

Understanding Spinal Cord Injury, Part 2— Recovery and Rehabilitation



January 2015 SCI Fact Sheet

This fact sheet is the second in a two-part series in understanding spinal cord injury (SCI). Part one, The Body Before and After Injury, contains terms and information that are discussed in this fact sheet.

Connect with Us:

Northern New Jersey Spinal Cord Injury System

1199 Pleasant Valley Way West Orange, NJ 07052 http://KesslerFoundation.org/NNJSCIS

Kessler Foundation

SCIResearch@kesslerfoundation.org www.Facebook.com/SCIRehabResearch http://KesslerFoundation.org Follow @KesslerFdn on Twitter

Kessler Institute for Rehabilitation

SCIRehab@kessler-rehab.com www.Facebook.com/Kessler-Institute-for-Rehabilitation www.kessler-rehab.com

University Hospital www.uhnj.org

The Spinal Cord Injury Model System is sponsored by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education. (See

http://www.msktc.org/sci/mod el-system-centers for more information).

Can paralysis caused by spinal cord injury be reversed?

Everyone wants to know if there is a "cure" for spinal cord injury (SCI). There continues to be significant progress made toward this goal, but, despite any claim that there is a cure, there is currently no proven way to reverse paralysis.

Will I gain any improvements?

There are three areas for potential improvement after SCI.

- Severity of Injury: At the time of your injury, your injury is graded as either complete or incomplete. Your grade my change. For example, you may be first classified as AIS C and improve to AIS D.
- Levels of injury: At the time of your injury, you are diagnosed with a neurological level of injury.
 You may regain levels of injury over time. For example, you may be first classified with a C4
 level of injury and improve to a C5 level. This means you gain control of more muscle
 movement.
- 3. Functional abilities: These are the activities you are capable of doing as you regain muscle strength and learn to use those muscles after injury. Pushing a wheelchair is one example.

How much improvement will I gain?

There is almost always hope for at least some improvement after SCI, but there are no guarantees. You have to wait to see what happens in the months after your injury. Here are a few rules of thumb.

- People with a complete injury often regain 1 or 2 levels of injury. This means you often regain control of 1 or 2 levels of muscle movement.
- People with an incomplete injury are more likely than people with a complete injury to regain control of more muscle movement, but there is no way to know how much, if any, will return.
- As long as you are seeing some improvement, like regaining muscle movement, your chances for improvement are better.
- The longer you go without seeing improvement, your chances for improvement are lower.

What is Rehabilitation?

Your body drastically changes after paralysis. You have medical needs that must be managed. You lose muscle movement and feeling. Plus, you probably have muscle weakness and fatigue after injury in the muscles that you can move. Simply put, you may not be able to do some daily living activities in the same way you did before your injury.

Rehabilitation (rehab) is a medical service that can help you reach your full potential after injury. Every injury is different, so rehab is tailored to each person's needs. Skilled specialists provide the necessary services to help you make the most of your abilities.

- Physiatrists (pronounced fiz-EYE-ah-trists) are rehab doctors who lead your treatment team and manage your medical care.
- Psychologists develop and apply treatment strategies in counseling to help you through your adjustment to life after injury.
- Nurses usually carry out orders from your doctor, and they often provide the essential education you need on how to manage issues like bowel and bladder management.



- Physical therapists use a wide variety of techniques to help you regain the strength and stamina to maximize your physical abilities.
- Occupational therapists use a wide variety of techniques to help you increase and maintain your independence in carrying out your daily living activities.
- Speech-language pathologists (speech therapists) treat any issues that may develop with swallowing or speaking.
- Social workers link you and your family to information and resources that help ease your transition from in-patient rehabilitation to home and community living.

What is my role in rehab?

You have to put all of your effort into rehab to get the most out of it. You will work with your rehab team to set goals that are a realistic expectation of what you should be able to do with the muscle movement you have after injury. To reach your goals, you have to work as hard as you can with your rehab team to help you get stronger and learn the skills you need to manage daily activities and be independent. Some common goals include using a wheelchair, transferring, driving a car, bathing, eating, and dressing.

Also, learn as much as you can about how to take care of yourself. Learn how to manage your daily concerns, such as bladder and bowel. Learn how to best prevent health problems like pressure ulcers, urinary tract infections, and pneumonia. Learn what you should do if you develop pain, autonomic dysreflexia, depression, or other medical problems.

What advice can be offered from other people with SCI about rehab?

People who have been injured and gone through rehab understand what you and your family are experiencing. They have been where you are now, and they can offer some valuable suggestions to help guide you during rehab. They offer the following advice.

