

going to walk away (although some do), but better in that you will understand your body and how to manage the functions that, at this point, seem very out of control. You will be physically stronger than when you arrived and you will have experts help fit you for a mobility device that suits you. You will know how to tell people what you and your body need in order to function well.

Peer Perspective

DIANE'S DECISION

When I was first injured, I didn't really grasp the many ways that my life would be impacted by my SCI. I also didn't understand the difference that SCI-specific rehab would have on my outcome. I was told that I should go to Lyndhurst, but I couldn't understand why I couldn't do rehab at my home hospital. Living in a remote Northern Ontario town, Toronto was very far from my home, my family and friends. I would be on my own if I went to Lyndhurst for rehab and I was afraid. My physiotherapist at the hospital played a big role in teaching me that there was a huge difference in what I would learn in my community hospital vs. what I would learn at Lyndhurst. Even though I really didn't want to go, I agreed to the application.

I remember the day I was transferred to Lyndhurst. I felt so alone, but right away I began to learn about how to take care of my body and how I was going to learn to transfer and get dressed. There were other people that were around my age, who were going through similar things. They had been at rehab a little while and had seen the benefits, so they welcomed and encouraged me. I can't stress how much my life began to change after I got to rehab. I got stronger and more independent. I was challenged by my health care team to do more for myself all the time. They provided me with the tools, information and support needed to get going; I provided the perseverance.

I can't stress enough the importance of going to rehab, even if it means travelling far from home. I was not the same person leaving rehab as when I entered.

Peer Perspective

MICHELLE'S STORY (C5-C6 INCOMPLETE) – FOLDING SOCKS JUST FOR FUN

I didn't have a lot of hand function when I came home from physio, but I have been working on gaining strength and dexterity ever since. I work with a kinesiologist every week and together we try to do new things. Instead of just traditional exercises, we are doing things that have improved my hand function, but also have meaning. I even made my own video that shows how I can now fold laundry and even socks! I know that all the work I have done to improve my arm and hand strength and function have led to me being able to hold my new grandchild.

Professional Points: Occupational Therapy (OT)

What is OT?

The goal of occupational therapy is to help you become as independent as possible prior to your discharge. Your first visit to OT will involve being assessed by the therapist who is assigned to be on your team. They will assess your strength (active and passive) and your range of motion (shoulders to fingers), as well as your trunk balance. You will be asked to describe your pain and your skin sensation will be tested.

What kind of therapy will I receive in OT?

Your level of injury will determine the type of therapy that you will receive. If you have a thoracic or lumbar level injury, you will work on core strength and balance as well as shoulder and arm strength. With higher level injuries (high T-spine and C-spine), you will be helped to learn how to find a pain-free range of motion for your shoulders, arms and fingers. You will also work on hand and finger strength, dexterity and co-ordination. OTs will help you learn the benefits of using finger/hand splints and aids for holding things (like spoons). You will learn how to do things that you used to take for granted like sitting up independently or scratching the top of your head!



NEW "SPORTY" FRIENDS

I have made some amazing friends by trying new sports. Well, I guess the sports are not new to me, but I have a new way of doing them. Skiing, biking and kayaking are all things I have done before, but doing them all with your arms (and little core) sure makes them challenging. My point, though, is if I had not given them a try, I would not have met these amazing women who have done so much with their lives, regardless of the fact that they have a disability. So give it a try; you never know where it will take you and who you will meet along the way.

Peer Perspective

MICHELLE (C5-C6 INCOMPLETE) AND YOUTUBE

When I got home, I kept talking to the SCIO peer volunteer, but I also wanted to find a community of more peers. Because I couldn't get out on my own yet, I started searching things up on the internet. What I found were a lot of SCI peers on YouTube. I am so thankful to all the people with quadriplegia who opened up their lives and shared how they do things. Everything from how to hold a fork by weaving in between your fingers to applying makeup.

