The Paralysis Center

PATIENT GUIDE

Understanding Spinal Cord Injuries

Justin M. Brown M.D.

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1. Introduction

In 2017, in partnership with Massachusetts General Hospital, Harvard Medical School and the Spaulding Rehabilitation Hospital, we founded the Paralysis Center, a world-class patient treatment and medical research center for all forms of paralysis.

Because we treat a significant number of paralyzing injuries, we've been able to develop some of the most advanced surgical strategies available today. These innovative techniques are providing real results for patients in reversing paralysis and restoring function, and we're helping educate our medical colleagues around the world by sharing our knowledge.

Spinal cord injuries are complex and require the expertise of paralysis specialists across several disciplines. From diagnostic evaluation to surgery, to post-surgical rehabilitation, you're going to need a team of specialists working together with you.

We realize there is a great deal of information for you to absorb about your injury and the options available. It's also very difficult to find up-to-date and medically accurate information about the best way to treat spinal cord injuries. That's why we've written this Patient Guide to help you.

This Guide was written for anyone who has suffered a spinal cord injury or whose loved one has suffered a spinal cord injury. In the following pages, we will take you through the anatomy of a spinal cord injury and explain everything to you as I would if you were a first-time patient seeing me in my office. We'll discuss what to expect when you see your specialist and the surgical options that may be available to you.

Right now, you probably have many more questions than answers. We hope this guide answers all your questions – but if it doesn't, I've provided my contact information at the back of this book.

We have a lot to discuss, so let's get started.

Justin M. Brown M.D.
Director & Founder
The Paralysis Center

2. Understanding Paralysis

Paralysis is the loss of one's ability to move one or more parts of the body in a useful way. This loss of movement is usually accompanied by loss of sensation and is typically the result of an illness or traumatic injury to one's nerves, spinal cord or brain. It can affect a single muscle, an entire limb, one side of the body, both legs, or even all four limbs.

Paralysis can be a permanent condition, meaning the body cannot repair the damage on its own without intervention. Paralysis can also be temporary, meaning the body can potentially recover on its own.

There are two broad categories of paralysis that are based on where within the nervous system the injury occurs: *upper motor neuron* and *lower motor neuron* injuries.

a. Understanding Motor Neurons

If you've had a spinal cord injury, you've probably learned more about the spinal cord than you ever thought possible. Chances are, though, you've never heard of motor neurons. These are key players in your brain-body connection.

Motor means *movement*. Motor neurons are a specialized type of neuron found in the brain and spinal column. These cells play a primary role in the control of movement and help maintain muscle tone. Motor neurons are classified as either upper or lower motor neurons, depending on their location and function.

Upper motor neurons originate in the brain and travel downward through the spinal cord to connect with lower motor neurons to set them in motion. They are the original source of the command to move. The lower motor neurons have a cell body that lives within the spinal cord but they extend their processes, or axons, out of the spinal cord, through the peripheral nerves and ultimately, connect to particular muscles. They are the final pathway that actually drives the movement that occurs.

When upper motor neurons are injured, this communication breaks down. The brain can't tell the muscles what to do effectively. The lower motor neuron remains connected to the muscle and tone remains, but the brain's ability to communicate an effective message to the spinal cord to move that muscle is impaired. An upper motor neuron injury can be incomplete and result in weakness with increased tone and more difficulty moving the limb. The movements can become clumsy and uncoordinated. Alternatively, it can be a complete injury, with no ability to move those muscles. In that case the only movements those muscles will make on their own will be spasms, or, reactions that are not intentional. They will often have increased tone and may be difficult to position. Some common causes of upper motor neuron injury are stroke, spinal cord injury, and multiple sclerosis. These injuries do not require early surgery to repair.

Lower motor neurons are found in the brainstem and spinal cord. They are the connection between one's spinal cord and one's muscles. Essentially, they receive the messages from the brain and relay the message directly to the muscles via the peripheral nerves. Some causes of lower motor neuron injury include injuries to the spinal cord (specifically where those neurons live), injuries to the cauda equina, injuries to the peripheral nerves, or even polio. These injuries do require early surgery – time is of the essence!

Spinal cord injuries are unique in that they typically demonstrate both types of injury – lower motor neuron where the site of impact occurred, and, upper motor neuron affecting all of the muscle groups below that region. For example, a cervical spinal cord injury typically has some lower motor neuron injury affecting the hands, but the legs remain with tone and spasticity due to the upper motor neuron component of the injury.

b. Understanding Your Spine's Anatomy

The spinal cord is a long, cylindrical portion of the central nervous system that is more like the brain than the peripheral nerves. This structure extends about 2/3rds of the way down your back. It originates in the brain stem, passes through an opening in the skull known as the *foramen magnum* and enters the spinal column at the first cervical vertebrae. Your spinal cord is enclosed and protected by your backbone, the vertebrae of your spine, that create a bony canal in which the cord rests. The spinal cord continues down your back, terminating in the upper portion of your lumbar (lower back) region. There, the nerve roots branch off into what's known as the *cauda equina*, so named because the nerve roots drape together within the spinal canal, taking the shape of a horse's tail.

The spine is divided into four areas: cervical, thoracic, lumbar and sacral.

- The **cervical** region refers to the seven bones of the neck. Injury to this region can cause weakness of the arms and legs.
- The **thoracic** region refers to the twelve bones of the back - all the bones that have ribs attached to them. Injury to this region can result in loss of leg function.
- The **lumbar** region includes the five bones of the lower back. Injury in this region typically results in a cauda equina injury and thus is a lower motor neuron injury.
- The **sacral** region or tailbone area. Injury at this level can disrupt bowel and bladder function

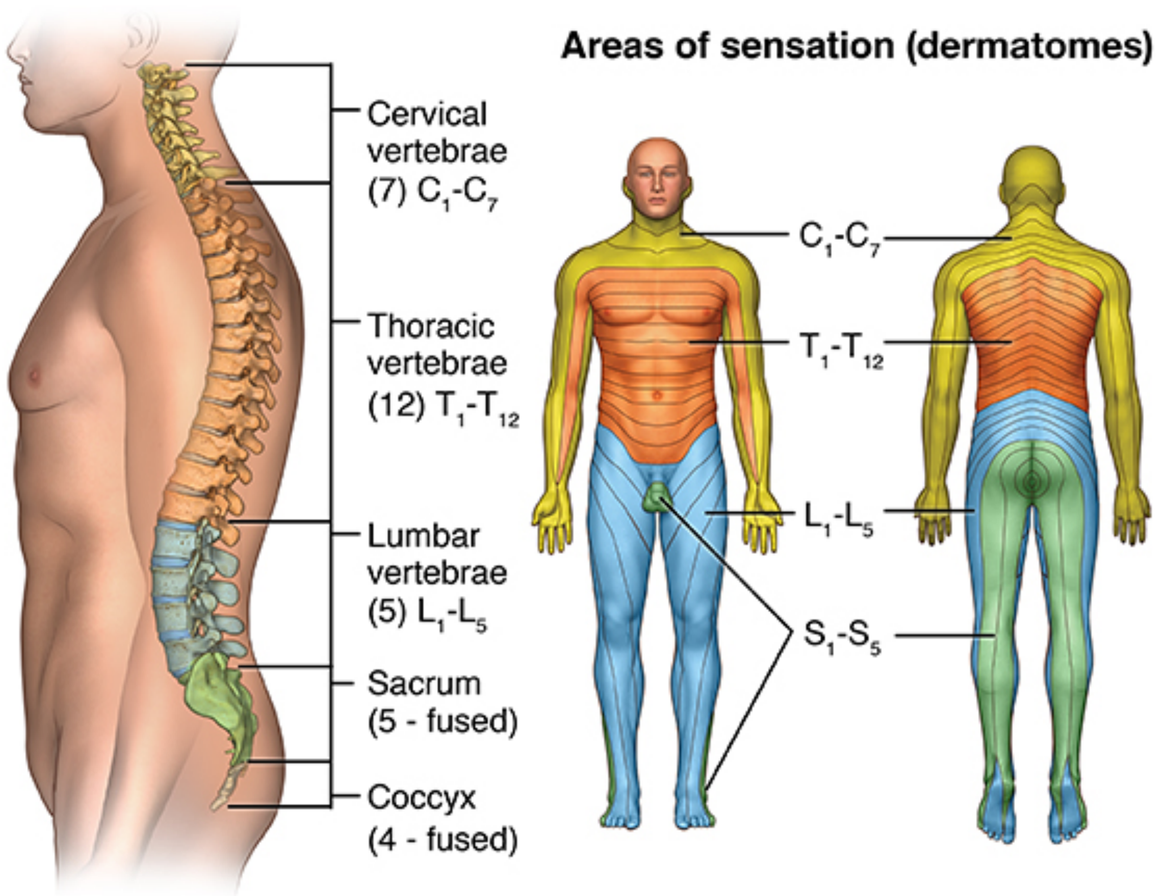


Figure 1. Regions and vertebrae of the spine. There are 4 major regions of the spine. Nerve roots which emerge between the vertebrae at each level provide sensation to specific areas of skin and function to specific muscles.

All along the spinal cord there are nerve roots which exit the spinal cord, becoming the peripheral nerves. These peripheral nerves connect the central nervous system to the muscles and skin. Whenever a message from the brain is sent to the spinal cord, it must be transmitted from the spinal cord, through the peripheral nerves, until they reach the target muscle and that muscle fiber contracts. The peripheral nerves contain sensory fibers whose cell body is located in what's called the spinal or *dorsal root ganglia*. These ganglia are small swollen portions of the nerve roots right after they leave the spinal cord. These sensory fibers extend from the ganglion in 2 directions. They send a process through the spinal nerve root into the spinal cord to convey sensory information back to the brain. The other process reaches out to the body to receive sensory information to convey back to the spinal cord.

c. *Understanding Your Spinal Cord Injury*

Now that you have some information about your spine, let's talk about spinal cord injuries and what they mean for functionality (one's ability to function normally).

Spinal cord injuries are usually the result of a high impact trauma, most commonly a car accident. We also see a lot of patients who've had a diving accident, who have fallen from a tree, dove into shallow water, or had a surfing or motorcycle accident. Because the neck is much more mobile than the back, it is particularly susceptible to a break in the neck bones and therefore, a resulting crushing of the portion of the spinal cord within the bony canal in that location.

The cervical spinal cord is the part of the spinal cord that conveys function to the arms and hands. When a patient has an injury to their cervical spine, injuring their spinal cord that is within its bony canal, they will lose some function depending upon which area is injured and how severe that injury is.

The brain communicates through the spinal cord and then out to peripheral nerves to get our body to function. So, at the level communication is disrupted, everything below that will be impaired, or sometimes completely absent of function. Everything above the site of injury generally retains normal function. This is an important factor as you'll see, as we talk more about the types of injury and treatment options.

Spinal injuries are graded on a scale developed by the American Spinal Injury Association (ASIA). This scale offers a standardized way of classifying and describing the severity of injury.

- An ASIA **A injury** means that there is no motor or sensory function below the level where the spinal cord is injured. You can't feel or move anything below the injury level.
- An ASIA **B injury** means you have some sensation, but no movement.
- An ASIA **C injury** means you have some movement, but function is limited.
- An ASIA **D injury** means you can stand and take steps, but it may require a lot of work.
- An ASIA **E** classification describes normal spinal cord functioning.

