Understanding Spinal Cord Injury, Part 2—Recovery and Rehabilitation

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SCI Factsheet

This fact sheet is the second in a two-part series in understanding spinal cord injury and answers some of the common questions people have during the early period after injury. Part one, The **Body Before and After** Injury, explains terms and information that are discussed in this fact sheet, including severity, level of injury, and changes in function.

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-systemcenters 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 cure or proven way to completely reverse paralysis caused by SCI.

Will I gain any improvements?

There is almost always hope for at least some improvement after SCI. Here are the three areas for potential improvement after SCI.

- 1. The severity of your injury may improve. At the time of your injury, your injury is graded as either complete or incomplete. One example of improvement is that you may be first classified as AIS C and improve to AIS D.
- 2. The level of your injury may improve. At the time of your injury, you are diagnosed with a neurological level of injury. One example of improvement is that you may be first classified with a C4 level of injury and improve to a C5 level.
- 3. Your functional abilities may improve. These are the activities that you are capable of doing with the movement that you have. This also includes what you can do with the help of home modifications, medical equipment, adaptive devices, assistive devices, and assistive technologies. One example of improvement is that you may not first have the strength or movement needed to push a wheelchair but gain the needed strength and movement over time.

How much improvement will I gain?

There is no guarantee and no way to know how much, or if any, improvements you will have. You have to wait to see what happens in the months after your injury. However, here are a few basic rules of thumb on improvement.

- Many people with complete injuries regain 1 to 2 levels of injury. The improved muscle movement can result in improved functional abilities.
- People with incomplete injuries are more likely than people with complete injuries to regain muscle movement.
- Your chances for regaining muscle movement are better as long as you are seeing gains in muscle movement or feeling.
- Your chances for regaining control of muscle movement get lower the longer you go without seeing any gains in muscle movement or feeling.





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What is Rehabilitation?

The way your brain and body work together changes after SCI. You may lose your ability to control muscle movement and your ability to "feel" things. Your brain may no longer be able to guide your ability to control your bowel, bladder, and other body functions. Simply put, you probably cannot do some daily living activities in the same way as you did before your injury.

Rehabilitation (rehab) is a medical specialty that helps you find different ways to do the daily living activities. Rehab offers skilled professionals who work as a team to help you achieve the best possible health, functional abilities, and quality of life after SCI.

Key Members of Your Rehab Team

- Physiatrists (pronounced fiz-EYE-ah-trists) are rehab doctors who lead your treatment team and manage your medical care. 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 the care plan set by your healthcare team, and they often provide the essential education you need on how to manage issues like bowel and bladder care. They also help reinforce what you learn in therapy.
- 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.
- Recreational therapists use activity-based approaches to improve or maintain physical, cognitive, social, emotional and spiritual functioning to ease the return to everyday life.
- Speech-language pathologists (speech therapists) treat the problems related to communication and swallowing.
- 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 will work with your rehab team to set personal goals. These goals will be based on a realistic expectation of what you should be able to do with the muscle movement you have after injury. These goals can change if you regain additional movement over time.

To reach your goals, you have to work as hard as you can to get stronger and learn the skills you need to manage daily activities and be as independent as possible. Some common goals include using a wheelchair, transferring to and from a wheelchair, 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 injuries, urinary tract infections, and pneumonia. Learn what you should do if you develop pain, autonomic dysreflexia, depression, or other medical problems.

• Learning how to take care of yourself also includes learning to direct others to assist with care when needed.





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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. Think of rehab team as a source of knowledge in your care and put trust in their advice. They can be key partners who work with you to help you set and reach your goals. They can also advise you on how to best avoid many of the common setbacks people experience during rehab. One example is that your rehab team will advise you on how often to do a weight shift (also known as pressure relief). This is important because most pressure injuries can be prevented but can severely limit your ability to participate in rehab and other activities if you get one.
- 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 life-changing event. It takes time to rebuild your life after injury, and your 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.
 - <u>www.spinalcord.org</u> provides information and resources to meet the needs of people with SCI and their families and friends.
 - www.facingdisability.com 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?

The chart on the following pages outlines the minimum goals that are reasonable for someone with a complete injury at the given levels of injury. This means the goals are expected if there is little to no muscle movement below that level. You may set additional goals if you have muscle movement below that level or you can do more with new and advancing adaptive and assistive technologies.

- You will work with your rehab team to set your own personal functional goals and find ways to reach your goals.
- New and advancing adaptive and assistive technologies continue to greatly enhance functional abilities, especially for those with more limited muscle movement. It can be in your best interest to stay informed on new and advancing adaptive and assistive technologies to continue to enhance your functional abilities.

