

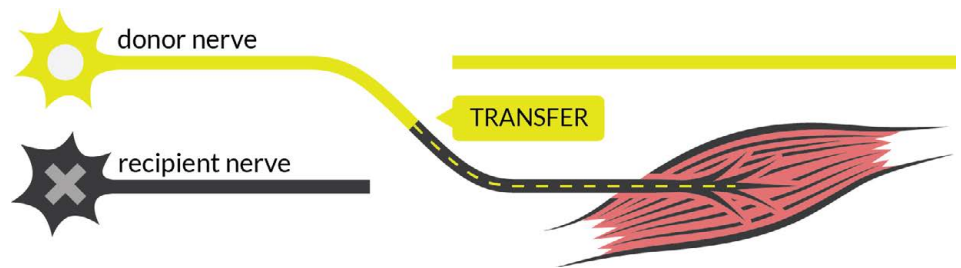
# Community Stories

## Experiences of nerve transfer surgery

Authors: Kelsey Zhao, Dominik Zbogar | Published: 14 May 2024

**N**erve transfer surgery can restore movement to the paralyzed arm or hand of someone with a high-level spinal cord injury (SCI), by connecting a healthy nerve to the nerve of the paralyzed muscle.

There is much about nerve transfers that we don't know but we can construct a nuanced view from the diverse experiences of people who have done the procedure. Ainsley, Dan, and Caleb graciously recount their experiences with nerve transfer surgeries, the obstacles they encountered, and the insights they have gleaned, for our readers.



Refer to our article on [Nerve Transfer Surgery](#) for more information!

### Introducing...



**Ainsley** is 17 and plans on doing a Bachelor of Arts at the University of British Columbia after graduating high school this year!

SCI level: C5-C6 complete



**Dan** is 37 and a full-time student at Douglas College in Recreation Therapy! He enjoys cooking and has a dog.

SCI level: C5-C6 complete



**Caleb** is 35 and likes to spend his time outdoors and doing sports like scuba diving, whitewater kayaking and sitskiing!

SCI level: C5 complete

### Nerve transfer options

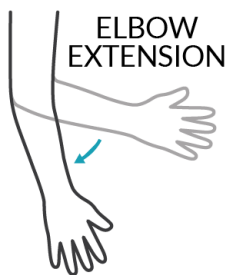
*Choosing to have surgery can be a tough decision. There are pros and cons to every procedure and a million factors to consider.*

**Ainsley** opted to have three nerve transfers on each arm: supinator nerve to posterior interosseous nerve (PIN) for hand opening, brachialis nerve to anterior interosseous nerve (AIN)/flexor digitorum superficialis (FDS) for hand closing, and teres minor nerve (with some deltoid) to triceps for elbow extension. Ainsley's surgical team was able to do her surgeries 6 months after her SCI, during a holiday break from school. Keeping in mind that nerve transfers are not always successful, the nerves were carefully selected to make sure *tendon* transfers could be done as backups. This precaution paid off when the right-side hand closing nerve transfer didn't work out.

**Dan** had two nerve transfers on each arm for finger extension and finger flexion. Unlike Caleb and Ainsley who had nerve transfers done only a few months after injury, Dan had been living with SCI for 5 years when he did the surgeries. Nerve transfer is not always possible for a chronic injury because the muscle might be too deteriorated to recover. However, it can still be an option if

electrodiagnostic tests show that there is still activity in the muscle and nerve. Dan said, “they did a test to see whether my nerves were still viable, and they were.”

**Caleb** had three nerve transfers on both arms 5 months after his cervical SCI: supinator nerve to



PIN for finger extension, brachialis nerve to AIN for finger flexion, and deltoid to triceps for elbow extension. In the first few months after his SCI, but before the nerve transfer surgeries, he had recovered good wrist function, but his fingers and triceps were not improving. At that point, he was told what the probability of getting hand function back was and decided that doing the nerve transfers was the best option. Caleb said, “Even if it works out slightly, it will still be better than not doing it”.