When describing a spinal cord injury, we also identify the level of injury:

- **C – Cervical:** There are 8 cervical nerve roots, although there are only 7 cervical vertebrae. We indicate the level of injury by the last root level that has modest strength. For example a **C5** injury patient must be able to flex his elbow against gravity. Thus the C5 nerve root must be able to still provide adequate function to the biceps muscle.
- **T – Thoracic:** In thoracic level injuries, the arms should be fully functional and the legs impaired. The muscles associated with the thoracic roots innervate the chest wall and abdomen and are therefore more difficult to associate with a specific root level. Therefore, in the thoracic region we look for the location of the lowest area with normal sensation to light touch and pin prick. For example, if the last level of normal sensation is at the mid-chest level, you have a **T4** injury. If it is at the navel, you have a **T10** level injury.
- **L – Lumbar:** In lumbar level injuries, we are typically looking at injuries to the cauda equina and not the spinal cord itself, because the cord typically ends at L1 or L2. Thus, such injuries are primarily -if not entirely- lower motor neuron injuries. Regardless, this is similarly graded by looking at the last key muscle with modest strength. For example, a patient with a **L3** level injury must be able to extend his/her knee against gravity.
- **S – Sacral:** Injuries at this level result in bowel and bladder dysfunction.

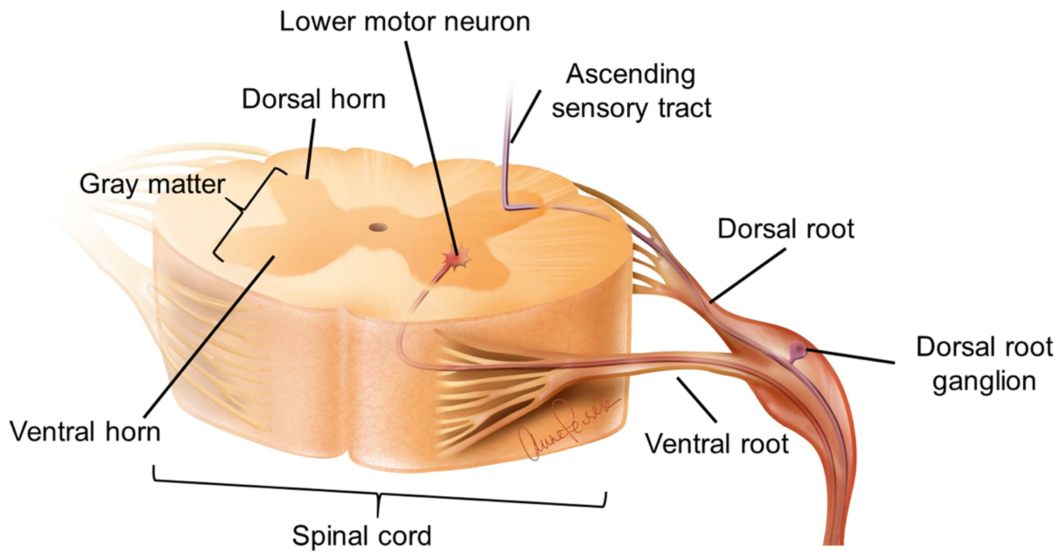
Again, where the injury occurs matters. When the spinal cord is injured, it's no longer able to convey the information as it did before to all the segments that are *below* the injury. Let's examine how that effect might be seen in spinal cord injuries:

To further break down the levels of a cervical spinal cord injury, if someone has a C5 ASIA A spinal cord injury, they typically have control of their shoulders and can flex their elbows. Thus, they have functioning biceps, but they have no motor function below that. Their hands and legs don't work.

At C6, we add the patient's ability to extend the wrist. So with an injury here, the knuckles go up towards the ceiling but there is no significant function below that. At C7, a patient starts being able to turn the palm down, to turn the palm up, and to extend at the elbow. The triceps come in and, with an injury at C7, sometimes a patient can flex the wrist, towards the direction of the palm. However, finger movements are still not possible

At C8, finger movements become possible. A T1 injury will have some loss of fine movements of the hand.

The spinal cord, like the brain, is made up of gray matter and white matter. In fact, if you look at a transverse section of the spinal cord, you'll see a distinctive "H" shape or butterfly pattern that is made up of the inner gray matter, surrounded by the outer white matter.



Spinal Cord Anatomy

Fig 2. Anatomy of the spinal cord: A segment of spinal cord demonstrating the central gray matter, dorsal and ventral roots as well, lower motor neuron and dorsal root ganglion.

The gray matter, located in the middle of the spinal cord, is divided into four areas, or *horns,* which give it its distinct shape: the right and left *dorsal horns, which receive and process sensory information, and the right and left ventral horns, which contain the lower motor neurons.*

Gray matter consists of dense, neural tissue that contains neuron cell bodies, axon terminals and dendrites, and their synapses. It provides the circuitry required for communication to occur between the central nervous system (the brain and spinal cord) and the peripheral nervous system. It also coordinates interactions between the muscles of a limb, such as relaxing one muscle to facilitate the activation of another muscle. The spinal cord circuitry is so complex that, in some animals, walking can take place without the brain's involvement at all.

The white matter consists of myelinated (insulated) axons of neurons. These axons are grouped into bundles or tracts that carry similar information. The role of the white matter is to carry information up and down along these tracts between the spinal cord and the brain. Ascending tracts carry sensory information from the spinal cord to the brain. For example, an ascending tract message tells the brain when your fingers feel something hot. Descending tracts carry information from the brain down to a specific spinal cord level which will then send that information out to body parts. A descending tract might send a message to bend your knee. The neurons in the spinal cord all play a part coordinating the movements that have been directed by the brain, and, sending those messages out to the various muscles that produce those movements.

Basically, the gray matter is like your computer's CPU. It does all of the technical work. The white matter is like all of your cables that connect it to the monitor and other components. It is the way information is sent back and forth.

So, what does this have to do with motor neurons and spinal cord injuries? Quite a lot actually...

Let's say we're talking about bending your elbow. The brain, in order to make your biceps muscle move, sends a message via its upper motor neuron down the white matter of the cord and the into the gray matter in the spinal cord segment that corresponds to C5. (It is important to understand that the gray matter that provides the C5 nerve root is actually found quite a bit higher in the cord than where the C5 nerve root exits the spinal cord - approximately at the bony C3 level). The message is then sent out from the C5 lower motor neurons through the C5 nerve root, which exits through a foramen (hole) between the C4 and C5 vertebrae. These axons extend out the nerve root into the peripheral nerves (the musculocutaneous nerve) that connect to the biceps muscle, telling it to contract – and the elbow flexes.

Now, if you injure the spinal cord at that level where the gray matter for the C5 nerve root lives, you will in fact, destroy that gray matter – right where the damage occurs. Remember, the gray matter in the ventral horn is where the cell body of the lower motor neuron lives. So if that is crushed or destroyed by the initial injury, that cell body is destroyed. When the cell bodies of the lower motor neurons are destroyed, their peripheral axons degenerate. Remember, this is the axon which reaches out from the spinal cord through the peripheral nerve all the way to its muscle in the limb.

Imagine that cell body as the trunk of the tree. The axon is then a branch of the tree and the muscle would correspond to the leaves of the tree. If the trunk is cut down, that branch will die and the leaves will fall to the ground. Similarly, when that axon in the peripheral nerve is lost, its target muscle will begin to waste. It can no longer be stimulated. With time, the muscle will undergo irreversible degeneration and, eventually, cannot be restored even if new axons are provided. With mid-cervical spinal cord injuries, the arms and hands of patients that have a lot of this type of gray matter damage become very thin and bony appearing. The muscle bulk that used to be in the forearm and hands simply wastes away with time.

And here is where knowing whether a patient's injury is an **upper or lower motor neuron injury** really matters. If the injury is primarily a **lower motor neuron injury** with this kind of muscle wasting, repairing the spinal cord years later will not recover these muscles. Even if and when a future therapy, such as the use of stem cells, becomes available to repair the damage within the spinal cord, unfortunately these muscles would not benefit. But there is good news... The patient arms described above can actually be recovered with nerve transfers. Moreover, even if the window for nerve transfers has passed, tendon transfers or muscle transplants may still offer a viable option to restore the described missing function.

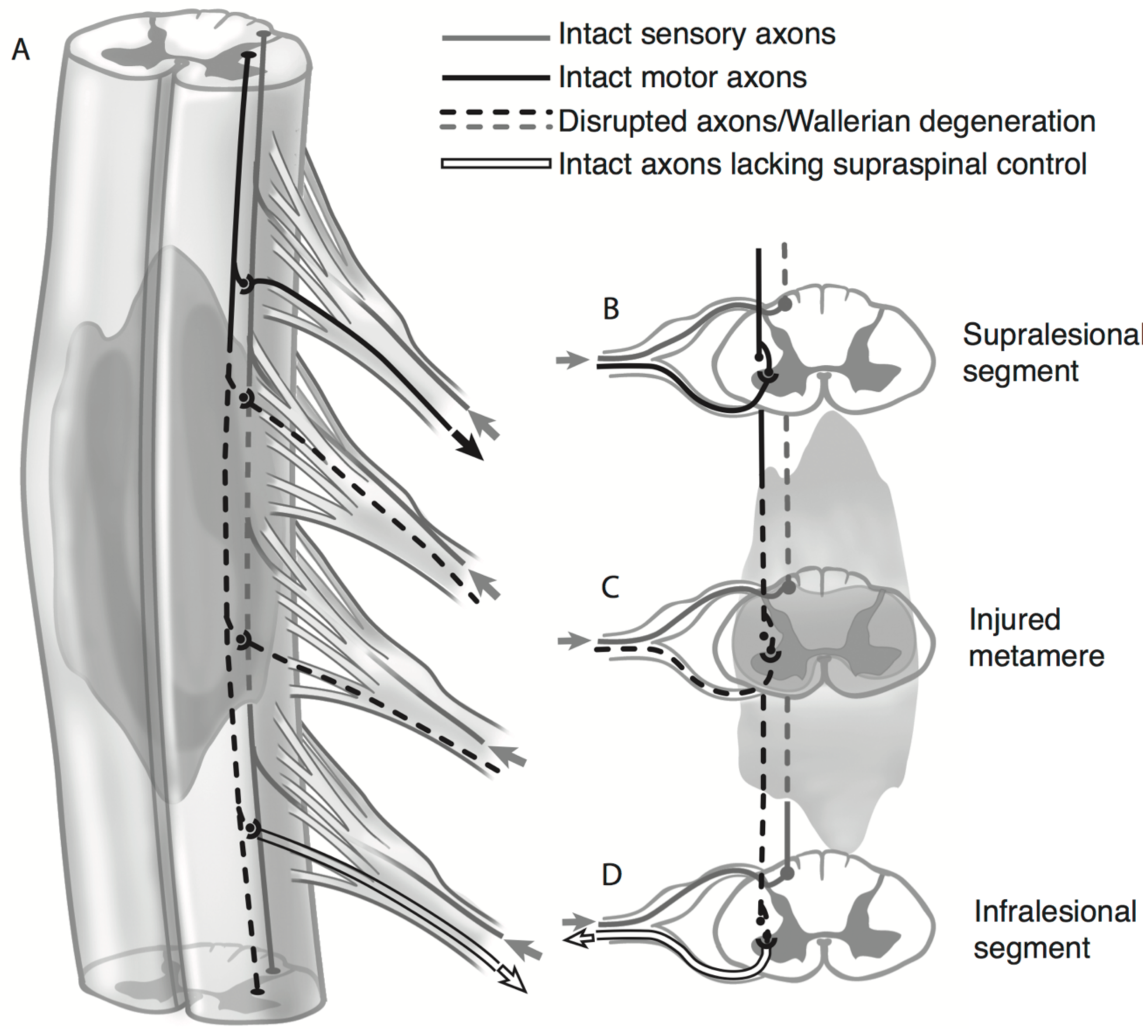


Figure 3. Upper and lower motor neuron injuries. If axons coming from the brain are disrupted before they reach the lower motor neuron in the spinal cord an upper motor neuron injury is the result. It the lower motor neuron within the spinal cord and its axon that extends out of the spinal cord into the peripheral nerve is injured, this is a lower motor neuron injury. These two different kinds of injuries are managed in very different ways. Permissions granted from Oxford University Press.

