

Some Walk, I Roll. Let's Learn Why.



International Center for Spinal Cord Injury
at Kennedy Krieger Institute



CHRISTOPHER & DANA
REEVE FOUNDATION
TODAY'S CARE. TOMORROW'S CURE.®

Acknowledgments

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Recommended Reading Age: 6 to 12 years old

This guide has been prepared based on scientific and professional literature. It is presented for educational purposes; it should not be construed as medical diagnosis or treatment advice. Please consult a physician or appropriate healthcare provider for questions specific to your situation

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You might be reading this book because you, a friend or family member have a spinal cord injury, or maybe you just want to learn more. For whatever reason you are here, welcome.

As you read this book you will meet kids and adults living with spinal cord injury. They are excited to tell you a little about themselves.



When you see an “Activity Break” sign, you can take a break and do a fun activity.



At the end of the book is a section called “Behind the Scenes.” This section provides more information about the spinal cord, spinal cord injury and the effects on the body.

The Spinal Cord

Have you ever heard of a spinal cord?

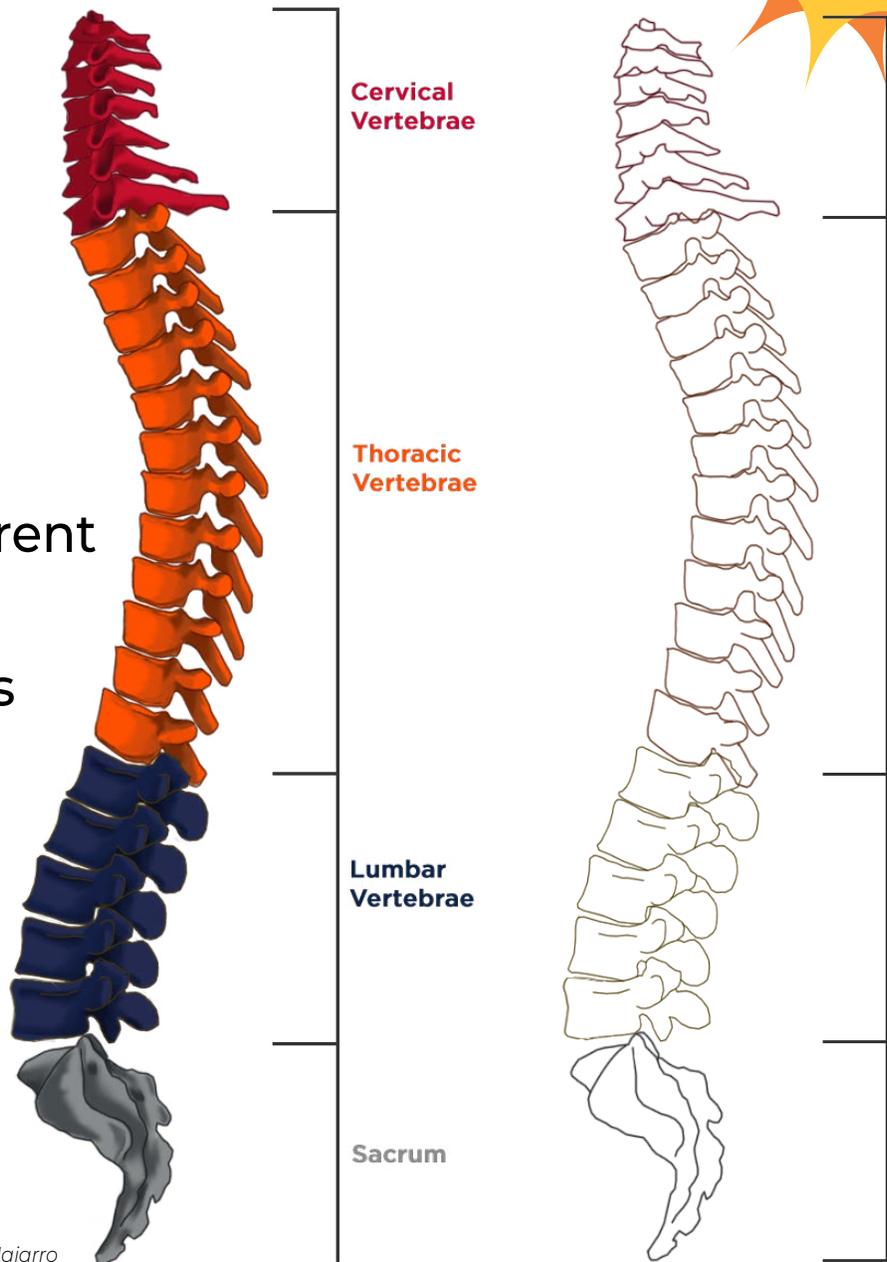
Everyone is born with a spinal cord. You have one, your parents have one, and your friends have one too!

