

Transition to Community: Special Considerations for the SCI Patient

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At the heart of health

Introduction

- ▶ Looking beyond the Hospital Walls to better understand the transition back into community living for individuals with a Spinal Cord Injury/Disease
- ▶ Illustrate the challenges they encounter
- ▶ Discuss how these challenges & barriers can be addressed
- ▶ Provide an outline of tools for coping and adjusting to SCI/D

MAJOR CAUSES OF SCI/D

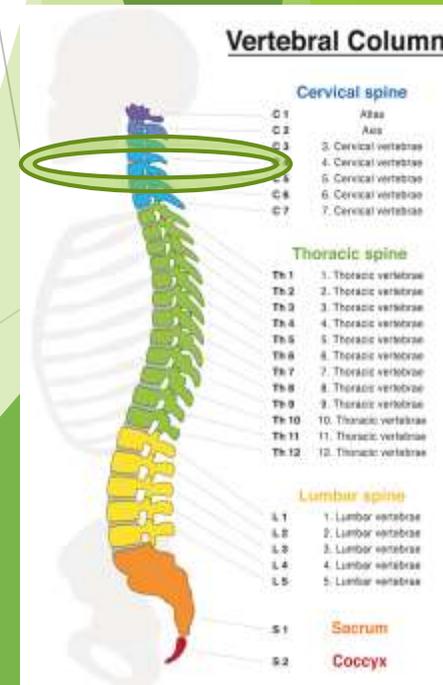
- ▶ Automobile & Motorcycle Accidents 40.4% (leading cause of SCI, Males 80%, ages 16-30)
- ▶ Falls 27.9% (especially in individuals over age 65)
- ▶ Acts of Violence 15% (Gunshot/Knife Wounds)
- ▶ Sports & Recreation Injuries 8%(impact sports, diving, risky behaviors)
- ▶ Diseases & Surgical Complications 8.5% (cancer, arthritis, inflammation)
- ▶ Alcohol (a factor in 1 out of every 4 SCI's)

LEVEL C1 - C4

- ▶ Complete paralysis of arms & legs
- ▶ Muscle atrophy
- ▶ Limited head & neck movement
- ▶ Compromised continence control
- ▶ Trouble breathing without apparatus & assistance (Christopher Reeves)
- ▶ Ability to speak reduced or impaired
- ▶ Requires complete assistance with ADL'S & 24 hour care
- ▶ Will be unable to drive

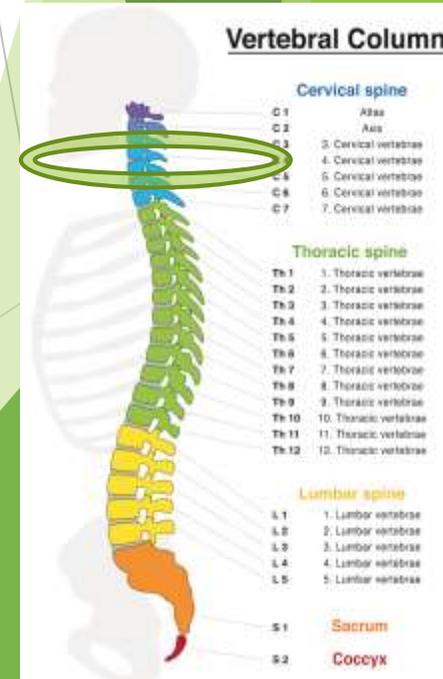
C5 Level

- ▶ Person can raise his or her arms and bend elbows.
- ▶ Likely to have some or total paralysis of wrists, hands, trunk and legs
- ▶ Can speak and use diaphragm, but breathing will be weakened
- ▶ Will need assistance with most activities of daily living, but once in a power wheelchair, can move from one place to another independently



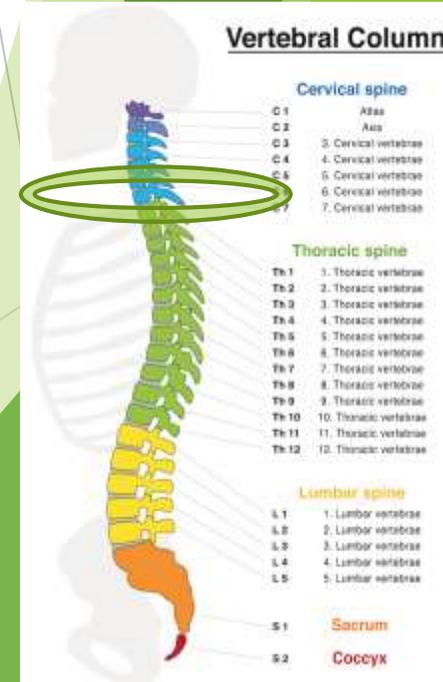
C6 level

- ▶ Nerves affect wrist extension.
- ▶ Paralysis in hands, trunk and legs, typically
- ▶ Should be able to bend wrists back
- ▶ Can speak and use diaphragm, but breathing will be weakened
- ▶ Can move in and out of wheelchair and bed with assistive equipment
- ▶ May also be able to drive an adapted vehicle
- ▶ Little or no voluntary control of bowel or bladder, but may be able to manage on their own with special equipment