We used a C5 injury as an example. The damage occurred **at that segment** – and this is really important to understand. When we're talking about spinal cord injury, we are talking about **injury to that segment of the spinal cord**. The flow of information is blocked at that point. The spinal cord below this level is still healthy, but simply cannot receive the information from the brain that it needs to perform useful movement. The missing information is the information that the upper motor neuron is trying to convey to the spinal cord and the lower motor neuron – hence this is the **upper motor neuron injury** portion of the spinal cord injury and accounts for the majority of the functional loss. The axon of the upper motor neuron is heading down the spinal cord within the white matter, bringing critical information from the brain. When this axon is divided, the end that is no longer connected to that cell body, that is found below the injury site, simply dies off. We simply have the cut end of the axon just above level of damage. Intense ongoing research is underway to find a way to enable these cut axons to grow past the damage and make their way back to the target lower motor neurons. At this time we have not been successful with this mission, but we are getting close!

When this disconnection happens, the gray matter of spinal cord **below** the injury is no longer receiving the information that it was receiving prior to the injury. These are healthy and preserved lower motor neurons, but they are not receiving information from above as they had been previously. This deprived region of spinal cord then goes into damage control mode and tries desperately to hear information from the brain. And it tries really hard!

The analogy I like to use with my patients is that the spinal cord starts to "turn up the volume". It wants to hear the messages coming down from those upper motor neurons. Because the spinal cord at this level is normal, but deprived of information from the brain, it still has nerves that reach muscles and nerves that are receiving sensory input from the body. Unfortunately, it cannot communicate this sensory information back to the brain. As the spinal cord tries desperately to hear the messages coming from above, it turns up the volume. As this progresses, it begins to have trouble distinguishing between the unimpeded sensory input coming from the peripheral nerves that are still healthy, versus information coming down from the brain. It's a lot to take in and the motor nerves become hyperactive. The spinal cord begins to increase tone in the muscles and overreact to any stimulus that comes in through those peripheral nerves. Reflexes are really exaggerated and any bump can result in dramatic movements that are difficult or impossible to control. This is what's known as spasticity.

In summary, with any injury to the spinal cord, a **lower motor neuron injury** occurs at that segment that was directly injured resulting in muscle wasting and no movement, but all the segments below the injury point instead have an **upper motor neuron injury**, with increased tone because the brain can't send information down adequately. The spinal cord will try desperately to hear the brain and increased muscle tone and spasticity inevitably result. This part of the spinal cord is anatomically normal. All the circuitry is there, but it just doesn't get adequate information from above – from the upper motor neuron. Thus the weakness in all muscles below that segment is from an upper motor neuron injury. In virtually every injury to the spinal cord, whether ASIA A, B, C, or D, patients will typically have some degree of increased tone below the injury.

This is a crucial fact because it indicates if we can find a way to reconnect the circuitry within the spinal cord in some way, we can restore a significant level of function. The healthy spinal cord below the injury is just waiting to be told what to do. If we can find a way to provide that information, the "waiting" region of the spinal cord could "wake up." You know you have the circuitry and you know you have potential for functionality below the injury. The task becomes re-establishing the communication network.

e. A Word About Restoring Function

Before we move on to assessment and treatment options, we need to talk about restoration of function and what that means. Our goal is to give our patients the greatest and most effective function possible.

For our patients with a cervical spinal cord injury, the most important thing that we're seeking to restore is function of the arms and hands, so that they can be independent. Why the hands?

There have been a number of surveys of people who have had cervical spinal cord injuries asking, "If you could have anything in the world, what would it be?"

Typically, what they tick on the survey box is they want their hands because if they have their hands, they can feed themselves. They can catheterize themselves. They can work at a computer. They can pretty much take care of themselves as long as they have arms and hands that work. Having hands that are functional not only is a priceless gift, but it also means patient independence.

Beyond hand function, patients cite bowel and bladder control, pain reduction and then, probably fourth or fifth down the list is …standing up and walking.

The next question to ask, and the one you're probably most interested in, is how much movement can be restored? The answer depends on many factors.

Our chances of success are greatest with early intervention. If there are large areas of lower motor neuron injury, the sooner we can re-establish connections from the spinal cord to the target muscles, the better our chances of restoring function.

It also makes a big difference if the patient works with us to achieve our optimal, desired goals. It is important to avoid nicotine products of any kind (even a nicotine patch will hinder axon growth). This is because regeneration requires the development of small blood vessels to supply nutrients to those growing neurites. If they don't have an adequate blood supply, they don't grow well and nicotine definitely hinders blood supply development.

Exercising or activating the nerves that were transferred helps "signal" them to grow. It is also crucial to ensure that the joints involved do not get stiff while we await recovery. Sometimes we can achieve excellent nerve growth, but the recovery is quite poor simply because the arm or hand has become "stuck" and difficult to move due to inadequate patient effort to maintain them. Therapy is critical! If you neglect your arms and hands and they develop contractures, our job becomes dramatically more challenging!

Now let's discuss the various diagnostic tests we use to properly assess spinal cord damage and why getting an accurate diagnosis of your injury is so important.

3. Assessing Your Spinal Cord Injury

We always emphasize that earlier is better in terms of diagnosis and assessment of spinal cord injuries. Time is of the essence when it comes to preserving tissue and function. The earlier we can intervene, the more treatment options we are likely to have. Ideally, we like to see patients as soon as possible following their injury, but at least within the first year.

Now, this doesn't mean that we cannot help you if your injury occurred more than a year ago. In a patient with minimal lower motor neuron injury who has had good therapy, we may still have most of our options available. If, on the other hand, most of that hand weakness was due to lower motor neuron injury, it is likely that there will be fewer surgical options. However, we can typically enhance the function of anyone to some degree, no matter the time elapsed or severity of their injury.

a. What Kind of Injury Do You Have?

At the Paralysis Center, we have a team of specialists with protocols in place to gather all of the data necessary to make the best diagnostic and treatment recommendations possible. Better data means better decisions. Better decisions mean better patient outcomes. We will now outline our diagnostic process for you.

When it comes to assessing spinal cord injuries and determining treatment, we first have to know the type of injury you have. How much of your injury is an upper motor neuron (increased tone and spasticity)? How much is a lower motor neuron injury (with nerve axon loss and muscle wasting)?

How do we know? **The difference is critical.**

b. Physical Exam

Because we're focusing on hand function, we will look at the muscles in your arms and hands. Are they full and toned? Or do we see muscle wasting?

We ask questions – a lot of them. The more we can learn from you, the more accurately we can understand your injury and your experience. We will ask you if you experience spasms and, if so, how you experience them. We will want to know which muscles move when they occur. We are interested in your response to different therapies and stimulation protocols that therapists may have used.

Asking about spasms is really important because it can tell us what we have to work with. Many patients experience spasms. If those spasms activate a muscle that we really want to restore, such as a spasm that causes a hand to open, the fists to clench, or an arm to extend at the elbow, then we know that the muscles involved have axons in them and are preserved. In that case, even if a patient's injury was years ago, we can often "wake them up" with a nerve transfer.

But what if you don’t experience spasms? If you don’t get those spasms, there is a chance the axons are not preserved. To be certain about the condition of the axons, we will evaluate you with nerve testing, which employs neurostimulation. If the axons tested stimulate the muscles and the muscles jump, then we know those axons are intact, and, you can make a decision about restorative surgery when you feel ready. Indeed, you can take your time deciding. In fact, time may well be to your benefit because of something called “plasticity”.

When we determine that the injury primarily involves upper motor neurons with very little loss of lower motor neurons, we even recommend waiting a bit. The data shows that while most people with this type of injury will recover some spinal cord function within the first three months, it can sometimes take more than 9 months for them to make progress. When we say “make progress ”, we mean that a patient’s injury may “descend” a couple of levels. For example, consider someone who originally had a C5 injury – able to flex the elbows but having no function in their hands. When we examine them six months or a year later, they may now present a C7 injury, with good movement of the forearms and triceps. In that case there are additional treatment options available and muscles that are available for transfer, and, more sophisticated hand function can be achieved.

Similarly, a patient who is initially classified as an ASIA B with feeling but no movement below the level of their injury, may gain movement over time. Conversion to a higher grade can occur with almost any severity of injury, but is more common with better grades. It is not uncommon for a B to become a C or a C to become a D. Although it is less common for an A to become a C, this can occur in some instances.

How do these progressions happen? Remember the spasticity description above and how the spinal cord beneath the injury site begins to “turn up the volume” to listen for signals? Sometimes, that process starts to create new pathways. A patient’s body goes through a period of “rewiring” the circuitry, turning up the volume, listening to what’s going on from above the injury and suddenly, the patient starts gaining control. This all happens through a process known as plasticity. Your body basically rewires itself from the remaining parts to regain control of the muscles.

To the contrary, with lower motor neuron injuries, waiting for indicated treatment is not advised or wise. If the muscles involved cannot be stimulated, that indicates that the patient lost that gray matter within the spinal cord at the time of the injury and time is of the essence to intervene with appropriate surgery, such as a nerve transfer. Decisions need to be made as soon as possible to ensure that the patient has the most, possible surgical options and to maximize their chances of functional restoration. With these injuries, we generally advise nerve transfer surgery be done within 6-9 months from the date of the injury. We prefer not to wait longer than 1 year, as these operations are likely to be considerably less effective at that point.

Note that it is also crucial for patients to work with our occupational therapists to assess their current ability to perform daily tasks and further determine what needs may be addressed with improved hand function. Sometimes we prefer a limited, more specifically focused approach to tackle and accomplish what may be the most important task for a particular patient. We discuss all, possible treatment options with you at your visit.

c. *Other Diagnostics*

Depending on your injury, your paralysis specialist may order additional tests to better understand the dynamics of your injury.

• MRI – An MRI can give us the best picture of your spinal cord and affected areas. MRIs can sometimes allow us to “see” what the injury to the spinal cord looks like, which can provide further information regarding the degree of injury and the likelihood of recovering function. Additionally, occasionally an injury may have a late complication, such as a syrinx (a rare, problematic, fluid-filled cavity within the spinal cord). We want to be aware of this, in case the problem needs to be addressed prior to any surgical reconstruction.

Figure. 4. MRI is a large tube that you slide into in order to get good images of your spinal cord and nerves.