Reading the Functional Goals Chart

- Find your level of injury in the "Level of Injury" column.
- The "Expected Muscle Control" column shows the minimum muscle movement you are expected to have at that level of injury. This is if you have little to no muscle movement below that level.
- The "Functional Goals" column outlines which activities are expected to be done with that level of injury and little to no movement below that level. You may be able to set additional goals if you gain better muscle control or can do more with new and advancing adaptive and assistive technologies.
- The "What is Needed" column offers suggestions for medical equipment, adaptive devices, assistive devices, and assistive technologies that might be helpful in achieving those goals.
 - Search the internet to find any items listed in the chart.
 - Some suggestions include items that may not be covered by insurance and must be paid using out-of-pocket expenses.





Level of Injury	Expected Muscle Control	Functional Goals	What is Needed
	C2-C3 – Limited movement of head and neck. C4 – Added shoulder shrugs.	Breathing <u>C2-C3</u> Depends on ventilator. <u>C4</u> May initially need a ventilator, but most adjust to breathing without a ventilator. <u>Communication</u> <u>C2-C3</u> Talking is sometimes difficult, very limited, or	 <u>C2-C3</u> Suction equipment to clear secretions. Two ventilators with a generator and battery on hand as a backup in the event of power loss. <u>C4</u> Cough assist device <u>Impaired Voice</u> Synthesized speech device Sin and puff switch activated attendant call chime
		impossible. If the ability to talk is impaired, typing and communication can be accomplished independently with setup assistance of synthesized speech device, smartphones, tablets, and computers. C4 Talking is normal.	 Onp and pull switch activated attendant call chine. Computer with camera and eye-gaze or motion-tracking technology. Mouth stick for physical touch typing. A stylus on mouth stick can be used for smartphone, tablet, and computer touchscreen use. <u>Non-Impaired Voice</u> Microphone with voice recognition software Mouth stick for physical touch typing. A stylus on mouth stick can be used for smartphone, tablet, and computer touchscreens.
C2-C4		Daily tasks With setup assistance, advancing technologies with smart devices paired with smartphones, tablets, or computers can allow independent environmental control when in bed or sitting in a wheelchair. This includes, but is not limited to, independent control of a TV, cable or satellite box, audio and multimedia systems, thermostat, electric door opener, door locks, cameras, and power on/off devices such as lights and appliances. Full assistance is needed for all self-care, including eating, daily skin checks, bathing and bowel and bladder management.	 Bathing Padded shower commode chair, may have tilt-in-space option. Eating and Drinking Extra-long, flexible drinking straw or hands free drinking system. Environmental Control Smartphone and tablet with voice recognition, a mouth stick with a stylus, and/or smart phone accessibility features. Bed and wheelchair phone mounts. Bluetooth earpiece with speech recognition for placing and answering calls. Computer access with speech recognition software/microphone, adapted mouse options controlled with head movement or a joystick. Wheelchair trays, height adjustable workstations. Bluetooth and Infrared assistive technologies built into power wheelchair controls. Cloud-based smart speaker for voice control if voice (speech devices can function as voice) Connected smart devices using WIFI network, smart hubs, smart plugs and switches, and other





Level of Injury	Expected Muscle Control	Functional Goals	What is Needed
C2–C4	C2-C3 – Limited movement of head and neck. C4 – Added shoulder shrugs.	Mobility Can operate a power wheelchair using a head control, sip and puff, or chin control. Can use a power seating system for independent pressure relief while sitting. Full assistance is needed for transfers and pressure relief turning in bed, but a power rotation bed can be used for turning in bed.	 Power or manual lift for transfers Although an electric or semi-electric hospital bed is most common, a power rotation bed Power wheelchair with power tilt and recline seating system Skin protection and positioning cushion
		Breathing Full to partial cough assist is needed to clear secretions.	 Cough-assist device recommended, but a manual cough assist can be used
C5	Added ability to bend elbows and turn palms face up.	 Daily Tasks After setup assistance, can expect to be fully independent with eating and brushing teeth. After setup assistance, may also be full to partially independent with some upper body dressing, some bathing, some grooming, and some make-up application. With setup assistance and when in a wheelchair, can usually have independent environmental control of smartphone, tablet, computer, TV, cable or satellite box, audio and multimedia systems, thermostat, electric door opener, door lock, cameras, and lowered light switches. and appliances, and other connected devises. With setup assistance, smart home technologies can be used for independent environmental control when in bed. Full assistance is needed for daily skin checks, bowel, and bladder management. After setup assistance, a manual or power leg bag emptier can be setup for independent emptying while in wheelchair. 	 Leg bag (if used) Manual or power leg bag emptier Eating and Drinking Extra-long, flexible drinking straw Assistive cuff for attachment of utensils Cup with handle High rim plate, scoop plate or plate guard Grooming Assistive cuff for attachment of tooth brush, comb/ brush, razor, makeup applicators Bathing Wash mitt Assistive cuff with long handle loofah or sponge Padded shower commode chair, may have tilt-in- space option Environmental Control Smartphone and tablet with voice recognition, a stylus in a cuff, and/or smart phone accessibility features. Bed and wheelchair phone mounts. Computer access with speech recognition software/microphone, trackball or wheelchair joystick mouse options. Wheelchair trays, height adjustable workstations. A stylus can be used with an assistive cuff for physical touchscreen use of smartphone, tablet, and computer. Cloud-based smart speaker for voice control. Connected smart devices using WIFI network, smart hubs, smart plugs and switches, and other smart home devices.