Where is the spinal cord?

It is in your back.
You can't see it because it is inside your body.

There are four sections to the spinal cord. Each section sends messages to different parts of the body.

Color the sections of the spinal cord.



Credit: Miguel A. Najarro

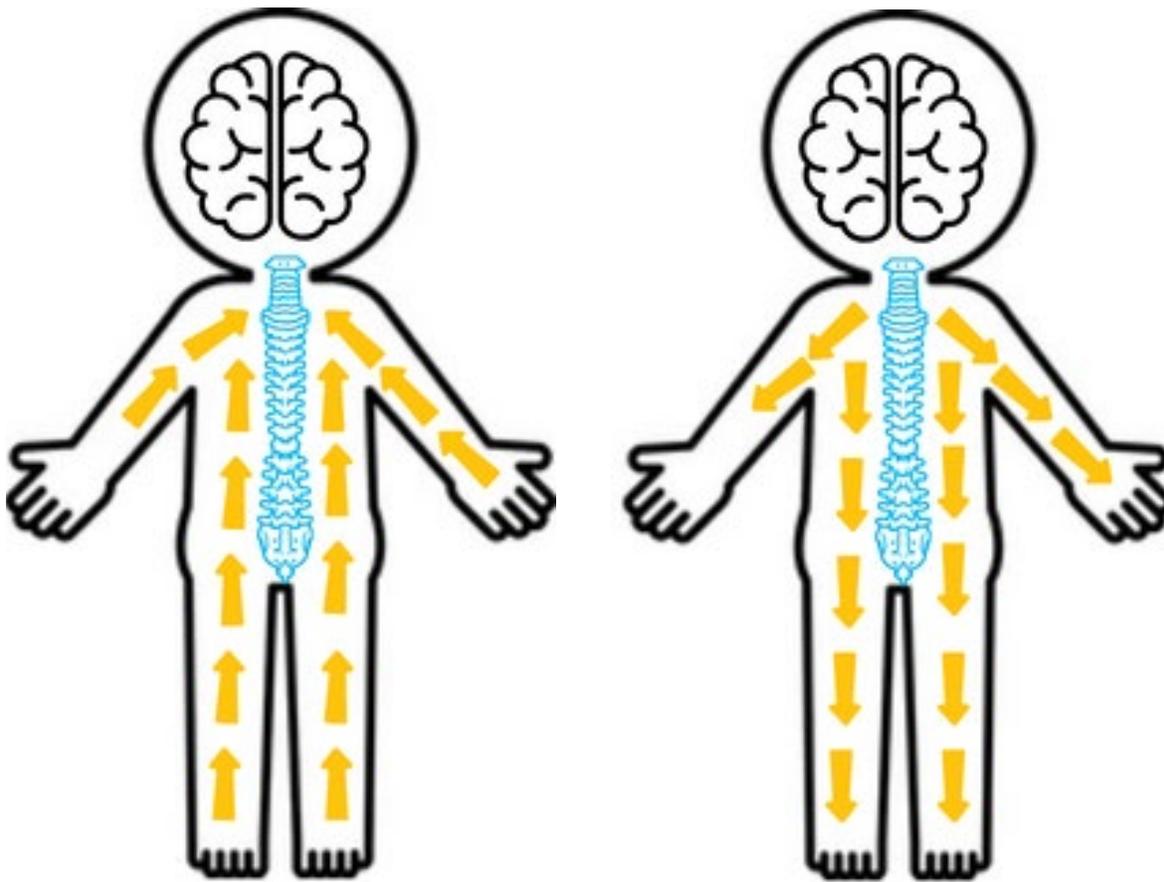
What does the spinal cord do?

The spinal cord is a very important part of the body—it has a very big job!

The spinal cord's job is to send messages between the brain, and the rest of your body.

Messages from the brain tell your body how to move your arms, walk and even play games!

Other messages tell the brain what your body is feeling, such as hot and cold, hard or soft, and pain if you are hurt.



What causes a spinal cord injury?

There are different reasons a spinal cord injury might happen. Most spinal cord injuries are caused by accidents or illness. Some children are born with spinal cord injury.