• Electromyogram (EMG) – Think of an EMG as comparable to inserting a microphone into a muscle. In this test, we place a needle into the affected muscle to look for muscle responses, which are made up of motor units. The number and configuration of these motor units tell us how healthy a muscle is and if its nerve can be safely transferred. This test also reveals what is called “spontaneous activity”. Spontaneous activity is electrical activity in a muscle which indicates that the muscle has recently lost axons (and thus suffered a lower motor neuron injury). Muscles and nerves support one another and when that support is removed – in this case by the loss of axons - the muscle membrane becomes hyper-sensitized and will begin to activate on its own - or with very little stimulus.

Muscle response is measured in motor units. When muscles are weak, and even when muscle movement is undetectable on examination, movement may still be present. The EMG can detect tiny motor responses. If only a very few axons are present, we can usually see motor units – evidence that there is “life” in the muscle and potential for recovery. EMGs may be repeated in a few weeks to determine whether function is increasing, with more motor units being identified, or remaining unchanged. Changes over time are followed closely to decide whether muscle recovery will progress to the point of useful function, or will stop early, and therefore require surgery to get the best, possible result.

• Nerve Conduction – A nerve conduction procedure involves essentially sending electrical current up and down a nerve to appraise its responses. Nerve conduction studies can tell us whether there are functioning axons present and sometimes whether the functioning axons are sufficient to allow for an effective nerve transfer procedure. When a muscle action potential can be demonstrated, even though the patient cannot make the affected muscle move, axons are present.

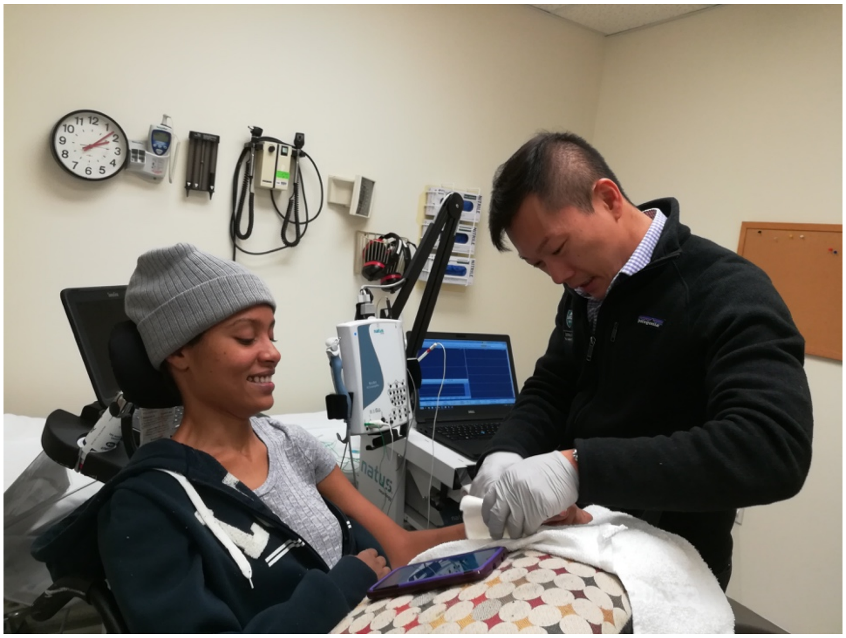


Figure. 5. EMG/NCS are performed by a device that both stimulates nerves and records from nerves and muscles.

Depending on your injury, you may undergo other diagnostic procedures such as a CT scan, Xrays, or other testing so that the team can get a clear understanding of your injury or other issues that may be present. Again, the exact procedures appropriate for you will depend on the circumstances of your particular spinal cord injury.

The first step undertaken is your comprehensive evaluation and the team at the Paralysis Center is ready to help. Later in this Guide you will find information about setting up your initial assessment.

4. Understanding Your Treatment Options

There are several treatment options and surgical techniques available to address spinal cord injuries and restoration of function. Following your complete evaluation, your treatment team may recommend one or more of these procedures, as part of your rehabilitation plan.

a. Tendon Transfer

Tendon transfers are frequently used to restore movement in limbs. This procedure takes a working tendon and moves it from its original attachment to a new attachment site to restore movement across a more important joint.

To understand a tendon transfer, it’s important to know a little about the relationship between muscles, tendons and nerves. Tendons attach our muscles to our bones. Every muscle has a starting point called the “origin”. The muscle tapers down to a tendon which attaches the muscle to a bone. Where the tendon attaches to the bone is termed the “insertion point”. When the muscle receives a signal to move, it contracts and the joint that it crosses moves. When the nerve that sends the message to move is damaged, the result is partial or complete loss of function, or, paralysis. The muscle is either weakened or no longer moves.

Tendon transfer surgery involves taking a tendon of a muscle that is not critical and attaching it to another site to achieve a movement that is more important. The starting point or origin of the muscle, the nerve supply and the blood supply are all left in place. The tendon is detached from its original insertion point on the bone and reconnected to another bone, or to another tendon, to restore function to the injured area. The original muscle will still fire. Once the transfer is completed, when the muscle contracts, it produces a new action, depending on where the tendon is inserted.

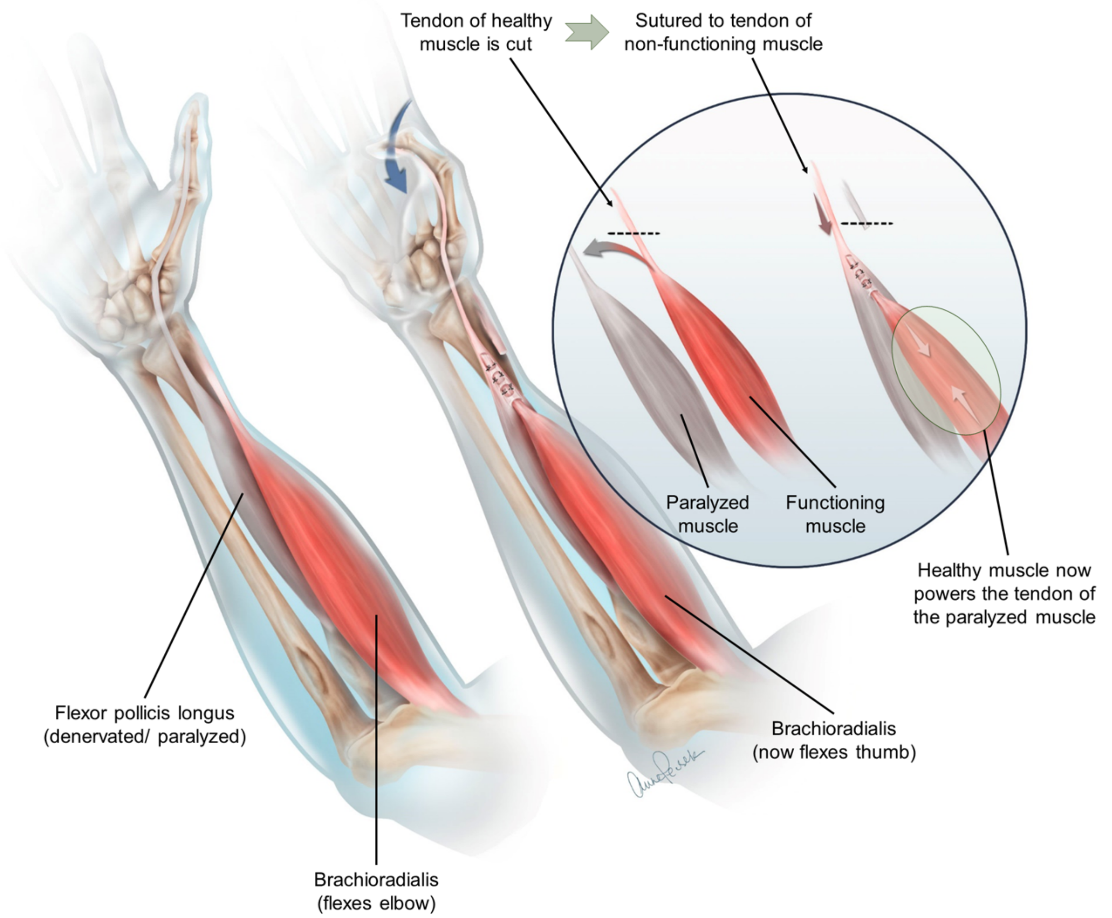


Figure. 6. Tendon transfer. A muscle that has retained goof control is transferred to the tendon of a non-functional muscle in order to provide that movement once again.

After this procedure is performed there is typically a period of immobilization during which the injured limb is placed in a splint to allow that tendon repair to heal and become more secure. The recovered movement is available almost immediately, but the limb must be treated with care for at least 6 weeks following the operation. Therapy is used as swiftly as possible to move the limb passively (without applying opposing force or resistance) and avoid scarring of the nerves. This procedure can be performed well after the nerve injury occurs as there is no prescribed procedure time limit.

Tendon transfers may have advantages over other procedures especially for patients who have a long-standing spinal cord injury:

- Tendon transfer can restore function even long after the window for nerve regeneration has passed. This procedure may be available no matter how long ago the injury occurred.
- Tendon transfers have withstood the test of time. We have decades of experience with them.
- The functional recovery accomplished by tendon transfers is almost immediate.
- There are certain functions for which a tendon transfer may actually be more effective than a nerve transfer.

b. Muscle Transplant

Sometimes a local tendon transfer is simply not an available option. If the time window for nerve repair has passed and no tendon transfers are possible, there is, however, one option that typically remains. In these cases, a procedure known as a *free functional muscle transplant* (FFMT) can be used to embed a muscle into the limb to provide the missing function.

Muscle transplants are often selected over a nerve graft because too much time has transpired since the injury and a nerve repair would no longer be effective. Muscle transplants can be done at almost any time, even years after a patient's injury.

In a muscle transplant, a healthy muscle is harvested from another part of the body and transplanted into the affected area. The transplanted muscle tissue is then connected to the blood supply in its new location in order for it to survive in its new location. The transplanted muscle is also connected to a working nerve so that movement is possible. Similar to other nerve repairs, when that nerve is connected to the transplanted muscle's nerve, the axons must grow into that transplanted muscle before it will contract. Therefore, after surgery it typically takes about 6 months before the patient's transplanted muscle can move.

One of the most common muscles transferred for brachial plexus injuries is the gracilis muscle. This is a thin, long muscle of the inner thigh. This is the smallest of several muscles that bring the thighs together. It is employed because its loss is well-tolerated. This muscle is often transplanted into the arm to help restore the ability to bend the elbow and flex the fingers. In fact, people can run and participate in sports with this muscle missing without a problem.