- Trust your rehab team. Rehab professionals are very knowledgeable, and it is in your best interest to follow their advice in setting and reaching your goals. They can also advise you on how to best avoid many of the common setbacks people experience during rehab. For example, pressure ulcers can severely limit your ability to participate in rehab, but most pressure ulcers can be prevented if you do your weight shifts (also known as a pressure relief) as directed by your rehab team.
- Remember that who you are does not change after injury. You have the love and support of your family, friends, and others in your community. They can be a valuable support network in helping you reach your goals.
- Approach rehab with a balanced mindset. Everyone hopes they will regain all of their lost movement and feeling. However, the reality is that people are more likely to regain some, but not all, movement and feeling. This makes it very important that you participate in rehab to learn the skills necessary to have the healthiest and happiest life after SCI. Attending education classes will help you learn about SCI And how to take care of yourself. If you do regain everything, you have lost nothing in the process of learning those skills. If you do not regain everything, you will have the valuable knowledge and skills you need for everyday living.
- Be patient. SCI is a traumatic event that tears your life apart in an instant, and it takes time to rebuild your life after injury. You body will need time to heal from the trauma of your injury. You will need time to regain the strength and stamina to reach your goals. However, you can do it in time.
- You will have bad days. It is only natural to feel sad, angry, or afraid at times. There may be times when it is hard to imagine how
 you can ever be happy after injury. However, most people do find happiness over time as they begin to realize they can live an
 active, healthy life.
- Take advantage of peer support. Your rehab team can likely arrange for you to talk with others who have SCI. They have been
 where you are and learned how to manage day-to-day activities. They can be a valuable source of information. There are also
 some online support networks. Here are a couple of recommended sites that have a focus in peer support.
 - www.spinalcord.org provides information and resources to meet the needs of people with SCI and their families and friends.
 - <u>www.facingdisability.com</u> is designed to provide Internet-based information and support for people with SCI and their families. The website has more than 1,000 videos of family members answering real-life questions about how they cope with SCI.
- Ask questions. You will probably have many questions. If you have questions, ask your rehab team. Most questions can be answered, but there may be some questions that cannot be answered. When it comes to regaining movement after injury, for example, sometimes it just takes time to see what happens.



What are my functional goals?

There is a chart on the following pages that outlines common functional goals. These goals are daily activities that most people can manage with the control of muscle movement that they have with a complete injury. You may be able to do additional activities if you have an incomplete injury or if you regain control of more muscle movement. You will work with your rehab team to set your goals and find ways you can reach your goals. Below is a step-by-step guide to using the chart.

- 1. Find your level of injury in the Level of Injury column.
- 2. The Physical Abilities column shows what muscle movement is common for anyone with a complete injury at that level.
- 3. The Functional Goals column outlines how people might manage typical daily activities based at that level of injury.
- The Equipment Used column suggests various equipment options that might be useful in accomplishing those functional goals.

| Level of Injury | Physical Abilities | Functional Goals | Equipment Used |
|-----------------|--|--|--|
| | C3—Limited movement of head and neck. | Breathing: Depends on ventilator for breathing. | Suction equipment to clear secretions, two ventilators with backup generator and battery |
| | | Communication: Talking is sometimes difficult, very limited, or impossible. If the ability to talk is limited, communication can be accomplished independently, with adaptive equipment. | Mouth stick and assistive technology (e.g., computer, communication board) for speech or typing |
| C1–C3 | | Daily tasks: Full assistance from caregiver for turning in bed, transfers, and all self-care (including bowel and bladder management). Assistive technology can allow for independence in such tasks as reading a book or newspaper, using a telephone, and operating lights and appliances. | Mouth stick, environmental control unit (ECU) |
| | | Mobility: Can operate an electric wheelchair by using a head control, mouth stick, sip and puff, or chin control. Can also operate a power tilt wheelchair also for independent pressure relief. | Power or manual lift, electric or semi- electric hospital bed, power wheelchair with pressure-relieving cushion |
| | Usually has head and neck control. At C4 level, may shrug shoulders. | Breathing: May initially require a ventilator for breathing; usually adjusts to breathing full time without ventilator assistance. | Cough-assist device |
| | | Communication: Normal. | |
| C3–C4 | | Daily Tasks: Individual requires full assistance from a caregiver for turning in bed, transfers, and all self-care (including bowel and bladder management). Individual may be able to use adaptive equipment to eat independently. May also be able to operate an adjustable bed and perform other tasks, such as painting, writing, typing, and using a telephone with assistive technology. | Eating: Sandwich holder on a gooseneck, feeder, long straw for liquids Other Activities: ECU for operating bed (e.g., head or voice activated, mouth stick controller), hands-free devices, mouth stick for typing, etc. |
| | | Mobility: Can operate a power wheelchair by using head control, a mouth stick, sip and puff, or chin control. Power tilt function on wheelchair allows for independence with pressure relief. | Power or manual lift, electric or semi- electric hospital bed, power wheelchair with pressure-relieving cushion |
| C5 | Typically has head and neck control, can shrug shoulders, and has some shoulder control. Can bend elbows and turn palms face up. | Daily Tasks: Individual can be independent with eating and grooming (e.g., face washing, oral care, shaving, make-up application) after setup from caregiver, with specialized equipment. Individuals will require total assistance from caregiver for bed mobility, transfers, and all other self-care. May be able to assist caregiver with upper body dressing and some bathing, with adaptive equipment. | Eating: Universal cuff for attachment of utensils, scoop plate, plate guard, long straw Grooming: Universal cuff for attachment of tooth brush, comb or brush, adapted or electric razor, makeup applicators; wash mitt for face Bathing: Roll-in padded shower and commode chair, or padded transfer tub bench; wash mitt; adapted loofah |