Level of Injury	Expected Muscle Control	Functional Goals	What is Needed
C5	Added ability to bend elbows and turn palms face up.	Mobility Some to full assistance is needed for transfers and pressure relief turning in bed. A power wheelchair with hand controls will likely be used for daily activities, but some may have the strength to push a manual wheelchair for short distances over level surfaces. Full independence with pressure relief with power tilt and recline seating system, and some may also do front and side-to-side leans for pressure relief in power wheelchair. Some may be able to drive using specialized, adaptive driving controls on a modified, wheelchair accessible van	 Bed Bed ladder, thigh straps, and bed rails May first use an electric or semi-electric hospital bed, but many transition into a more traditional bed. An adjustable, well-padded, air mattress is suggested. Wheelchair Power or manual lift for transfers Power wheelchair with power tilt and recline seating system Skin protection and positioning cushion Driving A driving evaluation is required to determine driving controls Accessible van with ramp or lift and wheelchair lock down system Chest strap
C6	Added ability to turn palms up and down and extend wrists.	 Breathing Full to partial cough assist is needed to clear secretions. Daily Tasks After setup assistance, can expect to be fully independent with feeding, grooming, and upper body bathing and dressing. Can do some light meal preparation tasks. Will need assistance for lower body bathing and dressing. Full assistance is usually needed for daily skin checks, bowel, and bladder management. However, some can gain greater independence over time using assistive devices with management of bowel and bladder. If needed, a leg bag emptier can be setup for independent emptying while sitting in the wheelchair.	 Cough-assist device recommended, but a manual cough assist can be used Eating and Drinking Assistive cuff for attachment of utensils Grooming Assistive cuff for attachment of tooth brush, comb/ brush, razor, makeup applicators Dressing Assistive cuff with dressing stick Buttoning aid hook Zipper pull grip Leg lifter or leg and thigh lifter Bathing Wash mitt Assistive cuff with long handle loofah or sponge Padded tub bench if transferring into tub Padded shower commode chair if using a roll-in shower Bowel Management Drop-arm padded bedside commode Digital bowel stimulator and suppository inserter Bladder Management Catheter inserter Thigh spreader Adaptive mirror





Level of Injury	Expected Muscle Control	Functional Goals	What is Needed
C6	Added ability to turn palms up and down and extend wrists.	Mobility Can be independent with turning in bed and with transfers over level surfaces. Most will need assistance for uphill transfers. Some may use an ultra-lightweight manual wheelchair for primary mobility, and some will use a power wheelchair for primary mobility for easier mobility over uneven terrain. Manual wheelchair users can do independent front and side-to-side leans for pressure relief. Power wheelchair users can also do pressure relief with power tilt and recline seating system. Independent with driving using adaptive driving controls. Most will use a modified, wheelchair accessible van.	 <u>Transfers</u> Transfer board, thigh straps <u>Bed</u> Bed ladder, thigh straps, and bed rails used for bed mobility May first use an electric or semi-electric hospital bed, but many transition out of it and into a more traditional bed. An adjustable, well-padded, air mattress is suggested. <u>Manual Wheelchair</u> Ultralight manual wheelchair Wheelchair gloves Pegs or rubber tubing on push rims Power-assist device Skin protection and positioning cushion <u>Power Wheelchair</u> Power wheelchair with power tilt and recline seating system Skin protection and positioning cushion <u>Driving</u> A driving evaluation is required to determine driving controls Accessible van with ramp or lift and wheelchair lock down system Torso stability belt
C7	Added ability to straighten elbows.	 Breathing Full to partial cough assist is needed to clear secretions. Daily Tasks Can expect to be fully independent with feeding, grooming, and upper body bathing and dressing, and may or may not need assistance for lower body bathing and dressing. With assistive devices, many can be independent with daily skin checks, bowel, and bladder management. Some may need some assistance.	 Cough-assist device is sometimes needed, but a manual cough assist is common when needed Eating, Drinking, Grooming, Dressing and Bathing May first use assistive cuff for attachments, but cuffs may or may not be used for long-term assists Dressing Dressing stick Buttoning aid hook Zipper pull grip Leg and thigh lifter Sock aid and long shoe horn Bathing Long handle loofah or sponge Padded tub bench if transferring into tub Padded shower commode chair if using a roll-in shower Bowel and Bladder Management Drop-arm padded bedside commode Digital bowel stimulator and suppository inserter Catheter inserter Thigh spreader Adaptive mirror