It's a mind set — I didn't think I would be able to travel until I saw that other people like me were doing it. We went to Florida and it was that first trip that helped me realize that I am capable of using a manual chair, not just a power chair. My YouTube peers gave me something to do that was constructive — research. It fed my desire to learn how to overcome the challenges that I was facing. It gave me hope.

ramps can be installed. Create access to the kitchen by taking off doors under the sink so you can roll under. Make a lower workspace from a desk, leave some dishes on the counter where you can reach and lower the microwave. Ask your OT for suggestions. Bigger changes can be made down the road but, for now, all your energy should go into recovery.

4. **Outdoor space:** As you think about your home, try to focus on what you will be able to do when you get there. It is really important that you are able to get outside. Maybe it means getting out on your veranda, driveway or just out onto your front step; in any case, you will welcome some fresh air and sunshine.

What will going home really be like?

It's best to just come out and say it. Going home is going to be challenging. In some ways, you will be excited about being home, but in many ways you will realize that being home could be hard. Very hard.

Peer Perspective

A CONVERSATION WITH MIKE (T11-T12) AND KAREN

When Mike was ready to leave rehab, his home was not ready for him. Multiple sets of stairs prevented him from moving back to the house he shared with his wife Karen. The option they decided on (supported by WSIB) was for Mike to get a private room at a residential care facility. Their plan was for Mike to stay there while they sold their house, bought and renovated another.

Mike lived with people who were 30 to 40 years older than him and he enjoyed their company. He is, after all, a pretty social guy! Mike was able to access the pool for fitness and physio. He wheeled downtown in minutes to get to all the places and appointments he needed to go to. Karen and Mike have since purchased a home and are making plans to renovate. After that, they will be able to find a new normal of being a couple again!

Peer Perspective

MICHELLE (C6-C7 INCOMPLETE) ON GOING HOME

When I came home from rehab, I felt really vulnerable. In the beginning, my quadriplegia left me without the use of my hands. I remember being at home when there was a spider crawling on my leg. I didn't have the ability to sweep it away or squish it. I couldn't get the spider off my leg. It took so much time for me to realize that it was okay that I was alive. Little by little, all the effort that I put into my recovery started to show, but it's a slow process. Nerve pain may not go away but you get used to it, you learn to tolerate it. I take medication sometimes to take the edge off when it is bad. Nerve pain used to preoccupy me, but now I can think over top of it. It took two and a half years to get that far.

The importance of SCIO Regional Services

No matter where you are on your journey or what plans you have, the experience and expertise of SCIO Regional Services Co-ordinators can help you move closer to your goals. Staff members — many of whom have a spinal cord injury — are in your community providing practical help, advocacy and assistance, from injury right through rehabilitation and into the community. Regional Services Co-ordinators are located across the province to provide highly individualized services by phone, email and in person in SCIO offices, in your home or at a mutually convenient location. These services are free to registered clients of SCIO.

You don't know what you don't know. Every person and situation is unique, so a Regional Service Co-ordinator will help you determine your needs and support you in finding the best path to living independently. They will work with you to navigate the system in your area, help you advocate for change, adjust to life with a physical disability and guide you to achieve your recovery goals.

SCIO provides information and education on a wide range of topics and can be your first stop when you need support. Because the Province of Ontario is

Peer Perspective

JULIE (C4-C5) — PSW SUPPORT MEANS INDEPENDENCE

I have PSWs that come in the morning to help me get up and at night for about an hour, to help me get into bed. I used community agencies for the first 5-6 years and then started hiring privately. If I can't find anyone through word of mouth, I'll put an ad on a website.

I don't drive so, if I'm not with friends, sometimes my PSWs will drive me places or I have a full-time person that takes me where I need to go. This person has always been hired privately.

I'm not much of a cook, so I often go to a little market that has pre-made meals. I have also ordered from a company that delivers individually portioned, pre-made frozen meals.

I am very fortunate that I was able to build my own home. It suits my needs and I think that really helps me live as independently as I can.

DRIVING

Why did they take my licence away?