I have transverse myelitis.



I have Acute Flaccid Myelitis (AFM).



I had a tumor that injured my spinal cord.



I was born with my spinal cord injury.



I was in an accident.

What is a spinal cord injury?

When the spinal cord is hurt, it has a hard time sending messages back and forth between the brain and the body. This is called a “spinal cord injury.”

Some people have trouble moving their legs or standing. Others have trouble moving their arms or hands making it hard to do things like drink from a glass.



Some people have trouble breathing—every injury is different.

To learn about living with a spinal cord injury, most people go to **rehabilitation**.

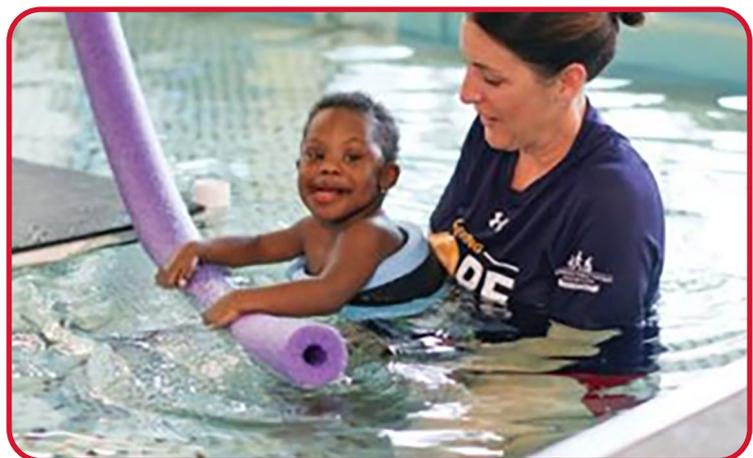


Rehabilitation

Rehabilitation is a big word, so let's talk about what that means. Most people say "**rehab**" for short. Rehab is a place where therapists, doctors, and nurses work together to help people with spinal cord injuries and their families learn about spinal cord injury and new ways to do things that are important to them.



During rehab people go to **therapy** to get stronger and learn how to move their body and keep it healthy. They also learn new ways to be **independent**.



What does being independent mean?

Some might think being **independent** means doing everything all by themselves. But everybody needs a little bit of help, right?

Being independent means trying new ways to do things and doing as much as you can for yourself.

It also means knowing that it is ok and important to ask for help when needed.



A volunteer helps me ski down the mountain.



My family helps me get ready in the morning.

Should I help someone with a spinal cord injury or other disability?
Only if they ask for help. Don't assume that someone needs help. They may have their own way of doing things.

Helping Hands

Some people with spinal cord injury may need an extra set of helping hands when doing everyday activities such as getting ready for school, using the bathroom, or playing a game. Service dogs can also help.



Not all helping hands are human hands. My service dog, Teddie, opens doors for me.

My little brother lends a hand to help me eat.



Another way people can be more independent is by using **adaptive equipment**.

Adaptive Equipment

Getting Around

Most people don't have to think about how they are going to move around and go places.

Someone with a spinal cord injury might use different types of equipment such as wheelchairs, crutches or leg braces to help them move around.



Can I touch someone's wheelchair or other adaptive equipment?

Not unless the person asks you to or gives you permission. It is important to remember that everyone has personal space. A person's wheelchair or crutches is part of their personal space.

Adaptive Equipment

Daily Activities

There are many handy tools that can help people be more independent in daily activities.

Depending on what the day looks like or what a person enjoys doing, there are many different tools to help.



Grabbing what I need with my reacher.



Adaptive equipment lets me feed myself.



My sink is lower and does not have a cabinet so I can roll under it.



Baby gets to ride the stair glide with dad.

Accessibility

Accessibility means making sure that everyone, of any ability can join in without barriers. There are many ways to make the world more accessible for everyone.

I roll my wheelchair up a ramp to get in and out of my car.



We have a very long ramp to get into our house.