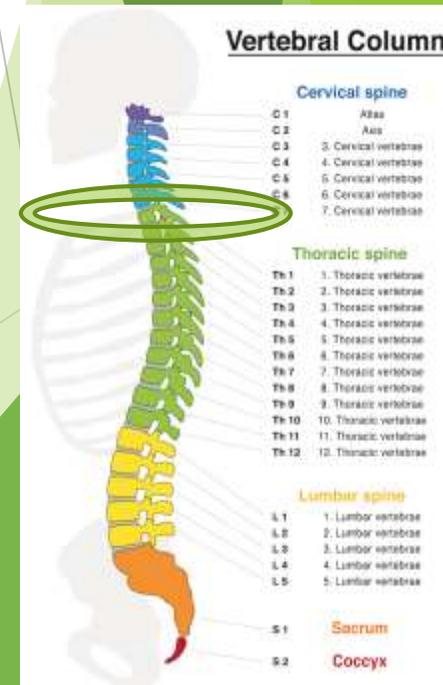
C7 level

- ▶ Nerves control elbow extension and some finger extension.
- ▶ Most can straighten their arm and have normal movement of their shoulders.
- ▶ Can do most activities of daily living by themselves, but may need assistance with more difficult tasks
- ▶ May also be able to drive an adapted vehicle
- ▶ Little or no voluntary control of bowel or bladder, but may be able to manage on their own with special equipment



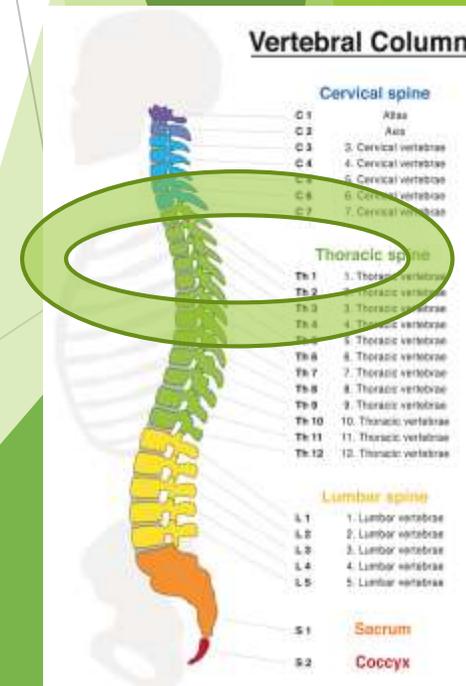
C8 level

- ▶ Nerves control some hand movement.
- ▶ Should be able to grasp and release objects
- ▶ Can do most activities of daily living by themselves, but may need assistance with more difficult tasks
- ▶ May also be able to drive an adapted vehicle
- ▶ Little or no voluntary control of bowel or bladder, but may be able to manage on their own with special equipment



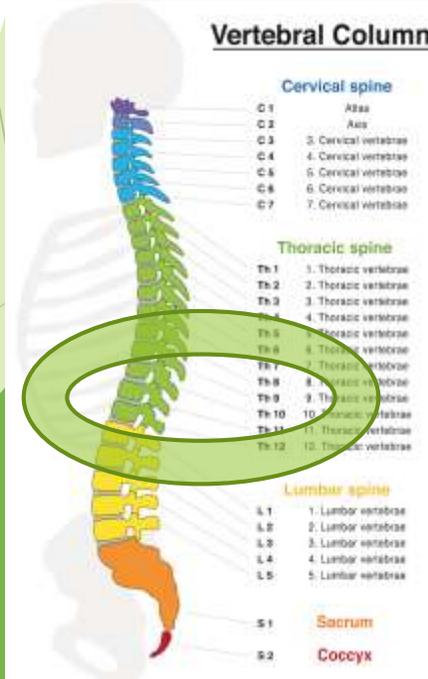
Upper Thoracic level (T1-5)

- ▶ Corresponding nerves affect muscles, upper chest, mid-back and abdominal muscles.
- ▶ Arm and hand function is usually normal.
- ▶ Injuries usually affect the trunk and legs(also known as paraplegia).
- ▶ Most likely use a manual wheelchair
- ▶ Can learn to drive a modified car
- ▶ Can stand in a standing frame, while others may walk with braces