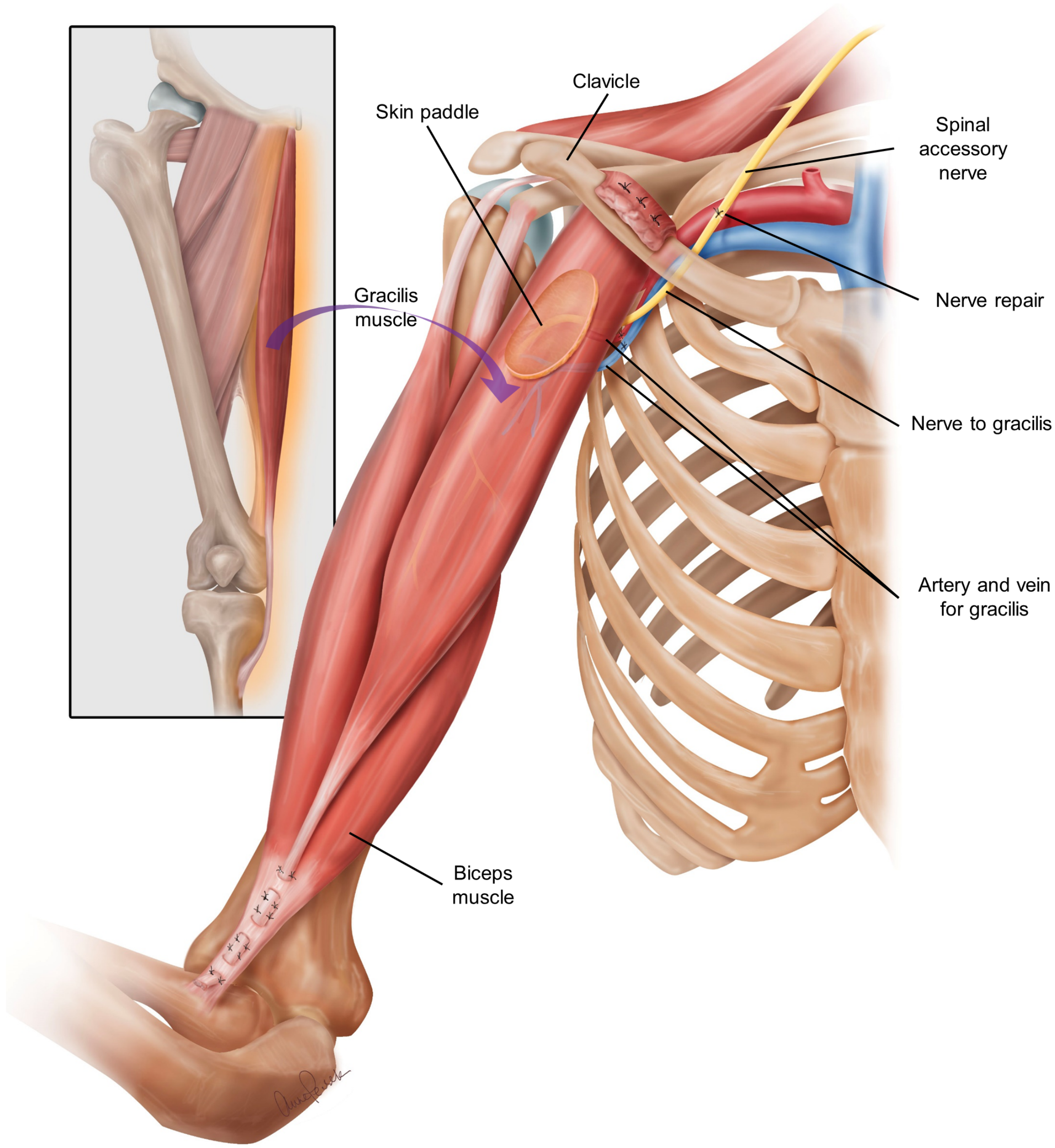


Figure 7. Muscle transplant: A muscle that is not critical for leg function, the gracilis, is removed and placed into the arm to replace a missing function. It must be connected to an artery and vein to survive in the new location. It must also be connected to a nearby nerve in order to recover function.

Some of the advantages of a muscle transplants include:

- Restoration of function is possible even after a long period of time has transpired; and,
- Muscle transplants are time-tested procedures and we have decades of experience; and,

- Transplants represent an option to restore function when no other procedures are available.

Following this procedure, the patient must remain in the hospital for several days to ensure that the transplanted tissue's new blood supply from the newly sutured vessels continues to flow well. Sometimes this includes a stay in the intensive care unit where a doppler machine is used to listen to the blood flow every hour. Once the muscle "takes" it will still be some time before it begins to function.

c. Selective Peripheral Neurotomy (nerve branch cutting)

Selective peripheral neurotomy is a procedure used to restore hand and arm movement and improve walking in patients who have motion-impairing spasticity. Sometimes muscle control is present but hidden because other muscles in the spastic limb are so tight that they do not allow useful movement. This is common in ASIA C and D injuries. Often movement can be performed and some function is present, but the movement is difficult and requires a lot of effort. Most commonly Botox and stretching are offered to help with this condition.

Selective peripheral neurotomy relaxes overactive muscles and allows the other muscles that have better control to work without interference. With spasticity, fists become clenched, wrists flexed, and arms can be difficult to straighten. Similarly, legs can straighten, feet can turn in and toes curl, making walking challenging. Allowing those muscles to relax allows for improved function and control.

During this procedure, nerves that are contributing to the spasticity are precisely "cut back" in such a way that reduces spasticity, but maintains control, allowing more normal functioning of the affected muscle. Cutting a portion of the nerve reduces the "noise" being relayed back to the spinal cord, which causes the spasticity, simultaneously leaving enough of the nerve to maintain function and control of the muscles.

D. Spinal Cord Stimulation (SCS)

Although spinal cord stimulation (SCS) is most commonly used as a pain-relief technique that delivers continuous , low-voltage electrical current to the spinal cord to block pain sensation, new applications for SCS have been realized. Numerous studies have demonstrated that spinal cord stimulation may also have a role in reducing spasticity and improving function in patients suffering from upper motor neuron weakness.

Indeed, at the Paralysis Center, we are developing a program using SCS to reduce spasticity and to enhance motor function for patients with spinal cord injury. At this time, it remains "off-label" and research into who are the best candidates and how effective the treatment will be, is ongoing.

We are also implementing a program using external transcutaneous (through the skin) stimulation coupled with rehabilitation. Instead of surgical implantation, electrodes are placed on a patient’s back and stimulation applied through the skin to provide some of these effects to the spinal cord. This method is less expensive and can sometimes be sufficient to promote sustainable improvements in movement. If this intervention is effective for a patient, but the effects do not remain when the stimulation is stopped, the patient may be a candidate for implantation of a stimulator unit.

e. Nerve Transfer

A nerve transfer is the MVP (most valuable player) of surgical paralysis reversal. Nerve transfers are one of the most commonly performed surgical procedures at the Paralysis Center.

Nerve transfers utilize nerves with less important roles — or branches of a nerve that perform the same function as another nerve — and connect or “transfer” them to a more critical nerve, restoring function to a muscle that was lost due to the spinal cord injury. In other words, sometimes we have more nerves than we need to run other muscles or perform a particular movement. When a nerve isn’t working, we can sometimes simply take a branch or a portion of a nerve from another location, reroute it and connect it to the site of nerve we are hoping to “wake up.” This rerouting allows the nerve to send its axons or wires down to that new nerve to connect to its muscle and restore its movement.

Motor nerves are transferred to recover muscles; sensory nerves are transferred to restore sensation. Your surgeon will use functioning nerves that are close to the target muscle or sensory area in order to restore those functions as quickly and effectively as possible. These nerves are transferred to the injured nerve that no longer functions. The nerve that has been transferred now takes over that function.

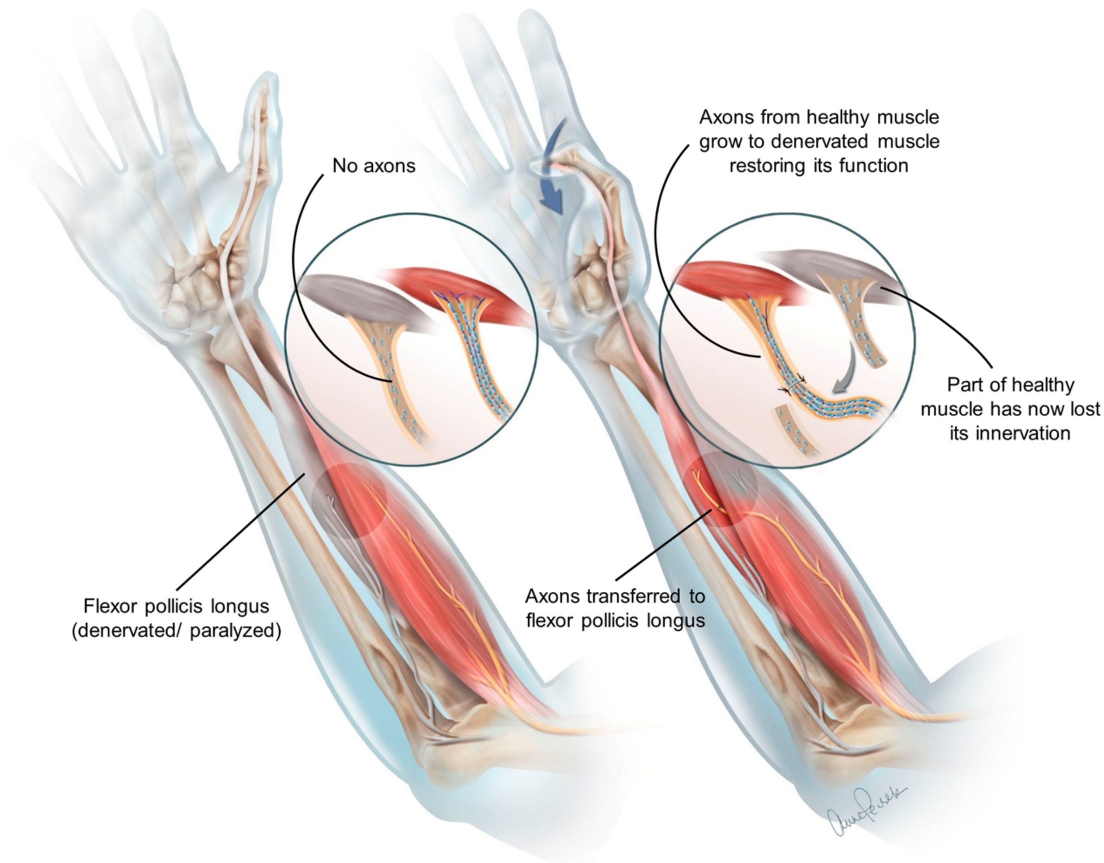


Figure 8. Nerve transfer: A nerve that is not critical is cut and transferred to a nerve that serves a more important muscle in order to recover its function and provide that movement once again.

At the Paralysis Center, we've developed surgical approaches that allow us to use nerve transfers to help restore hand function for patients with spinal cord injuries . Nerve transfers are particularly important for patients with spinal cord injuries when there are no muscles below the elbow that work. And this is where things get really exciting for restoring function...

Back in the 1970s, hand surgeons who were doing tendon transfers began classifying the degree of injury. They developed what's called the *International Classification For Surgery Of The Hand in Tetraplegia or ICSHT*. In that system, a patient was an International Classification grade 0 (IC-0) if he/she had no muscles below the elbow and there were no restorative remedies available for the patient. Recovery of hand function was literally hopeless.

Today, with nerve transfers, most patients classified as IC-0 have viable nerves which can be transferred. While tendon transfer surgery provides no options for such a patient, since there are two nerves available, we can redirect or transfer those nerves and often achieve hand opening and closing. So what does this mean for that IC-0 patient?

Answer: HOPE ! For patients who previously had zero options to restore their hand function, we now have the surgical ability - with nerve transfers - to get fingers to both open and close. Nerve transfers offer patients with spinal cord injuries hope for restored function in ways not possible even a few years ago.

One of the main advantages of a nerve transfer is the potential for additional options for functional restoration. Other advantages of choosing a nerve transfer include:

- Restoration of the original muscle's function without changing the arm's anatomy; and
- No, or minimal, casting and immobilization;and,
- Sacrifice of one simple function can potentially restore multiple functions

f. Hybrid Procedures

For many patients, the best approach isn't an "either/or" but a "both/and". At the Paralysis Center, we strongly believe that in many cases the optimal patient function will be realized by a combined approach to restoration.