Upon injury, your medical team is required by law to complete the paperwork that revokes your driver's licence. It's a process, but if you have enough manual dexterity and upper body strength, you will be able to get your licence back and drive again.

What do I need to do to get my licence back?

The first step is having your rehab doctor write a "prescription" for you to be assessed. The assessment will be done by an OT with specific driver-training qualifications. You will need to choose the location where you will do your assessment, lessons and final test. Most places will have wait-lists, so get your name on it as fast as you can.

info you need. If you have unanswered questions, ask members of your health care team, or use SCIO's InfoLine at 1-877-422-1112, ext. 213 or info@sciontario.org and they'll share the info and resources they have.

Starting a family

If you were a parent before your injury, things will have changed for you and your family, but there's no question that your role of parent will be just as much a part of your life after injury.

If you have sustained a spinal cord injury and are wondering if it will impact your ability to become a parent, read on. From issues surrounding sexual function and conception to birthing and raising children, people with SCI face certain challenges and issues, but they are not insurmountable by any means to starting a family.

Peer Perspective

GABRIELLA CARAFA ON SEX AND SCI

If you will be dating sometime in the future, you might anticipate the question, "How do you have sex?" My suggestion is that you find an answer for yourself first and then decide what you are willing to share with a potential partner.

If you are in a relationship, your partner will be going through a transition as well. They will be relearning how to give and receive pleasure. Luckily, you can explore this together! For example, the two of you may change or broaden your definitions of pleasure and intimacy. It's important for both of you to be honest about what has changed and how you can go forward together. Encourage your partner to share their needs as you share yours.

Exploring sexuality requires honest and trusting communication. But what specific conversations might you have? Here are some common topics: physical changes in sensation; the need for planning and forethought; personal assumptions and biases about "right" and "wrong" ways to be intimate; and what new approaches you can try. There may be additional physical details to share, such as whether your ability to be aroused has changed. Good communication is vital for intimacy.

Peer Perspective

CAMILO ACERO, BECOMING A FATHER AFTER SCI

I always knew I wanted to be a father. After being married for ten years, my wife and I decided to investigate how we might start a family. Having sustained a spinal cord injury over 20 years ago, I knew the process could be complicated. I worked with an expert urologist and then a fertility doctor to begin a process of trial and error to determine the best way for us to conceive. Depending on the level of injury, there are different ways for men with SCI to provide sperm – some can get erections and ejaculate, some cannot. There are options to encourage ejaculation (penile vibratory stimulation or electroejaculation) and options to retrieve sperm surgically.

And then there's the issue of sperm quality. Which is where the fertility experts come in. We understood that success was not a certainty and that there were other resources and options such as adoption. But by using in-vitro fertilization and intracytoplasmic sperm injection (injecting individual sperm in the female eggs), we got lucky! Our beautiful three-year-old daughter is an immense source of joy to us both. My next question is: how will I teach her to ride a bike? Some say it'll be easy because I'll be on wheels too!

LUBNA ASLAM, GIVING BIRTH AFTER SCI

I was 25 years old when I sustained an SCI at T10 level. Parenthood was an important life goal and, as a spinal cord injury does not impact female reproduction, it was a dream fulfilled post injury. In October 2003, a neurosurgeon gave me the green light to try for a baby. Before long, my husband and I were ecstatic to find out I was pregnant. My weight gain was rapid and my doctor needed to frequently monitor my blood pressure and sugar level. Since a lot of physician's examination tables are not accessible, my husband had to pick me up. Transferring became increasingly taxing and I lost my independence to some level, but I had a good support network among family and friends.

On September 30, 2004, I entered the delivery room and was given an epidural to avoid Autonomic Dysreflexia. Though I didn't feel pain, I could feel all the pressure during contractions. Fourteen hours of intensive labour later, I gave birth naturally to our son. We named him Zayed. Holding the newborn in my arms, I finally felt like my life was made whole. Two years later, our daughter Zara was born. I hope my experience will help newly injured women believe their disability does not compromise their desirability and their body. They can still be the partner and mother they may have dreamed of being.