SCITIBITEURN | Center

| | | Health Care: Individual will require assistance from caregiver for cough assist. Can perform pressure relief with power tilt in power wheelchair. | Cough-assist device |
|----|---|--|---|
| | | Mobility: May have strength to push a manual wheelchair for short distances over level surfaces; however, a power wheelchair with hand controls will be required for daily activities. At this level, the individual may be able to drive with specialized hand controls in a modified van with a lift, but still may require attendant to assist with transportation. | Wheelchair: Power or manual lift, electric or semi-electric hospital bed, power wheelchair with pressure-relieving cushion Bed: Bed ladder, thigh straps, and bed rails used for bed mobility |
| | | Bowel and Bladder Management: Individual requires total assistance from caregiver for bowel and bladder management. Individual may have indwelling catheter or the caregiver may perform intermittent catheterization for bladder management. Bowel management can be performed with use of specialized equipment or medication. | Bowel: Roll-in padded shower and commode chair, or padded transfer tub bench Bladder: Leg-bag emptier |
| | Has movement in head, neck, shoulders, arms, and wrists. Can shrug shoulders, bend elbows, turn palms up and down, and extend wrists. | Daily Tasks: With use of some specialized equipment and setup from a caregiver, an individual can be independent with most feeding, grooming, and upper body dressing. Will still require some assistance for lower body dressing and will be able to assist with upper body during bathing. Can perform sliding board transfers to padded shower commode chair and/or tub bench for toileting and bathing, with some to total assist from caregiver. Can perform some light meal preparation tasks. | Feeding: Universal cuff, built-up utensils, scoop plate, long straw, plate guard Grooming: Universal cuff, adapted electric razor, or toothbrush Dressing: Dressing stick, leg lifter, thigh straps, dressing hook splints; adapted or specialized clothing Bathing: Adapted loofah, long-handled sponge with universal cuff Transfers: Power or manual lift, sliding board, padded drop-arm bedside commode, padded tub bench with cutout, padded shower and commode chair |
| C6 | | Health Care: Can independently perform pressure relief with power tilt and may require some to no assist for forward or lateral lean pressure relief. Mobility: An individual may require some to no assist for turning in bed, with use of special equipment. May be able to perform sliding board transfers on level surfaces with some to no assistance from caregiver. Can use a ultralightweight manual wheelchair for mobility, but some may use a power wheelchair for greater ease | Bed: Bed ladder, thigh straps, bed rails Wheelchair: Wheelchair pegs, specialized wheelchair gloves, and rubber tubing on wheels. Also, powerassist wheels can be used for independence with manual wheelchair propulsion. |
| | | over uneven terrain. Can be independent driving a vehicle from power or manual wheelchair with specialized equipment. Bowel and Bladder Management: Some to total assist with adaptive equipment for management of bowel and bladder. | Transportation: Modified van with lift, specialized hand controls, tie-downs Bowel: Digital stimulation splint device, enema insertion device Bladder: Catheter inserter, penis positioner, thigh spreader with mirror |