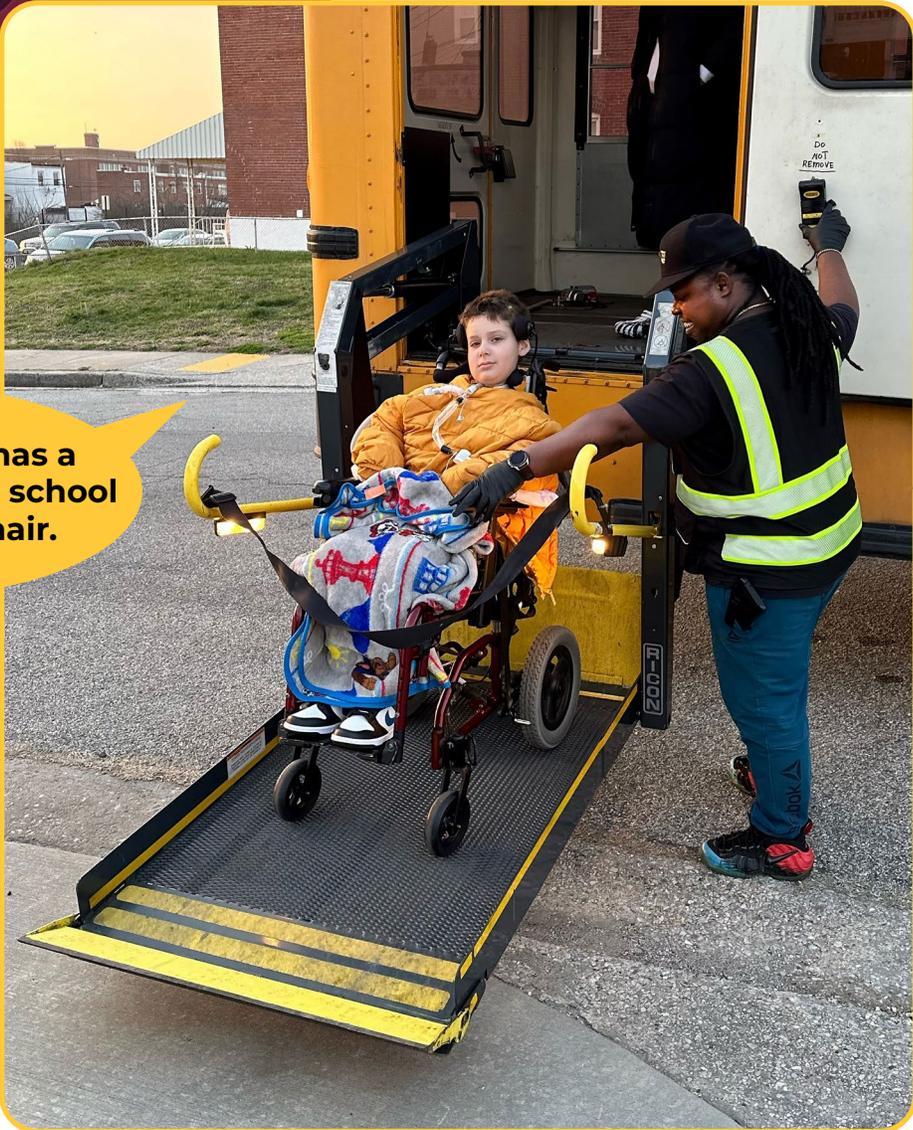
Since I can't move my arms, I use my voice and my mouth stick to work at my computer and do things like turn the lights on and off.



Curb cuts make the neighborhood more accessible for everyone.



I drive my car while sitting in my wheelchair and use my hands instead of my feet to brake or speed up.



My school bus has a lift so I can ride to school in my wheelchair.

Let's Play

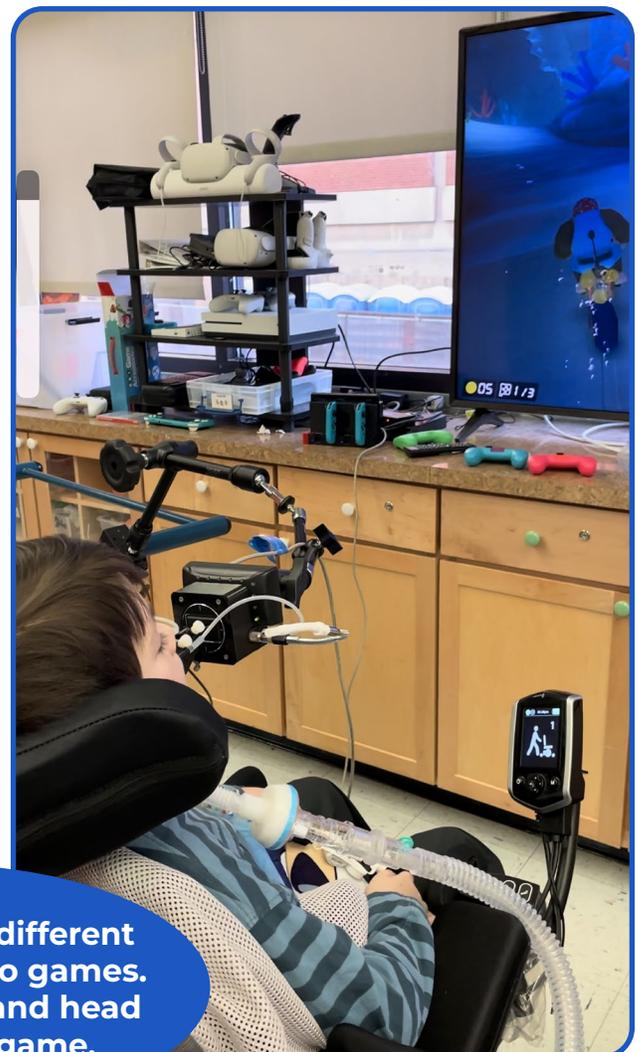
Who doesn't like to play, right? There are lots of adaptive equipment, tips, and tricks to help everyone play!