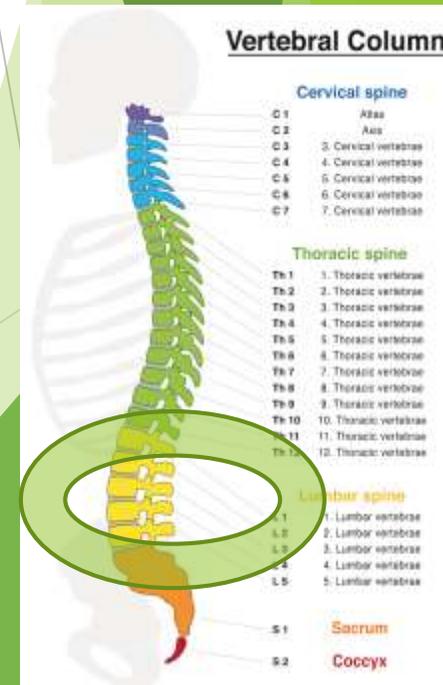
Lower Thoracic level (T6-12)

- ▶ Nerves affect muscles of the trunk (abdominal and back muscles) depending on the level of injury.
- ▶ Usually results in paraplegia
- ▶ Normal upper-body movement
- ▶ Fair to good ability to control and balance trunk while in the seated position
- ▶ Should be able to cough productively (if abdominal muscles are intact)
- ▶ Little or no voluntary control of bowel or bladder but can manage on their own with special equipment
- ▶ Most likely use a manual wheelchair
- ▶ Can learn to drive a modified car
- ▶ Some can stand in a standing frame, while others may walk with braces.



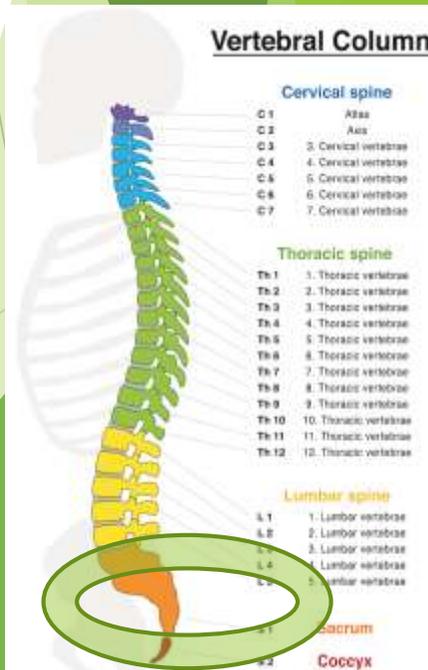
Lumbar Nerves (L1-5)

- ▶ Injuries generally result in some loss of function in the hips and legs.
- ▶ Little or no voluntary control of bowel or bladder, but can manage on their own with special equipment
- ▶ Depending on strength in the legs, may need a wheelchair and may also walk with braces



Sacral level (S1-5)

- ▶ Injuries generally result in some loss of function in the hips and legs.
- ▶ Little or no voluntary control of bowel or bladder, but can manage on their own with special equipment
- ▶ Most likely will be able to walk



COMPLICATIONS OF SCI/D AS THEY RELATE TO CARE/NEEDS

- ▶ Bladder control (increased risk of UTI's, kidney infection)
- ▶ Bowel control
- ▶ Respiratory System (increased risk of pneumonia)
- ▶ Muscle Tone (spasticity/uncontrolled tightening or flaccidity/soft & limp)
- ▶ Depression (life changes and Pain)
- ▶ Pain (nerve, muscle or joint)
- ▶ Sexual Health (sexual function, fertility)
- ▶ Skin Sensation (pressure sores, hot & cold)
- ▶ Circulatory Control (low BP, swelling, blood clots, life threatening

AUTONOMIC DYSREFLEXIA or HYPERREFLEXIA-
(rise in blood pressure coupled with low heartbeats)

TRANSITION TO HOME

LOOKING BEYOND THE HOSPITAL WALLS

- ▶ Responsibility of the Interdisciplinary Care Team in preparation for discharge
 - ▶ Patient must be fully involved in the discharge planning process for a smooth community integration
 - ▶ Family and or Caregiver must be involved, trained & educated with an understanding of how the level of the injury will determine the needs of the individual.
 - ▶ Adaptive & Medical Equipment (wheelchair/manual or power, shower chair, environmental controls)
 - ▶ Home Modifications (ramps, bathroom, doorways) These are often costly and not covered by insurance
 - ▶ Getting Around (vehicle adaptation if possible, SCAT) Adapting a vehicle is expensive as is buying a new adapted vehicle which may not be possible. Assistive Technology for those with the ability to drive and training from a certified rehabilitation specialist who will also assess safe driving ability.