| | Has movement similar to C6 level, with the added ability to straighten elbows. At the C8–T1 level, has added strength and precision of hands and fingers. | Daily Tasks: Independent with all feeding, grooming, and upper body dressing, with equipment. Individuals may require some to no assistance with lower body dressing and bathing with equipment. Can perform sliding board transfers with some to no assistance to padded shower commode chair and/or tub bench for toileting and bathing. | Feeding: Universal cuff, built-up handles, curved utensils, long straw, plate guard, adapted techniques for grasp Grooming: Universal cuff, splint material to adapt devices Dressing: Leg lifter, dressing stick, zipper pull, hooks on shoes Bathing: Adapted loofah, long-handled sponge with universal cuff Transfers: Sliding board, padded droparm bedside commode, padded tub bench with cutout, padded shower and commode chair |
|--------|---|--|---|
| C7-T1 | | Health Care: Independent with wheelchair pushup or lateral lean for pressure relief. | |
| | | Mobility: Independent with manual wheelchair propulsion and level surface sliding board transfers. Some assistance may be required from caregiver for uphill transfers. Can be independent with driving if able to load and unload wheelchair. | Wheelchair: Rigid or folding lightweight wheelchair, wheelchair pegs, wheelchair gloves Transportation: Hand controls, modified van if unable to perform transfer or load–unload chair |
| | | Bowel and Bladder Management: Depending on hand function, some to total assist for bowel management, with use of adaptive equipment or medication. Can be independent or need some assist for bladder management with ICP or condom catheter. | Bowel: Digital stimulation splint device, enema insertion device, toileting aid Bladder: Catheter inserter house hold (for men), thigh spreader with mirror (for women) |
| TO 740 | Has normal motor function in head, neck, shoulders, arms, hands, and fingers. Has increased use of rib and chest muscles, or trunk control. At the T10–T12 level, more improvements in trunk control due to increase in abdominal strength. | Daily Tasks: Independent with all self-care, including bowel and bladder management, with adaptive equipment if necessary. | Dressing: Thigh straps, reacher, dressing stick, sock aid Bathing: Long-handled sponge Transfers: Sliding board, padded droparm bedside commode, padded tub bench with cutout, padded shower/commode chair Bowel/Bladder: Mirror |
| T2-T12 | | Health Care: Independent with wheelchair pushup for pressure relief. | |
| | | Mobility: Independent with all bed mobility and transfers, with or without use of equipment. Independent with wheelchair propulsion on uneven and even surfaces and up and down curbs. Able to load and unload wheelchair independently for driving with hand controls. | Wheelchair: Ultra-lightweight wheelchair Transfers: Sliding board, leg straps Transportation: Hand controls |
| L1–L5 | Has additional return of motor movement in the hips and knees. | Mobility: Independent with all bed mobility and transfers with or without use of equipment. Independent with wheelchair propulsion on uneven and even surfaces and up and down curbs. Ambulation possible with use of specialized leg braces and walking devices. Functionality of ambulation depends on strength and movement in legs. Individuals' ability to ambulate depends primarily on their level household distances. Individuals may use a wheelchair for community mobility. Able to load and unload wheelchair independently for driving with hand controls. | Wheelchair: Ultra-lightweight wheelchair if necessary. Walking: Leg braces that extend to the hip, the knee, or just the ankle/foot and varying assistive devices Transportation: Hand controls |



| l | | | | |
|----|-------|----------------------|---|---|
| | | , , | Mobility: Increased ability to walk with fewer to no bracing or assistive devices. | Walking: Braces that support the ankle/foot |
| | S1-S5 | degrees of return of | bracing or assistive devices. | ankie/100t |
| 51 | 51-50 | voluntary bladder, | | |
| | | bowel, and sexual | | |
| | | function. | | |

Authorship

"Understanding Spinal Cord Injury: Part 2—Recovery and Rehabilitation" was developed by Phil Klebine, M.A.; Olivia Smitherman, M.O.T.R./L.; and Laney Gernenz, P.T. in collaboration with the Model Systems Knowledge Translation Center.

Source: Portions of this document were adapted from materials developed by the UAB SCI Model System, Northwest Regional SCI System, Southeastern Regional Spinal Cord Injury Care System, Rocky Mountain Regional Spinal Injury System, and Paralyzed Veterans of America Consortium for Spinal Cord Medicine.

Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this fact sheet were developed under a grant from the Department of Education, NIDRR grant number H133A110004. However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the federal government.

Copyright © 2015 Model Systems Knowledge Translation Center (MSKTC). May be reproduced and distributed freely with appropriate attribution. Prior permission must be obtained for inclusion in fee-based materials.

More in the "Understanding Spinal Cord Injury" series: Part 1: The Body Before and After Spinal Cord Injury