Not all people with spinal cord injuries play the same way or enjoy the same things. Everyone has different interests!

Let's see how some kids play.



Painting lets me express myself.



There are lots of different ways to play video games. I use my mouth and head to control the game.



I can't move my arms or legs, so I paint with a "mouth stick" that I hold with my teeth.

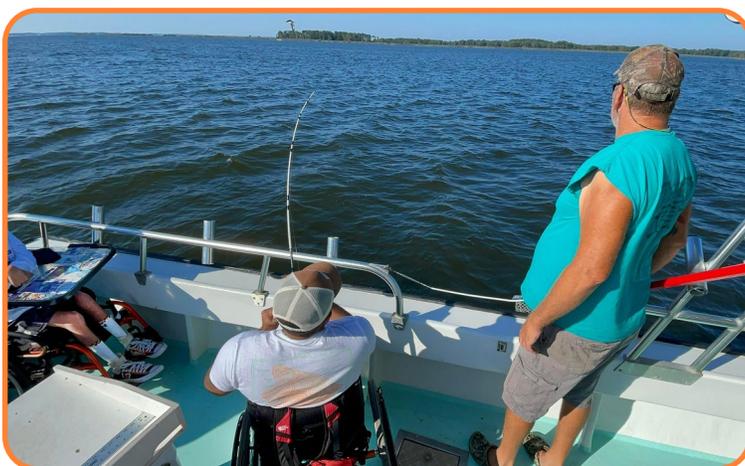


I use my stander to play the drums.

Adapted Activities and Sports

There are many adapted sports and activities for people with disabilities.

Being active is a great way to stay strong, improve self-confidence and meet other people with spinal cord injuries.





Adapted Activities and Sports





A large, empty rectangular area with a rounded bottom-right corner, outlined in orange, intended for drawing a picture of a favorite activity.

Draw a picture of you doing your favorite activity!

Changes After Spinal Cord Injury

While spinal cord injury can cause many changes to how the body works, it does not change who the person is or how they think.

They can talk, laugh, go to school or work and have fun. They can still care about their family and friends, and they still need people to care about them.

Living with a spinal cord injury or having someone close to you living with a spinal cord injury may bring up lots of different feelings.

I feel silly.

content happy sad scared shy

guilty angry annoyed relaxed confused

surprised crying bored tired disgusted

**ACTIVITY
BREAK**

Circle how you feel when you think about spinal cord injury. You may have lots of emotions, so circle as many as you want.

Finding Support

It is important to remember that you are not alone. There are lots of people in your life who can listen to you, offer support, and help you understand these feelings.

Your support team might include family members, friends, therapists, teachers, doctors or nurses, counselors, or other people with spinal cord injury.



Who is on my support team?

1. _____
2. _____
3. _____
4. _____
5. _____

Everyday Life

People with spinal cord injury like to do lots of things. They go to school or work, drive a car, travel, make new friends and do things with their family.

Sometimes figuring out how to do something in a new way can be hard. Meeting others with spinal cord injury or other disabilities can be a great way to help figure things out.



Asking someone about their spinal cord injury.

If you meet someone with a spinal cord injury it is ok to ask them about their injury in a nice way. It is not very nice to ask personal questions like how they go to the bathroom. It is important to remember, it is up to them to decide what they want to share with you.