### Recovery: the good and the bad

*Although the evidence so far shows that nerve transfer surgery rarely causes any lasting harms, the general risks that accompany any surgical procedure do exist, and the recovery period can be challenging. Negative experiences do exist alongside the overall success of the procedure.*

**Ainsley** had her nerve transfer surgeries while recovering from SCI at a rehabilitation centre. She stayed at the centre for a few days after the surgery but went home for the holiday season, then returned to continue rehabilitation. After the surgery, there was no cast, splint, or movement restrictions, but the incisions were quite large and painful for the first few days. Over time, the pain became more manageable with pain medication and the stitches dissolved, but it took two or three months before the incision scars stopped bothering her completely. For the first couple of weeks, Ainsley needed a lot of assistance with everyday tasks and had to be careful with big movements like getting dressed.



Because Ainsley used a power wheelchair, she was able to move around after the surgery like before, but she imagines it would be challenging for someone in a manual chair. Pain and loss of strength after surgery could make pushing a manual wheelchair difficult.

This was very true for **Dan**. After his nerve transfer surgery, he lost some muscle strength in his left hand and arm. He was still strong enough to push his chair but not to stop. As a result, he went from strictly using a manual chair to using a power wheelchair for about 10 months. The rest of Dan’s recovery did not go so smoothly either. He explains, “in my left arm, when I moved my arm in a certain way, I would get a twang. It felt like I hit my funny bone but times 100. It was really bad and that lasted about two weeks. I also

had some numbness in my left thumb all the way down to my palm. I still have numbness but it’s mostly the tip of my thumb so it’s better.”

On top of everything, Dan was living at home and not at a rehabilitation centre when he had his surgeries. He came to realize post-surgery that he did not have all the necessary supports in place to accommodate the temporary losses in function. Reflecting on these struggles, he suspects that since people with chronic SCI don’t get nerve transfers often, there is less awareness of how much the surgery can affect their functional abilities.



Like Ainsley, **Caleb** was living and recovering at a rehabilitation facility up until when his nerve transfer surgeries were done, and was able to extend his stay a bit to include the first few days of his surgical recovery. He had pain for one day after the nerve transfers were done, followed by the normal aches of surgery. Caleb was still pretty weak from his SCI accident, but he did not feel any difference in strength from before to after the surgery. All in all, nothing unexpected.

What stuck out the most to Caleb about recovery was the amount of time he spent imagining movements (visualization exercises) while no

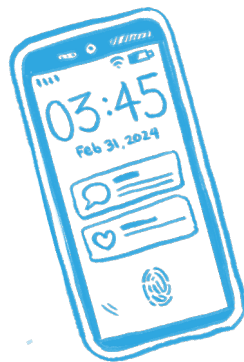
movement was actually happening! Coming from a big sports background, he understood what it meant to visualize actions and the benefits of the exercise. Even so, before the first signs of movement showed up, Caleb had moments where he thought, “Oh man, this is just not doing anything. Will it ever happen?”.

### Good to have a back up plan

Around a year and a half after **Ainsley’s** nerve transfer surgeries, her hand closing was improved and strong in the left, but her right hand produced only a flicker of movement. With her surgeons, it was determined that her right hand was not improving further so Ainsley went ahead with Plan B – a *tendon* transfer for the thumb to index finger pinch grip. Ainsley describes the *tendon* transfer recovery as “hard” compared to *nerve* transfer because “I was in a cast and not allowed to move for 6 weeks”. In contrast, she was able to move around immediately after nerve transfer surgery with pain medications. That said, the tendon transfer was a success!

### Where they are at today

**Ainsley** is now 2 years after the nerve transfers and has gained the ability to fully open both hands. On the left, her restored hand closing from nerve transfer is very strong and she can pick things up. The right-hand pinch gained from the tendon transfer is functional and continues to build strength. All these improvements in her fingers and hands mean that Ainsley can use her cell phone with finger gestures, scratch an itch, adjust her hair, and hold and use things like cutlery, a toothbrush, makeup, and bank cards. The triceps nerve transfer has recovered to the point where she can now extend both arms against gravity. These days, Ainsley is getting ready to hit the road in a custom hand control vehicle, something that would not have been possible if not for the triceps surgeries that improved her strength enough to turn a steering wheel. Hopeful for the future, Ainsley says that she is “still improving everyday”.