With a nerve transfer alone, we can get affected fingers to move well, but the impaired hand often won't be in an ideal position/condition to allow/create the best pinch and grasp. Tendon procedures can straighten the fingers out to bring them into a better position. Sometimes a fusion of one of the bones in the thumb can position the thumb so that it will be capable of pinching effectively.

In some cases we can move a tendon around to mobilize the thumb out of the plane of the hand so the patient can reach out to grasp, or, they can reach and close for a pinch. These particular mobility goals are usually best achieved with a tendon transfer.

In our experience, a combination, or what we call a "hybrid" procedure, starting with nerve transfers and then following that with additional tendon transfers, often provides much better results than nerve transfers alone.

At the Paralysis Center, we can proudly say that we have done more nerve transfers and hybrid procedures with spinal cord injuries than any other comparable facility in the world. We have the experience and the expertise to identify the best procedures and treatments to offer every patient the best chance for optimal function restoration.

5. Why A Nerve Transfer Is The MVP (Most Valuable Player) In Reversing Many Forms of Paralysis

Of all the types of reconstructive procedures that a neurosurgeon can offer a patient with a paralyzing injury, the nerve transfer procedure is the one that has taken the concept of nerve repair to a whole new level of sophistication. Patients who once had little hope of regaining functional use of their extremities are now able to have movement restored in ways not previously believed possible.

Today, so much more is possible. Technology has given us the ability to see even the tiniest nerve fibers and blood vessels. We are able to explore the anatomy of an injury through noninvasive types of imagery such as MRIs, high-frequency ultrasounds, and more. Moreover, we now know far more about how nerves work, heal and grow in the body.

Nerve transfers, more than any other of the reconstructive procedures, have yielded results that are making a substantial difference in the lives of our patients. They result in more robust, noticeable results that have a lasting impact on function, independence, and quality of life. Of course, the degree of restored functioning is unique to each individual, but these outcomes mean that more people with different types of paralysis have the potential to be helped in ways that were previously impossible. With the success of nerve transfers with other paralyzing injuries, such as brachial plexus injuries, reconstructive neurosurgeons are now utilizing this procedure with spinal cord injuries as well as other nervous system injuries to restore function throughout their bodies.

6. Post-Operative Rehabilitation

It is key to emphasize here that successful nerve reconstruction does not end with the performance of the indicated surgery. Following surgery, it is imperative that a patient begins physical rehabilitation to mobilize and strengthen the affected area. It is urgent for a patient to seek an OT (occupational therapist) or PT (physical therapist) who is competent and conscientious in this important step.

A nerve transfer is like planting a garden. The “wires” inside the nerve need time and nurturing to take root and grow down to the muscle they are going to re-innervate. This process takes time – from a few months to as long as two years. Rehabilitation, including physical and occupational therapies, will help to maintain passive range of motion, recognize and activate new muscle movements, and accelerate strengthening. After some patient strength is achieved, therapy is helpful in learning how to incorporate those new movements into daily activities.

Once a patient has had a nerve transfer, their muscles and nerves have to learn to coordinate new movements. Over time and with training, the brain learns the new pattern and the patient will be able to move their arm just by deciding to do so. Establishing this pattern takes time, and rehabilitation lays the required foundation for that learning.

Typically, once the surgeon has cleared a patient to begin the rehabilitative process, the patient will need to follow up with the surgeon and lead therapist every 3 months for up to 3 years, depending on the complexity of the reconstruction.

7. What About Stem Cell Therapy?

You have probably done a lot of research on spinal cord injuries and available treatment options. You have no doubt heard quite a bit about stem cell therapy. Let's consider stem cell therapy as it relates to paralysis and spinal cord injuries.

Stem cell therapy has become quite popular and been touted as the cure for almost everything. While stem cells hold great promise, research for the application of this technology to spinal cord injury is in its early stages.

Here's what we do know:

Only a very few types of stem cell treatments are currently approved by the FDA. Some of these approved interventions that have shown promise include:

- Hematopoietic (or blood) stem cell transplantation for certain cancers
- Skin stem cells used to grow skin grafts for patients with severe burns
- Stem cell therapy for corneal regeneration
- Mesenchymal stem cells for bone, cartilage and blood vessel damage

You may be thinking, "If they can create new skin and bone, why can't they fix the injured spinal cord?" The short answer is, we are trying.

Researchers at some of the major medical research centers are exploring the possibility of using stem cells to stimulate regeneration of axons within the spinal cord. Just a few of the many clinical research projects related to stem cells and nerve regeneration include/involve:

- Immune response and neuroregeneration
- Spinal cord repair
- Peripheral nerve regeneration and repair
- Stroke neuroregeneration

This sounds very exciting, right? Stem cells are one path of hope for many diseases and conditions. But what do the outcomes tell us so far?

There have been a number of clinical trials and research projects that have attempted using stem cells to treat spinal cord and brain injuries. However, at this point, there has been no noteworthy degree of clinical success for patients. Unfortunately, there are many instances of patients travelling abroad and paying tens of thousands of dollars (sometimes hundreds of thousands) for stem cell treatments from clinics which claim they can reverse paralysis. The best resultant reports are mild subjective improvement, while the worst have described devastating consequences.

But it's not all bad news...

There have been some exciting and promising successes in animal studies:

- Stem cells have been shown to remyelinate and restore the insulation to nerve fibers after damage.
- Stem cells have been shown to help white matter axons that have been disrupted to grow a little further.
- Stem cells could play a role in neuroplasticity. They may provide additional neurotrophic factors that help axons grow. Those factors are at play inside the central nervous system, in the brain, and the spinal cord and could help to stimulate and enhance the rewiring we referenced earlier..

We are very encouraged by these discoveries and earnestly hope they can be translated into successful human trials in the near future, but we are not quite there yet.

One of the applications that our labs are currently researching is using stem cells to preserve nerve and muscle so that the “window of opportunity” to recover a lower motor neuron paralyzed muscle might be extended, allowing nerve reconstruction years after injury. We think this will lead to a critical breakthrough for these disorders . . . but we have a lot more work to do!

Exciting results are emerging with stem cell research in our animal models. At the Paralysis Center, we are at the cutting edge of research and collaborate with other labs within the Harvard system on a regular basis, trying to translate their basic science knowledge into remedial clinical applications. In other words, we do numerous collaborative studies where we work with the ideas that apply clinically with animal models, and, consider every conceivable, creative way to dynamically utilize stem cells.

We are very optimistic that in the near future these studies will lead to new procedures to restore increased and enhanced patient function, but further research is required to reach our ultimate goals.

8. Myths About Surgical Rehabilitation

We have presented to you a lot of facts and information. However, please be advised, when it comes to spinal cord injuries, there are many misleading promises and myths to be aware of. Patients desperate for help hear these, and want to believe so badly, that they will sometimes put off treatment that is available now, for something that may not even be feasible in the future.

1. A Cure Is Right Around the Corner

I wish that were so. Some patients erroneously believe that there will be a stem cell cure soon, and if they just wait long enough, science will be able to give them a pill or an injection that will repair their spinal cord, good as new. They worry that surgery now will permanently alter and impair their hands, a result they could have avoided if they just simply waited for the supposedly imminent cure.

2. Holding Out for Stem Cells To Regrow Lost Muscles and Nerves

Even if stem cell therapy was available and could repair a spinal cord, for people with significant lower motor neuron injuries and muscle wasting that are years from their injury, peripheral nerves and muscles unfortunately cannot be re-vitalized, or, made healthy again. Yet, patients will often decide to hold out for the possibility of regrowth, not realizing that they don't have the tissue they'd need for this regeneration to benefit their hands.

These beliefs hold many patients back from pursuing treatment that can give them improved functionality and improve their quality of life now. Before you decide to rely on a "someday" cure, be sure you are willing to risk missing the window of opportunity to restore your function and independence, now.

Spinal Cord Injury - Patient Stories

Andres

I was a mountain biker and I got injured in a mountain biking accident in 2008.

I fractured the C5-C7 in my neck and that resulted in paralysis, pretty much from the chest down. I had arm motion but I didn't have finger motion. And that obviously, is very, very, very tough for day to day activities. I continued on that way until about 2014.

Dr. Justin Brown had visited the Sharp Hospital where there's a men group that are treated there for spinal cord injuries. They had arranged a presentation by Dr. Brown for people that had spinal cord injuries. He gave a speech on a new type of surgery that he was doing and he was the only one at that time doing this type of surgery. And that was fantastic.

Almost at the same time, my friend used to work as a newscaster for a local television news. Her name was Lynda Martin, and she worked for the CW channel So then I'm not really sure how they linked up with Dr. Brown but the point is when she heard about him and was to interview him, she called me. Being her friend, I showed up. We had a little blurb on TV where we presented his services and the miracle science. And then I went through with the surgeries - it was in several stages.

He had to do tests to see and make sure that there were enough nerves being fired into the arm for them to work his electrical magic and make sure that I could regain some of the hand controls. After the testing there was all kinds of lab stuff. And then he went ahead with the surgery. He did two surgeries per hand or arm. They transferred nerves and they rewired things.

And then miraculously, within days, I could start to see movement and because there were nerves that were rewired, he taught me to flex different bicep muscles to then activate the hand, because he was using different channels to reach them. You are taught to activate different nerves that weren't there before because we have a memory of lift up your leg and you have a certain sensation but then if it says "twist your back to lift your leg" then it's a roundabout way but then eventually your mind likes to take shortcuts and then later on you just think about using your hand and then it works. It's an interesting miracle how you have to think of something differently and then your body eventually rewires it to then do the shortcut version.

So this all happens at different stages - the surgeries are spread out for healing.

One of the things that I've always promoted to other people considering the surgery is you've got to make sure your diet and your health are the best they can be so then your body has an opportunity to fix things. You have to come in really with a clean diet, and with good knowledge of what your body's going to need through rewiring. These are electrical signals that have to be rewired. Then post-surgery you should be really cautious about stuff because everything has been rewired, carefully and gently. Being cautious leads to a good result.

So the end result for me was two functioning hands. I can’t play the piano, but I can definitely grip. I can brush my teeth, holding a toothbrush, zip down a jacket, open the fridge, uncap bottles and things like that. These seem very mundane in daily life but as a quadriplegic, you don't have that ability, so these things are huge.

I have a manual wheelchair and when you don't have hands you kind of push with your palms and I couldn't ever go out in the rain. You know, I couldn't go anywhere that's wet because you start sliding around. But now I can slow down the chair and control movement in a wheel chair and that gives me safety in the streets. That’s a big one.

So it has been life changing and it was successful twice, which is great, because you can have a 50-50 or less chance of success, but Dr. Brown did great work. He was very, very kind and we had great follow-ups.

The first surgery was just re-transplanting nerves so what he does is ‘borrow from Peter to pay Paul.’ So he ‘borrows’ good nerves to put down and lay tracks down for something else. They have to attach to the muscles and tissue. Then at the second surgery he attaches the ends for one hand. So let's just say that he lays down the wire, and after about 3 months, when it’s strong and then he connects point to point.

If the signal fires on a nerve and it's not well grounded, then you could just rip it out of its full foundation. The tendons and the nerves all have to solidify and then you connect. After Dr. Brown did the grafting on the right arm, I needed a little bit of time to make sure the pain and things had settled down. So then within six months to eight months we finished on the right arm.