TRANSITION TO HOME LOOKING BEYOND THE HOSPITAL WALLS continued...

- ▶ Health Needs (medications, self-care & self-awareness) AD recognize symptoms such as a severe headache, high blood pressure, sweating. Bladder Care proper use of catheter. Bowel Care diet and medications. Check your skin daily. Monitor water temperature 120 degrees max. Dysphagia/difficulty swallowing. May need RN, PCA, ongoing therapy. Stay hydrated.
- ▶ Finances (loss of income, medical bills) Can you return to work? Train for a different job? Apply for benefits such as Medicaid and Social Security. This can be started while individual is in the hospital. May qualify for presumptive disability. COBRA
- ▶ Staying Active (support groups, recreation) Adaptive Sports
- ▶ Resources and Supports (Peer Mentor)
- ▶ Discuss Alternative Living Situations (if necessary) Skilled Nursing & Rehabilitation, Senior Housing

HOME SWEET HOME

What they didn't teach me in rehab

- ▶ Don't rush the healing process (inpatient & outpatient)
- ▶ You can use your injury as a catalyst for change (new job, education, hobby)
- ▶ Research SCI (seating options, coping, doctors & specialists)
- ▶ Your wheelchair is your “new legs” try to embrace it
- ▶ Focus on what you are able to do
- ▶ “Before your injury, you could do 10,000 things. Now you can do 9,000. So are you going to worry about the 1,000 things you can't do or focus on the 9,000 things you can do?”
- ▶ Work on your wellness and keeping up strength through exercise
- ▶ Become as independent as possible (Mitrofanoff procedure & in-dwelling catheterization for bladder control)
- ▶ You are a sexual person
- ▶ You are a survivor and resilient
- ▶ Your new journey begins be creative

Advice to patients for the first day home

- ▶ Learn to accept privacy at home may be a little skewed for a while
- ▶ Don't expect too much of yourself and take it one day at a time
- ▶ Create your own methods and procedures
- ▶ Talk to people with similar condition
- ▶ Remove things which may upset you
- ▶ Be accepting of change
- ▶ Be patient with your loved ones
- ▶ Be at peace with asking for help
- ▶ Enjoy being home after a spinal cord injury

COPING STRATEGIES

- ▶ Adopt a positive attitude
- ▶ Allow yourself to grieve
- ▶ Acknowledge the difference of “illness” vs “disability”- **You are not sick!**
- ▶ Your injury does not define you as a person
- ▶ Using adaptive equipment at home or work makes you more functional and independent
- ▶ Recognize some degree of dependency will lead to more independence. A Personal Care Aide (PCA) will give you more freedom to be out.
- ▶ Always be Hopeful but also be Realistic
- ▶ Make new goals “your new normal”
- ▶ Join a support group or search online

Helpful Resources

Benefits.gov

- ▶ Search for government benefits by state; www.benefits.gov

Christopher & Dana Reeve Paralysis Resource Center

- ▶ Promoting the health and wellbeing of people living with spinal cord injury, mobility impairment and paralysis by providing comprehensive information, resources and referral services
- ▶ www.paralysis.org | 800-539-7309

Family Voices

- ▶ Aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities
- ▶ www.familyvoices.org/states | 888-835-5669

National Spinal Cord Injury Association

- ▶ Leading the way in maximizing the quality of life and opportunities for people with spinal cord injuries and diseases since 1948
- ▶ www.spinalcord.org | 800-962-9629

NTAF

- ▶ NTAF helps families address financial hardships arising from uninsured medical expenses related to catastrophic spinal cord or brain injury. Established in 1983 by medical professionals, NTAF is a 501(c)(3) nonprofit organization that provides expert fundraising guidance to patients, families and communities nationwide, while offering fiscal accountability for funds raised.
- ▶ www.ntafund.org | 800-642-8399

Office of Disability Employment Policy

- ▶ Federal government agency within the U.S. Department of Labor helping ensure that people with disabilities have equal employment opportunities
- ▶ www.dol.gov/odep | 866-487-2365

Unite 2 Fight Paralysis

- ▶ Working to unite and empower the international spinal cord injury community to cure paralysis through advocacy, education, and support for research
- ▶ www.u2fp.org | 888-564-2228
- ▶ Project Walk
 - ▶ Provides a customized recovery program to meet individuals needs

HELPFUL RESOURCES

Empowerment Project - A program designed to foster healthy aging and quality of life after an SCI.

▶ www.empowersci.org

SILO (Suffolk Independent Living Organization) - Provides advocacy, education, empowerment

▶ www.siloinc.org

ACCES-VR (Adult Career & Continuing Ed Services) - Provides vocational rehabilitation, education, career development, job-coaching & adaptive driver training.

▶ www.access.nysed.gov/vr/Hauppauge-district-office