**Dan** is coming up on 3 years after the nerve transfers. Although his grip is not strong, it is



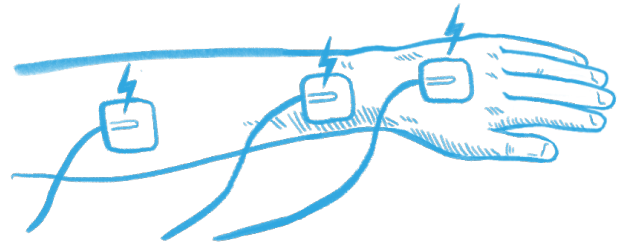
strong enough that he can use and squeeze the brakes on the new e-bike attachment for his wheelchair, which he would not have been able to do without the nerve transfer. Being able to extend his fingers has made it much easier to open his hand to grasp things and move them around. He

has more function in his hands than before, but he still has not recovered some of the strength he lost after the surgeries. Dan described how “Before the surgery I could lift a full backpack of groceries off of the back of my chair now I have difficulty if there’s any weight in my bag.” That said, he is still waiting to see how much he improves, explaining, “...it’s coming, it’s just not there yet. I think they say the plateau is four years for this surgery...”, referencing experts who say that improvements for nerve transfers typically reach their peak at around 4 years.

Even though **Caleb** is only 1 year and 3 months after the nerve transfer and still has a long way to go, he is already happy with the improvements. “Going from zero movement in my fingers to now, it’s kind of huge”. The first big impact the nerve transfers had in Caleb’s day-to-day life was probably around four months in, when he was able to open his hand to grab his toothbrush without any kind of assistance. He can now grab a toothbrush or pop can and hold on to it without a problem. His triceps progress has been harder to pin down. There is some movement in his left arm and a small amount in his right arm but he wonders if that would have come back naturally after SCI regardless of the nerve transfers. Whether or not the improvements came from the nerve transfers or from natural recovery, it has been a big help for Caleb’s mobility and being able to shift and transfer.



*It is clear that the functions gained and the rate of recovery for nerve transfer surgeries can vary widely. However, what determines the success and speed of recovery after surgery is still an area of active research.*



## Advice and recommendations

*There is a sense of excitement about nerve transfer surgeries and their potential for helping patients with SCI. The procedure has had many successes but so much research remains to be done to improve outcomes. Reflecting on their own journeys, Ainsley, Dan, and Caleb offered some words of advice on nerve transfers for both the clinicians who make them happen and the people who will need them in the future.*

**Ainsley** encourages others to advocate for their treatment options. She and her family found a specific nerve transfer that they believed would be a good option for her, and worked closely with the surgical team. The results were good and Ainsley tells us that since then, that surgical team has had many successes with that same procedure on other people. Overall Ainsley believes that the surgery was “very much worth it. The benefits outweigh the cons, and I was very lucky that I had great surgeons”. Ainsley and her dad also strongly recommend considering tendon transfers as a backup for nerve transfers.

**Dan** offered some words of caution as a nerve transfer recipient with chronic SCI. He felt like he went into the surgery with rose-coloured glasses on, only to discover that the recovery was not seamless and there were many unforeseen obstacles. Having lived with an SCI for many years, Dan says, “...there were so many things that I had learned how to do in those five years that all of a sudden, I wasn’t able to do.” and he thinks the doctors did not realize these adaptations would be impacted by the surgery. He had the impression that he would “be able to do everything you could do before”, but in reality, he lost some abilities for a while, including being able to transfer and use a manual wheelchair.

Considering his rehabilitation, **Dan** wonders if more could be done at home. For example, he heard of other people who did a lot of functional electrical stimulation (FES) for their nerve transfer rehabilitation and proposed, “You can set up somebody to do FES by themselves on their arms, right?... The client can be shown how to

do it... and do it at home.” On the other hand, Ainsley had the chance to try FES but found that even when working with an occupational therapist, it was too difficult to correctly place the electrodes. That said, rehabilitation is specific to the individual and what doesn’t work for one person might work for another!

Dan also suggested that rehabilitation after surgery could be more structured, “like a program that you do after the surgery, then for the next three months after”.