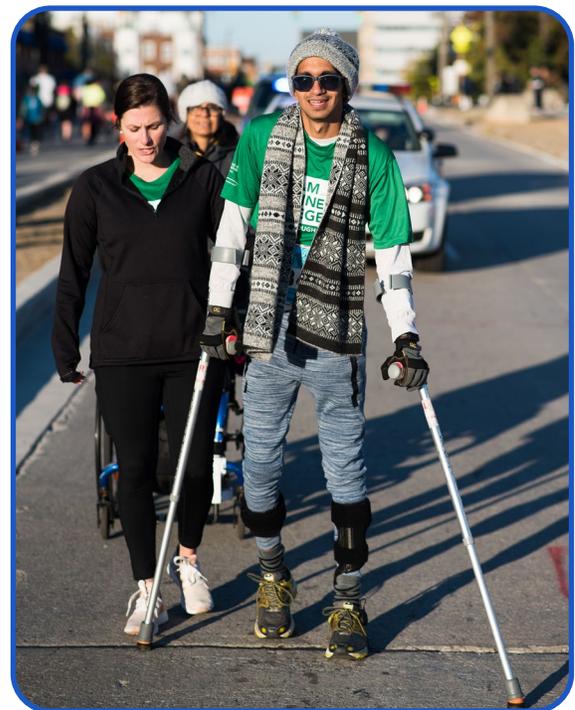


Photo Credit: Leisa Thompson



Living with Spinal Cord Injury

As you can see from this book, with determination, an adventurous spirit, adaptive equipment, and a bit of help from others, people with spinal cord injury lead happy and active lives.

The best part is everyone gets to decide what is important to them and how they want to live their life.

ALL ABOUT ME



My name is _____ and I am _____ years old.

One word that best describes me: _____

Things I am good at: _____

Things I need help doing: _____

My superpower is: _____

Something important to remember about SCI is: _____

When I grow up, I want to: _____



What to Know... Levels and Function of the Spinal Cord

Have you ever heard someone say they have a **C5 spinal cord injury** or a **T8 spinal cord injury** and wondered what that means? Well, let's learn what that means.

The **spinal cord** is a bundle of cells called **neurons** that start at your brain and travel all the way down your back. These neurons are connected to many nerves which travel all through the body. Nerves carry messages to and from the brain using tiny **electrical signals** that tell the body how to move and feel.

The spinal cord is inside of your **spinal canal**, surrounded by the vertebral bones, ligaments, and muscles to keep it strong.

There are 4 parts of the spinal cord that get their names from the **vertebral bones** that surround it. Each vertebrae have a letter and a number that tells the level of the spinal cord injury.

The **cervical spinal cord (C) is numbered C1-C7**. The cervical cord sends signals to muscles that move your arms, back and legs. It also carries signals to a big muscle called the diaphragm that helps you breathe.

The **thoracic spinal cord (T) is numbered T1-T12**. The thoracic cord sends signals to the muscles in the back used to sit up and balance and move the legs and feet. This part also sends signals to the abdominal muscles that help you breathe and cough.

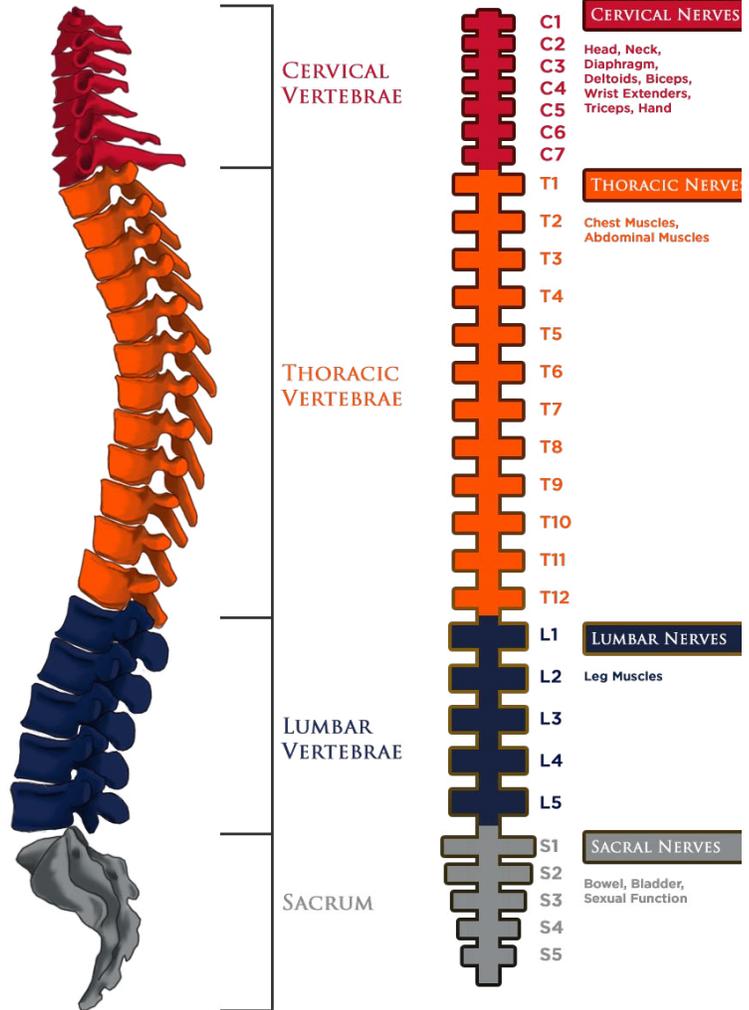
The **lumbar spinal cord (L) is numbered L1-L5**. The lumbar cord sends signals to the muscles that move your hips, legs, and feet.

