Series' section. A video player is embedded, showing a play button and a 0:00:00 duration. Below the video, there are two columns of text. The left column contains introductory text and a photo of a man in a white shirt and a woman in a blue shirt. The right column contains the main text of the fact sheet, including sections on 'What is the spine?', 'What is the spinal cord?', and 'What does the spinal cord do?'. A diagram of the human spine is also visible on the right side of the page.

Factsheets

• Urinary Tract Infection and SCI



The screenshot shows the MSKTC website factsheet page. At the top, there is a navigation bar with the MSKTC logo (SCI • TBI • BURN) and the text "Model Systems Knowledge Translation Center". A search bar and social media icons (Facebook, Twitter, YouTube) are also present. Below the navigation bar, the page title "Urinary Tract Infection and Spinal Cord Injury" is displayed in a large blue font. To the left of the main content, there are two PDF download buttons: "English PDF" and "En Español PDF". Below these, a "On this page:" section lists several topics with corresponding links: "What causes UTI?", "What are bacteria?", "Is UTI common after spinal cord injury (SCI)?", "What is my risk for UTI?", "Can I prevent UTIs?", and "Should I take antibiotics to prevent UTI?". The main content area is titled "Urinary Tract Infection and Spinal Cord Injury" and includes a date "March 2017" and the URL "www.msktc.org/scifactsheets". The text explains that a urinary tract infection (UTI) is an infection in the urinary system, including the kidneys, ureters, bladder, and urethra. It notes that UTI is one of the most common medical problems after SCI. The page is divided into several sections: "What is a urinary tract infection?", "What causes UTI?", "What are bacteria?", "Is UTI common after spinal cord injury (SCI)?", "What is my risk for UTI?", and "Can I prevent UTIs?". A diagram of the urinary tract is included, showing the kidneys, ureters, bladder, and urethra for both male and female. The text also mentions that the contents of the fact sheet are based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the Spinal Cord Injury Model Systems, which is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research.



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



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Home Spinal Cord Injury - Traumatic Brain Injury - Burn

Home » SCI » Factsheets

SCI FACTSHEETS

Wheelchair Information

3 Part Series

The wheelchair is a complex piece of engineered and studied. Most individuals because doing so increases their needs. So, it is critical to

While it is not possible to teach you these 3 factsheets include some of

On this page:

- Getting the Right Wheelchair
- The Manual Wheelchair
- The Power Wheelchair

Getting the Right Wheelchair

The Manual Wheelchair

The Power Wheelchair

Getting the Right Wheelchair

Spinal Cord Injury Model System Consumer Information

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

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. H133A60070.

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

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.

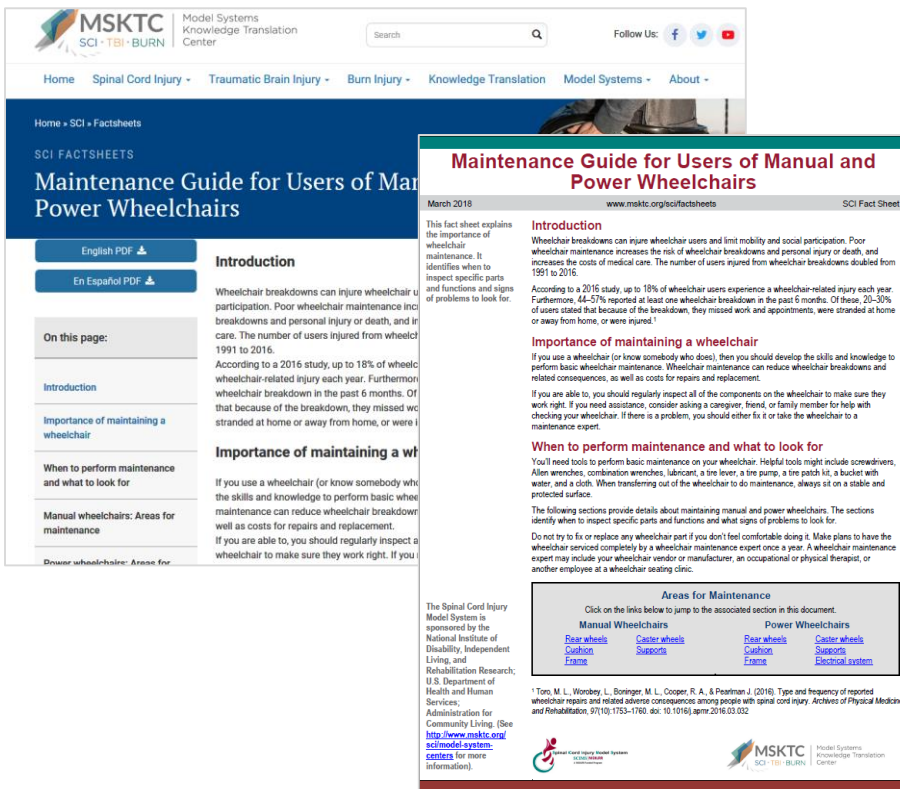
- **You:** The most important member of the team is you, the wheelchair user. Even if this is your first wheelchair, your opinions and desires are essential in order to make the best selection.
- **Family members or caregivers:** Individuals you live with or who care for you will also be affected by 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.