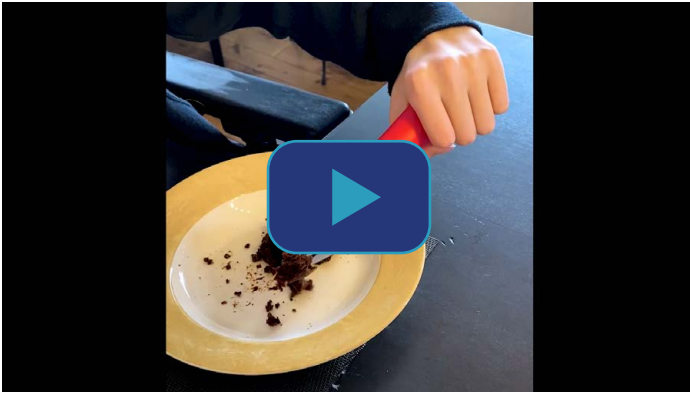
Having spoken with Dan about this before, **Caleb** agrees that following a program would be useful. He thinks his occupational and physical therapy team did a great job but a clear step-by-step handbook or video outlining the exercises and the braces used would be nice. While Caleb did exercises in rehabilitation, some videos of him were recorded for him to refer back to but he thinks it would also be beneficial to see someone demonstrate the exercises, like a guide.

When asked what he would say to someone considering nerve transfer, **Caleb** admits, “Because mine went so well, when I talk to people, I’m like yeah it went really good. It’s gonna be all benefit...”. Still, he recognizes that it does not go that well for everyone, adding that “it would be awesome to have this larger compilation of all the things that went well and didn’t go well (for different people), so that way, people could really see the options...”

*All in all, we can see that every experience with nerve transfer surgery will be different; every person will encounter unique obstacles, surprises, and benefits. Even with all the research papers and educational resources, nothing can portray an experience in full colour quite like a conversation with a person who has been through it.*

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Continue to the next page to see videos of Ainsley, Dan, and Caleb demonstrating some of the movements and functions they have gained in rehabilitation after nerve transfer surgery.



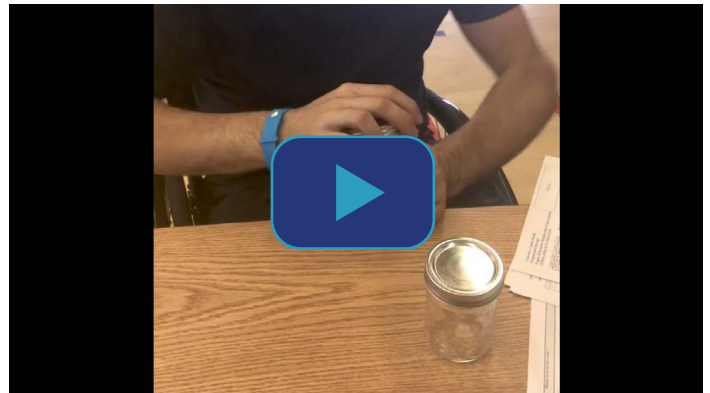
Ainsley demonstrating functional recovery of hand opening and closing by using a fork to eat.



Ainsley demonstrating functional recovery of triceps shoulder extensions by reaching up to adjust a wall thermostat.



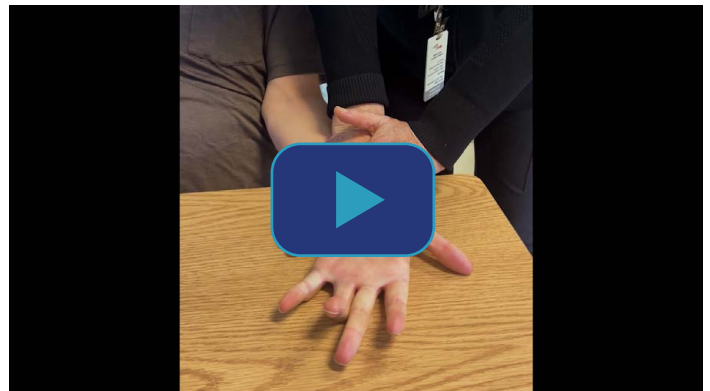
Dan demonstrating functional recovery of hand opening and closing by driving and squeezing the brakes on an e-bike wheelchair attachment.



Dan demonstrating functional recovery of hand opening and closing by opening and closing the lid on a jar.



Caleb demonstrating an elbow extension exercise for triceps nerve transfer rehabilitation.



Caleb demonstrating a hand opening exercise for supinator to PIN nerve transfer rehabilitation.