The **sacral spinal cord (S) is numbered S1-S5**. The sacral cord sends signals to muscles in the legs and the muscles that are used to go to the bathroom.

What to Know... Types of Spinal Cord Injury

There are words to describe a spinal cord injury.

Quadriplegia (quad) or Tetraplegia: An injury to the neck or cervical spinal cord. People with quadriplegia have trouble moving and feeling their arms and legs. Some people have trouble breathing and need a machine called a ventilator or diaphragm pacers to help them breathe.



Credit: Miguel A. Najarro

Paraplegia (para): An injury to the back or thoracic spinal cord and lower. People with paraplegia have strong arms but have trouble moving and feeling in the lower half of the body and both legs.

There are also words to describe how much signal can travel through the injured spinal cord.

Complete spinal cord injury: No signals from the brain for movement or feeling can travel through the level of the spinal cord injury.

Incomplete spinal cord injury: Some signals for movement or feeling can travel from the brain through the level of the spinal cord injury.

What to Know...

Changes After Spinal Cord Injury

After a spinal cord injury there are changes to how the body works. Let's learn about some of these changes.

Autonomic Dysreflexia

Have you heard anyone talking about Autonomic Dysreflexia (AD for short) and wondered what that means? AD is something that happens to people with a complete or incomplete spinal cord injury at the T6 level or higher. People with SCI can't feel parts of their body and may not know something is wrong, but the body does, and it sends an alarm, AD. AD can signal the need to use the toilet, that braces are too tight, that there is an infection or that toenails need trimming! The first signs are usually feeling hot and getting a red flushed face. Some people get goose bumps. Another sign is a headache that starts small and get worse. When someone has any of these signs, they may need help to figure out what is wrong and take care of it. AD can become an emergency if ignored.

Muscle Spasms

A muscle spasm is when a muscle moves by itself. A spasm can look like a twitch or a jump in the arms or legs. Muscle spasms help keep muscles strong and can sometimes help with standing or walking.



Temperature Control

In the summer people with spinal cord injury often need extra help keeping cool, especially when playing outside. That does not mean they can't play outside; it just means they may need a squirt bottle, fan or cool cloth around the neck to stay cool. In the winter it is good to dress in layers to keep the temperature just right.



Pressure Reliefs

When someone can't easily move or feel, they will need to do something called a pressure relief to keep their skin healthy. Most people will shift positions by leaning forward or side to side when they are sitting still. People using power wheelchairs will tilt their wheelchair back.



Nerve Pain

Nerve pain usually happens below the level of the spinal cord injury. Some people describe it as the feeling you get when your leg or arm falls asleep. Others

say it feels sharp or burning. There are medicines that can help make this pain better.

Using the Toilet

Let's just say everyone poops and pees!! Some people may need assistive tools like a catheter after a spinal cord injury.



Having Children

You might wonder if someone with a spinal cord injury can have a baby or father a child. The answer is yes, they can.