Then he did the transplant and then we waited another approximately three months. That rolled into the beginning of the next year. And that then reconnected and that worked great. He not only did the nerve but he also did the tendon transfers.

So part of the surgery involved reconnecting tendons so it would open and close the hand, or the tendons would adjust the positioning of the hands when the nerve activated.

My recommendations are that you have to be healthy and go into surgery in the right frame of mind. You also have to do the rehab, be patient and stay positive to get the best results. I was athletic beforehand so I knew that you can’t just walk your way into a marathon. So it’s a marathon, that's life. And now, in my particular case, it’s two arms.

With any type of injury I think you need to take some time after the injury to figure out what's coming back, what's going to heal by itself. But I would have been more than happy to have had Dr. Justin Brown in my life in the second or third year for sure, rather than to have struggled for 6 years before the surgeries that changed my life.

Dr. Brown comments

Andres had suffered his spinal cord injury several years before, so he was a chronic injury. As a result, some movements were amenable to nerve transfers, but others required tendon transfers to accomplish. When this is the case, we often have to approach the reconstruction in stages. We also cannot use a cookie cutter approach. We take an inventory of what methods are available to achieve each movement and what we can spare. Nerve transfers were used to create grip and since we had 2 sources, we were able to separate the thumb movement from the rest of the fingers. Finger extensors were primarily lower motor neuron injury, therefore tendon transfers had to be pursued. Positioning the thumb was again with tendon transfers. In the end, his reconstruction was quite functional and he was very happy that he had pursued the reconstruction. OF note, the second hand that was reconstructed took quite some time before the nerve transfers became active. We were becoming concerned when we were reaching a year with very little movement. Sure enough, at about 1 year, the movement began and became quite strong in the months that followed. Patience and hard work paid off.

Zarina

I broke my neck in 2010, the exact date was April 26, 2010.

Basically, what happened was, I had just bought my house and there was no rail by the staircase. It was going to be put in the day after I broke my neck. I fell down the stairs and hit my neck on a table that was nearby. That was the reason for the paralysis.

When I first got taken to the hospital there was a 50-50 chance of me living or passing away. The doctors didn't think I was going to make it. My parents were called and flew in from Singapore. Doctors told my parents not to expect much from me. Basically, they said I wasn't going to be able to breathe on my own. I wasn't going to be able to move my arms. In fact, I only had control of my head.

So after the injury it was incredibly tough and really intense for me. I wasn't accepting of the diagnosis but I went to therapy a lot. When I went for therapy, in 2012, Dr. Justin Brown came and made a presentation, and he talked about the nerve transfer surgery that he was doing. I was very interested, but I didn't follow up with it until about a year after. And when I did follow up with it, I had a series of three surgeries, between June 2013 and April 2014.

One of the surgeries was on my hand. He weaved a tendon across my knuckles. There was a little cut in my wrist and Dr. Brown tried to anchor my wrist because it was turning inwards, and he did a tendon transfer there, too.

The next surgery was for my triceps. It was a really long line from my triceps halfway down to just before my elbow, and then I had another really long line on the inside of my forearm. *And what has happened is that the surgeries worked so well for me that I have full tricep function on my right arm and I can grip things in my right hand that I couldn't do before when I had no grip.*

With the third surgery, I asked Dr. Brown if I could watch it, because he had said, “You can get local anesthesia or general anesthesia” and I asked him if he did the surgery under local anesthesia could I watch it? So he let me do that! My last surgery was in April 2014.

In 2014 I went back to school, so I’m still in school. I took a year and a half break so I am doing my masters in rehabilitation counseling, and I'm going the psychiatric rehab route. Dr. Brown facilitated having my hand back. Being able to grip really helped, with school stuff, with really everything in the city life.

I can now hold a fork, or a knife or spoon in my right hand. You wouldn’t think that that would make so much of a difference, but it does. Because of my triceps brachial nerve transfer I am able to move my arms. I am breathing on my own and I am able to do a lot of things that they said I couldn't do. Dr. Brown had a different perspective completely because, when I asked him, if I could walk again, his answer was “You know, I don't know because there are people who have been able to walk again even after an injury like this.” So that was different from every single other doctor that I've spoken to about being able to walk again. Every one of them categorically stated, “No, it's not going to happen,” and one of them actually even said, “Well, if Christopher Reeve can't do it, with all the money that he has, what makes you think you can?”

Before my injury, I was at the peak of my fitness because I worked out. I did all kinds of things. I think that that helped me because I was not out of shape when I fell.

You talk with the other people with paralysis and you hear their stories and most of them were in the hospital for six months, at least. I was in for four. So I'm thinking that because I was in good shape, that really helped.

I've been very lucky, if you could say that, because I've been surrounded with people who are amazing. You know, who really, really care and they became my support system. The thing that I would say to others would be, get yourself a really good network of people that you can rely on, whether it's a caregiver or a family member or a neighbor.

I don't know how it happened, but I got really lucky that I have all these people. Because you’re going to need help, like it or not. *The other thing I would say is don't give up because you don't know how far you can go, and keep an open mind.* Do the therapy and even if you don't get any return back, you will keep your body a lot healthier. Keep eating right, working out. You can get some exercises you can do, even with a C5-C6 injury. Stay healthy because you want to be healthy if there’s some kind of a cure available. You know, you want to make sure you're able to take advantage of that.

What I would say about Dr. Justin Brown is that I would definitely go for a consultation with him. He's really brilliant. He's an amazing surgeon. And really one of the best in terms of not just his skill, but his bedside manner. I would have liked to have started the surgeries sooner, but I had insurance issues at the time. I will graduate, next spring in 2020. I got married last year in Singapore and I could not have traveled there if it wasn't for the surgeries that Dr. Brown did, for my support team, and my determination.

Dr. Brown comments

Zarina was one of the brave patients that had surgery before she knew anyone else who had tried it. Like many patients, she preferred to achieve the best function in one hand before moving on to do the other. We were able to use a combination of techniques to restore triceps function. This, like Andres, took well over a year. At about 14 months she came in and simply said, “watch this.” She immediately extended her arm right above her head with very good strength. Somehow retraining was not critical in her case like it is for so many. Sometimes the movements are just intuitive. Hand function required a staged approach and after the second stage, it wasn't but a couple months before she began to demonstrate an excellent grasp. With Zarina, we used a bony fusion to position the thumb. IN other patients we have done this with tendon transfers. In each case the available options may differ. In the end she achieved very useful function of the arm and hand and plans to visit us in Boston for the other arm in the near future.

Sean

In September of 2001 I broke my neck playing high school football, in the third week of my senior year. That left me as a C5-C6 quadriplegic. I was competitive, skilled and in good shape before the injury. After it, I was just incomplete. The spinal cord wasn't severed, so I had feelings still throughout my body. I just couldn't move from the chest area down.

After that I did as much rehab as I possibly could, just to regain strength and get back to some sort of a normal life. I ended up graduating with my class on time later that year.

My goal was to get back into some sort of normal routine in life, and I ended up finding sports again. I played pod rugby for the local team out here which is sponsored by one of the hospitals. So with that I got stronger and I learned more about what I physically could do with such limited function: no hand function, no triceps but I still had some arm function. Knowing that I'd get back into sports again made life a little bit easier.

I learned as much as I could about how to do the daily tasks again, the cleaning, bathing, cooking, eating, all the little stuff you've taken for granted when you could just easily open a refrigerator and pick something up.

Without the hand function, I had to figure out how to open up the refrigerator and lift something out of it. I wanted to go as far as I could. It was about 12 years into my injury, and I finally decided to pull the trigger to have surgery done. It's always something that I knew about because I'd met other people through playing rugby that have had tendon transfer surgery. I just wasn't ready to commit to such an invasive procedure and a recovery process. But I got to the point where I still wanted to do more but my body wouldn't let me. So I continued with my research to find the best possible solution for it, along with the best possible doctor. And that's how I came across Dr. Justin Brown.

Immediately after my injury I had no surgical procedures to help my injury, except the surgery to fix the broken neck. So I just relied on what I'd learned from rehab when I first got injured, along with years and years of sports training. I pushed myself as far as I could, but you just have to work around what you can't do.

I've met some of the guys from the New Zealand national team through rugby as well, the guys that got hurt playing traditional rugby and ended up playing wheelchair rugby for the All Blacks. They traveled to the States to play for some of our teams out here. It's a global community and we all share as much knowledge as possible with each other.

After I found Dr. Brown, I made the initial appointment to see what the options were. I knew through my research that there were a handful of different ways surgeries can go, but it all depended on what my actual level of function was, and what we could use in order to strengthen or give a return in another area.

So I met with Dr. Brown to basically give him a blank canvas and said, "This is what I would like to do. This is what I'm hoping to get in return from either a surgery or several surgeries".

And that's when we figured out a game plan. We found three or four different options that we could go with to not only restore some functional movement in my right hand, but also give me some sort of a tricep function as well in that arm.

So going from zero hand function and zero tricep function, I would be happy with a little bit of movement.

And I come to find out that I can now almost fully extend my index finger and my thumb. I have control over closing them. And Dr Brown gave me a partial triceps, even though its function is slightly different, but I can fully straighten my right arm out as I hold it over my head. But my left arm would not get anywhere close to that and would just fall and hit me.

But of course, I was not going to be satisfied with just that. We might as well go a little bit further. We did one more surgery after that and that gave me a strong pinch between my thumb and my index finger. Now I could open up the refrigerator, and I could open my hand just enough to put around something and then I could pinch and close it, so I have some sort of a grasp.

He did amazing work with shockingly little function that I had. I say it's a little function but I've definitely met people with less function than me. I didn't think I could get it done, but he was extremely confident and he said, "Yeah, let's do it. "

The first surgery we did was a nerve transfer where I believe he took a nerve from the back of my left leg. And I believe we used that to lengthen the nerves for the triceps. And then we did a nerve transfer in my wrist which gave me the ability to open the index finger and the thumb and then control the closing function of it and that allowed me more, dexterity-wise. And then after that, we did the tendon transfer and it was the last forearm area that gave me the pinch.

Recovery period has to be taken slowly. I had to be patient. But for the most part, I was able to move relatively freely either the next day or a couple of days after surgery. It was just hard to slow down again when I was going so fast before the injury.

I have noticed daily life activities are a bit easier. Now, when I reach over to grab something like a cookie or a cracker or a drink or something, I can actually pick it up with one hand instead of having to use two to grab it most times. I can lock my arm out and reach something on a higher shelf now where I wasn't able to reach as high before because my arm couldn't extend.

But it's the little things that we wouldn't have noticed before that make such a huge difference. And as soon as I started noticing the little things I could now do I immediately said to myself, "Why didn't I do this sooner?"

I've actually had people reach out asking me about the surgeries on a couple of support groups online and on Facebook. A lot of people have been looking into it because they have heard of options like this. Well, I say it worked great for me. I say that they always have to speak with the doctor performing the surgery or reach out to Dr. Brown.

I always tell them, that every situation is slightly different because every injury is different. My recovery isn't going to be the same as someone else's. Just because something worked for me doesn't mean it can work for you. While I want to give someone hope and excitement there has to be that level of understanding that you might have a different experience.