Maintenance Guide

<https://msktc.org/sci/factsheets/maintenance-guide-users-manual-and-power-wheelchairs>

Factsheets

• Maintenance Guide for Users of Manual and Power Wheelchairs





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SCI FACTSHEETS

Maintenance Guide for Users of Manual and Power Wheelchairs

English PDF  En Español PDF 

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- When to perform maintenance and what to look for
- Manual wheelchairs: Areas for maintenance
- Power wheelchairs: Areas for maintenance

Introduction

Wheelchair breakdowns can injure wheelchair users and limit their participation in daily life. Poor wheelchair maintenance increases the risk of wheelchair-related injury or death, and increases the costs of medical care. The number of users injured from wheelchair breakdowns doubled from 1991 to 2016.

According to a 2016 study, up to 18% of wheelchair-related injury each year. Furthermore, 44-57% reported at least one wheelchair breakdown in the past 6 months. Of these, 20-30% of users stated that because of the breakdown, they missed work and appointments, were stranded at home or away from home, or were injured.¹

Importance of maintaining a wheelchair

If you use a wheelchair (or know somebody who does), then you should develop the skills and knowledge to perform basic wheelchair maintenance. Wheelchair maintenance can reduce wheelchair breakdowns and related consequences, as well as costs for repairs and replacement.

If you are able to, you should regularly inspect all of the components on the wheelchair to make sure they work right. If you need assistance, consider asking a caregiver, friend, or family member for help with checking your wheelchair. If there is a problem, you should either fix it or take the wheelchair to a maintenance expert.

When to perform maintenance and what to look for

You'll need tools to perform basic maintenance on your wheelchair. Helpful tools might include screwdrivers, Allen wrenches, combination wrenches, lubricant, a tire lever, a tire pump, a tire patch kit, a bucket with water, and a cloth. When transferring out of the wheelchair to do maintenance, always sit on a stable and protected surface.

The following sections provide details about maintaining manual and power wheelchairs. The sections identify when to inspect specific parts and functions and what signs of problems to look for.

Do not try to fix or replace any wheelchair part if you don't feel comfortable doing it. Make plans to have the wheelchair serviced completely by a wheelchair maintenance expert once a year. A wheelchair maintenance expert may include your wheelchair vendor or manufacturer, an occupational or physical therapist, or another employee at a wheelchair seating clinic.



Areas for Maintenance

Click on the links below to jump to the associated section in this document.

Manual Wheelchairs		Power Wheelchairs	
Rear wheels	Caster wheels	Rear wheels	Caster wheels
Cushion	Supports	Cushion	Supports
Frame		Frame	Electrical system

¹ Tom, M. L., Wronsky, L., Boring, M. L., Cooper, R. A., & Peckham, J. (2016). Type and frequency of reported wheelchair repairs and related adverse consequences among people with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 97(10), 1753-1760. doi: 10.1016/j.apmr.2016.03.022

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