General Paralysis and Spinal Cord Injury Information

Christopher & Dana Reeve Foundation's National Paralysis Resource Center

www.ChristopherReeve.org | 800-539-7309

Siegel Rare Neuroimmune Association

<https://wearesrna.org> | 855-380-3330

Spinal Cord Injury Information Network

www.spinalcord.uab.edu | 205-934-3450

Unite 2 Fight Paralysis

www.u2fp.org | 888-564-2228

Adapted Sports, Play and Leisure

Able Gamers

<https://ablegamers.org>

Craig Hospital: Resources for Universal Video Game Access

<https://craighospital.org/inpatient/assistive-technology/adaptive-gaming>

Move United

<https://moveunitedsport.org>

Online Resources

Facing Disability

<https://facingdisability.com>

SPINALpedia

<https://spinalpedia.com>

Parenting with a Disability

National Research Center for Parents with Disabilities

<https://heller.brandeis.edu/parents-with-disabilities/about/index.html>

SCI Parenting from the Spinalis Foundation

<https://sciparenting.com/>

Through The Looking Glass

<https://lookingglass.org>

Education Resources

Christopher & Dana Reeve Foundation: Education for Children Living with Paralysis.

<https://www.christopherreeve.org/todays-care/living-with-paralysis/for-parents/education-for-children-living-with-paralysis-1>

Kennedy Krieger Institute: A Guide for School Personnel Working with Students with Spinal Cord Injuries.

<https://www.kennedykrieger.org/sites/default/files/library/documents/community/specialized-health-needs-interagency-collaboration-shnic/guide-school-personnel-spinal-cord-injuries.pdf>

Books for Adults

Being Heumann: An Unrepentant Memoir of a Disability Rights Activist by Judith Heumann and Kristen Joiner (2021)

How I Roll: Life, Love, and Work After a Spinal Cord Injury by J. Bryant Neville (2012)

Just One of the Kids: Raising a Resilient Family When One of Your Children Has a Physical Disability by Kay Harris Kriegsman and Sara Palmer (2013)

Look Both Ways by Brooke Ellison (2021)

Mindfulness for Carers: How to Manage the Demands of Caregiving While Finding a Place for Yourself by Cheryl Rezek. (2015)

Paralysis Resource Guide Christopher & Dana Reeve Foundation (2023). Free download available at www.ChristopherReeve.org/Guide.

Spinal Cord Injury: A Guide for Living by Sara Palmer, Kay Harris Kriegsman, et al. (2008)

Spinal Cord Injury and the Family: A New Guide by Michelle J. Alpert, MD, Saul Wisnia, et al. (2008)

Yes, You Can!: A Guide to Self-Care for Persons with Spinal Cord Injury. Fourth Edition. Edited by Stephen P. Burns, MD and Margaret C. Hammond, MD. (2009). Free download available at Paralyzed Veterans of America <https://pva.org/>.

Books for Children

Preschool

The Abilities in Me: Spina Bifida by Gemma Keir (2020)

Dad has a Wheelchair by Ken Jasch (2014)

Mama Zooms by Jane Cowen-Fletcher (1995)

We Can Go Anywhere: My Adventures on Daddy's Chair
by Glen Dick (2016)

School Age

Alfredo's Magic Wand: A Children's Book About Acute Flaccid Myelitis by Rachel Scott and Laura Grimmer (2021)

Ali and the Sea Stars by Ali Stroker (2022)

All The Way to The Top: How One Girl's Fight for Americans with Disabilities Changed Everything by Annette Bay Pimentel (2020)

Dr. Dinoh's Kids: A Learning and Activity Book for Pediatric Spinal Cord Injury by Jennifer Wu, MD (2023)

Ed Roberts: Father of Disability Rights by Diana Pastora Carson (2013)

Gus Wheelchair Races by Tracilyn George (2024)

Just Ask!: Be Different, Be Brave, Be You by Sonia Sotomayor (2019)

Making a Difference (Young Change Makers series) by Stacy C. Bauer (2021)

No Time for the Moon by Eric Arnold and Diane Roston.
Free download from SRNA at: <https://wearesrna.org/no-time-for-the-moon>

The Chance to Fly by Ali Stroker and Stacy Davidowitz (2021)

We Move Together by Kelly Fritsch, Anne McGuire and Eduardo Trejos (2021)

Teen

Demystifying Disability: What to Know, What to Say, and How to be an Ally by Emily Ladau (2021)

Rolling Warrior: The Incredible, Sometimes Awkward, True Story of a Rebel Girl on Wheels Who Helped Spark a Revolution by Judith Heumann with Kristen Joiner (2021)

Spinal Cord and Nerves: Injury, Illness, and Health by Steve Parker (2009)

The Oracle Code: A Graphic Novel by Marieke Nijkamp (2020)



International Center for Spinal Cord Injury
at Kennedy Krieger Institute



We're here to help.
Learn more today!

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