But you also have to make sure you have support around you and in place and be able to take time off from whatever you're doing in order to recover. Because if you go into this not fully mentally prepared, you might end up rushing your recovery or injuring yourself and not getting the full benefits and output that you would want or hope for

And it's also a very slow process in the recovery especially with the nerve transfer. You're not going to get instant results. At least, I didn't and everything from my research said that. The results are going to take time for the nerve transfer. So you just have to be patient.

With the tendon transfer, it was relatively immediate that I noticed a difference. But it still takes time to build that strength up and then the new muscle memory of “Oh, I could do it this way now, instead of the way that I've been doing it for 12 years.”

I chose Dr Brown because I found that he was the best surgeon, not only the best surgeon for this type of injury, but also the best surgeon in my area. I was very fortunate that he was here in town at that time when I decided to pull the trigger with these procedures.

I did talk to a few other people in the industry, whether they were doctors or physical therapists or trainers. A lot of them were excited to see my results from the surgeries because they’d only heard rumors of things like this.

I was very comfortable with Dr Brown. He explained everything to me and we discussed anything I was concerned about. I basically said, “Here’s my arm. Give me as much function as possible without losing as much as possible.”

When I was doing the research, I wasn’t super comfortable traveling for surgery. But after Dr Brown told me, he was going to the East Coast, I know he's the only doctor I would actually get on a plane to have surgery with. If he said now, “Hey, I’ve got an idea. I want to do something.” I would book the next flight out there. I have every confidence in him.

Dr. Brown comments

Sean is a hard worker as can be seen by the fact that he is a rugby player and does not let his injury slow him down. We are always enthusiastic about receiving a patient like him because we know that they will do their best to make the reconstruction successful and not get lazy and stop rehab too early. Once again, a hybrid approach was pursued. He was truly chronic, having has his injury more than a decade earlier. The nerve transfers were effective but not quite as strong as others. When we added the tendon transfer, though, this made a huge difference. Sean now has a very versatile hand. He can easily pick up a chip as well as get his hand around a can using a normal appearing hand posture. He does not use trick maneuvers, but has a very sophisticated pinch and grasp. His outcome has really changed the way we approach these injuries and including a tendon transfer for pinch is now something I offer relatively early to patients who want a strong pinch and to separate the function of the thumb from the fingers.

9. Are You A Candidate for Restorative Surgery?

Now that you've learned more about spinal cord injuries and the surgical procedures that can restore functionality, you may be wondering whether these procedures are right for you.

As a reconstructive neurosurgeon, I believe that anyone with a debilitating paralyzing injury is a potential candidate for such interventions. Even for people for whom nerve reconstruction isn't an option, there is usually something we can do to help alleviate impairment and restore some level of function beyond what you have been living with.

There are a few types of patients that require special consideration: the elderly, those who are not committed to the hard work required of post-surgical patients, and those with debilitating chronic pain.

- With the elderly, special consideration has to be given to their health status and the risk of undergoing major surgery. As we age, our ability to tolerate surgical trauma, anesthesia and the demands of recovery can pose a danger. Age doesn't disqualify someone from a nerve reconstruction procedure, but it does require special consideration and evaluation.
- When people learn that nerve construction can potentially reverse their paralysis and restore function, they are willing to agree to almost anything to get their surgery. However, what they're sometimes less willing to agree to, is the long, hard road to recovery. Recovery can mean hours of physical therapy, which is not always pleasant. Recovery requires home exercise. Recovery requires on-going follow up appointments for months or even years in some cases. Not surprisingly, people who cannot commit to the post-surgical requirements tend to have less than optimal outcomes. Compliance matters.
- Finally, people who have ongoing, debilitating chronic pain may have difficulty with the post-operative rehabilitation program because of their pain levels. Having chronic pain doesn't exclude someone from surgery. It is a factor to consider in the patient's overall plan of care. Rehabilitation is critically important to the restoration of movement and strength. There are not many of these patients that I wouldn't recommend for a procedure because if they give up now, there are no options. They may be able to regain hand function now and learn how to use that function with new tasks later.

None of these situations automatically exclude a patient from consideration for treatment. Each patient is evaluated independently and a determination is made based on their clinical presentation and the best treatment options for their injury.

While you're waiting to see your specialist, there are things you can do to improve your chances of being a good candidate for treatment.

- Focus on strength. Build strength where you can. Maintain what you have. There are actually fitness programs for spinal cord injury patients. The stronger your muscles are, the more options we will have to help you.
- Maintain your range of motion. A PT(Physical Therapist) or OT (Occupational Therapist) can help if available for you.
- Educate yourself about your injury. You want to be an active participant in your treatment.
- Maintain your health. Do NOT smoke.

Ideally, we want to see patients within six months of their injury. The sooner that you are seen, the more options that are available for reconstruction. If it’s been longer than six months since you were injured, there are still many options that can be considered.

But even if it has been many years since your injury, don’t despair. The fact is, there is most likely something that can be done to help. **There are viable options and there is always hope!**

10. Tips To Help You Prepare For and Get the Most out of Your First Appointment

We know that seeing a new specialist can be stressful. We want you to be fully informed and to be an active participant in your care. You will be sharing a lot of information at that first visit. You'll be asked a lot of questions. You may be sent for tests. It's a lot to take in.

Here are some tips we give to our new patients to help them prepare for that first appointment:

- Bring along a family member or friend. You'll be receiving a lot of information. It's hard to remember everything. Having someone along will help you remember key information.
- Write down the details of your injury. Understanding when it happened and the relevant injury circumstances is important information for your doctor.
- Bring a CD with your MRIs, CT scans and x-rays. These images are critical and a paper report is not enough for the doctors to review.
- If you have copies of pertinent medical records, bring them. If you don't, that's ok. We can request what is needed from past physicians.
- Make a list of any past treatment(s) for your injury. Knowing what treatment occurred is important for your doctor to know.
- Bring a list of all medications you may be taking. Don't forget to include any supplements or over-the-counter meds you may take.
- Don't be afraid to ask questions. Make a list of any questions you have.
- If tests are ordered, be sure to ask about any special preparation, precautions or actions you might need to take, before the test.

Once your diagnostic evaluation and testing are complete, you and your specialist can discuss treatment options and recommendations that can offer you the best chance of restoring function to your injured nerves and muscles.

Coming for a consultation or evaluation doesn't necessarily mean surgery is imminent. As healthcare providers, our role is to give you our best recommendations and provide you with the best care possible. Once your evaluation is complete, the steps you take next are up to you. We understand that you may not be ready for surgery yet. It's ok if you need to take some time to think it through. There are obviously many key factors to consider and we want you to make the best decision for you – a decision you are **totally** comfortable with.

We are here when you are ready.

11. Conclusion

It is my hope that you've found this Patient Guide informative and you now have a more thorough understanding of your spinal cord injury and the best treatment options available.

Science and technology have given us so many tools that were unavailable even just a few years ago. We now have a number of surgical procedures available to treat injuries once dismissed as untreatable. Whether it's nerve transfers, tendon transfers, muscle transplants or spinal cord stimulation, ***there is almost always something we can do to help.***

We have now reached the end of our journey together in this guide, but I hope, not forever.

If you have a specific question about something I didn't cover, then I welcome your email that you can send to me at the Paralysis Center at: contact@paralysiscenter.com

If there is one takeaway from this Guide it's that you need to see a paralysis specialist as soon as possible following your spinal cord injury. A paralysis specialist can evaluate your injury and provide you with the best recommendations for treatment.

If you would like to schedule an initial consult with me at the Paralysis Center in Boston, Massachusetts, we are accepting new patients. Mass General accepts most forms of medical insurance and also offers a financial assistance program. Additionally, if you are an international or out-of-town patient, Mass General provides you with support to book your travel and accommodations. Please visit: www.MassGeneral.org for more information.

For more information about spinal cord injuries, including medical papers I have written and recordings of medical conferences I have taught at, please visit the Paralysis Center Education Center on our website: www.ParalysisCenter.org

I encourage you to never give up hope, to always ask the hard questions and see a paralysis specialist as soon as possible.

God bless you and I wish you good health and good luck as you continue on your journey!

Justin M. Brown M.D.
Director & Founder
The Paralysis Center

12. About Dr. Justin M. Brown

Justin M. Brown M.D. is a board-certified neurosurgeon and global pioneer in Reconstructive Neurosurgery – an emerging specialty focusing upon surgical interventions to reverse the effects of paralyzing conditions. Dr. Brown believes that patients suffering from conditions of paralysis have had limited access to the treatments that would improve their condition because most centers across the world focus on only a single type of paralyzing condition. Specialists in Brachial Plexus injury did not see patients with spinal cord injury. Specialists in spinal cord injury hand reanimation often did not have expertise in spasticity. Developing expertise across all of these disorders both provided benefit for each of these individual conditions, and opened up options for conditions not previously focused on in surgical programs. Bringing all of the treatments for each of these conditions together into a single Center has now allowed for all comers to receive the best in paralysis reversal care without the obstacles that would otherwise limit care to those who do not fit the most commonly treated diagnoses. Dr. Brown has received widespread, international recognition for this work. He is an avid educator and a regular featured speaker at medical symposiums around the world.

Dr. Brown's own training has been multidisciplinary in nature. He earned his medical degree from the Eastern Virginia Medical School in Norfolk, Virginia and completed an internship in General Surgery and residency in Neurosurgery at Baylor College of Medicine in Houston, Texas. Thereafter, based on his desire to understand these problems from the perspective of another surgical specialty, Dr. Brown completed a Peripheral Nerve Surgery Fellowship in the Division of Plastic and Reconstructive Surgery at Washington University School of Medicine in St. Louis, Missouri. Then, in collaboration with a notable pioneer in Restorative Neurology, Milan R. Dimitrijevic, MD, PhD, he helped establish the International Society for Restorative Neurology. Dr. Brown is also a member of the American Society for Peripheral Nerve, The American Association for Hand Surgery, the AANS/CNS Section on Disorders of the Spine and Peripheral Nerve, the Congress of Neurological Surgeons, the American Association of Neurological Surgeons, and the Pan-African Association of Christian Surgeons.

Dr. Justin Brown currently serves as Director of Reconstructive Neurosurgery at Massachusetts General Hospital, is Associate Professor of Neurosurgery at Harvard Medical School, and is the Founder and Director of the Paralysis Center.

13. The Paralysis Center at Massachusetts General Hospital

Founded in 2017 in conjunction with Spaulding Rehabilitation Hospital, the Paralysis Center is a world-class patient treatment and medical research center for all conditions resulting in weakness and paralysis

Using a team approach, the Paralysis Center unites a multi-disciplinary team “under one roof” who are leaders in their respective fields: Neurosurgery, Neurology, Physical Medicine and Rehabilitation, Physical and Occupational therapy, Orthopedics and Plastic Surgery. We employ the best imaging and neurophysiology techniques available to give us the best information to inform our treatment plan.

At the same time, our research endeavors both to inform our current practice, as we collect detailed diagnostic, intervention and outcomes data for each patient, and, to pave the way for new interventions that we hope to implement in coming years, which will further enhance the lives of our patients.

Such comprehensive care gives patients access to the most cutting-edge technology and proven paralysis-reversal treatments — providing a best-in-class treatment facility for every aspect of patient recovery.

No matter what form of paralysis you or a loved-one suffers from, or what medical advice you may have received before – there is genuine hope. We *can* help you get movement back. Schedule a consult with Dr. Brown today to better understand your treatment options by calling (844) 930-1001.

For more information, please visit: www.ParalysisCenter.org