Level of Injury	Expected Muscle Control	Functional Goals	What is Needed
C7	Added ability to straighten elbows.	Mobility Can be independent with turning in bed and with transfers. An ultra-lightweight manual wheelchair is used for primary mobility. Can do independent lifts, front and side-to- side leans for pressure relief. Independent with driving using adaptive driving controls. Some may be independent in car loading and unloading of manual wheelchair.	Transfers • Transfer board, thigh straps Bed • Bed ladder, thigh straps, and bed rails used for bed mobility • May first use an electric or semi-electric hospital bed, but many transition out of it and into a more traditional bed. An adjustable, well-padded, air mattress is suggested. Manual Wheelchair • Ultralight manual wheelchair • Wheelchair gloves • Rubber tubing on push rims • Power-assist device • Skin protection and positioning cushion Driving • A driving evaluation is recommended, and hand control driving devices are commonly used • Chest strap
C8–T1 Added abilit precise han and finger movement.	Added ability for precise hand and finger movement.	Breathing Self-assist for cough to clear secretions. Daily Tasks Can expect to be independent with all self- care. Some assistive devices may be helpful.	Helpful Aid • Long reacher/grabber Dressing • Dressing stick • Leg and thigh lifter • Sock aid and long shoe horn Bathing • Long handle loofah or sponge • Padded tub bench with cutout or padded shower commode chair Bowel and Bladder Management • Digital bowel stimulator and suppository inserter • Drop-arm padded bedside commode • Thigh spreader • Long handle mirror
		Mobility: Can expect to be independent with manual wheelchair transfers, bed mobility, pressure relief, driving, and car loading and unloading of wheelchair.	Transfers • Transfer board, thigh straps may be needed Bed • Bed ladder, thigh straps, and bed rails Manual Wheelchair • Ultralight manual wheelchair • Wheelchair gloves • Skin protection and positioning cushion Driving • A driving evaluation is recommended, and hand control driving devices are used • Chest strap
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Level of Injury	Expected Muscle Control	Functional Goals	What is Needed
T2–L1	Added ability for trunk control with gains in chest muscle control and abdominal muscle control.	Daily Tasks Can expect to be independent with all self- care. Helpful devices may be used, but few to no assistive devices are usually needed. Mobility Can expect to be independent with manual	Helpful Aids Long reacher/grabber Dressing stick Leg and thigh lifter Sock aid and long shoe horn Long handle loofah or sponge Bathing Padded tub bench with cutout or padded shower commode chair Bowel Management Padded drop-arm bedside commode or padded shower commode chair Transfers Transfer board, thigh straps may be peeded
		wheelchair transfers, pressure relief, driving, and car loading and unloading of wheelchair. Can expect to be independent with manual wheelchair on all surfaces and up and down curbs.	 Transfer board, thigh straps may be needed Bed Bed ladder, thigh straps, and bed rails Manual Wheelchair Ultralight manual wheelchair Skin protection and positioning cushion Driving A driving evaluation is recommended, and hand control driving devices are used along with vehicle seatbelt
L2-S1	Added movement in the hips and knees, ankles and toes.	Daily Tasks Fully independent with all self-care and daily activities using no assistive devices.	
		Mobility Higher levels of injury will likely use a manual wheelchair for primary mobility, but many can walk short distances using leg braces and walking devices. Lower levels of injury will likely walk using fewer to no bracing or assistive devices.	 <u>Wheelchair</u> Ultralight manual wheelchair if necessary with skin protection and positioning cushion <u>Walking</u> Leg braces that extend to the hip, the knee, or just the ankle/foot and varying assistive devices





Authorship

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