SPORTS & RECREATION

Say yes to new things

This is what is going to help you get back to life. Be brave and that is where change will come. Things won't always go your way, but that is how you learn. You can't expect everyone in your life to bend to your needs — you may sometimes need to manage in a tiny bathroom, or sleep on a pull-out couch. Travel will lead to strange hotel room set-ups and dining tables that you can't quite get under. Having help is key, especially as you start to venture away from home, but that doesn't mean you can't try things out on your own. If you don't try, you'll never know...

There are lots of new activities to try and experiences to explore and, as you do, you will lessen any sense of isolation. So try travel or sports or new social situations, or a combination of those things. Choose whatever may suit your mood, finances and energy at any given time in your life. The point is that the decision to get and stay involved is a powerful one.

DAVE WILLSIE – LIFE FROM SPORT

At the age of 27, Dave sustained a C6 incomplete injury playing hockey. While still in rehab, he learned about wheelchair rugby, an indoor court sport played mostly by those with quadriplegia. At the time, Dave was not particularly keen on wheelchair sports; he felt like they were more of a “consolation” sport where it was “good you came out” and not much more.

The day he left rehab, he went to a gym to watch a local group that played wheelchair rugby. As the door was opened for him, he saw two players collide with their chairs pretty much going full tilt. One of the guys fell out of his chair and someone called, “Time out!” Dave signed up that day.

The rest, as they say, is history. Dave has been playing wheelchair rugby (both competitive and non-competitive) for 22 years. He is Assistant Coach for Team Canada and the former captain of that same team. I interviewed Dave to provide some context about the importance of sport for those with SCI (or other types of disabilities).

You have won a lot of championships and travelled the world as a part of Team Canada. What has been the best part of all that?

Two things, really. When I started playing wheelchair rugby, without realizing it, I was learning how to be a quad in real life. I had gained some strength and abilities in rehab, but being with all the guys on the team as we played and travelled, I gained more foundational skills that I would need to be independent. We stayed in hotels that were not accessible, flew around the world and learned how to navigate in unfamiliar environments. Being with other “quads” exposed me to driving with hand controls, grabbing things and riding roller coasters. Playing rugby allowed me to be fierce again; it helped me get my swagger back.

How did playing rugby improve your fitness?

Although it was fun and educational (learning how to navigate life as a quad), it also really helped me get in shape. Often, it was the kind of fitness that I didn’t even realize that I was doing. The more I played, the stronger I got. As that fitness increased, so did my stamina and energy, allowing me to do more, which included playing more rugby and at higher levels of competition. The other thing about being a quad and doing exercise is that I don’t sweat – I can roll 10km at the gym and then go right to work, no shower needed!

AN INTERVIEW WITH DIANA MCCAULEY, MANAGER, SCIO EMPLOYMENT SERVICES

How will I be able to work again?

After a newly sustained SCI, most are more concerned with figuring out their new life and their changed body; work is lower down the priority list. The people SCIO Employment Services work with are (generally speaking) NOT newly injured; they more likely are a couple of years into their new reality.

We do, on occasion, hear from people who are patients in rehab because they want to know about peers who have returned to work, how they got there and what type of work they are doing. We tell them that yes, you can do it, but getting back to work is a full-time job in itself. You have to be ready for interviews, respond to postings, have résumés tailored — be on your game!

There are always exceptions. One client, after an injury and a few months of rehab, was ready to go back to his previous job. His employer had kept him in the loop with what had been going on and said they were ready to have him back as soon as he was ready. He was motivated and, once he figured out his morning routine and his transportation, he was back in his former position.

What is the responsibility of the employer to someone who wishes to return to their previous position?

Employers are obligated under the Ontario Human Rights Code to find a comparable position, a job that the individual is able to perform. According to the Code:

“... the goal of accommodation is to ensure that an employee who is able to work can do so. In practice, this means that the employer must accommodate the employee in a way that, while not causing the employer undue hardship, will ensure that the employee can work. The purpose of the duty to accommodate is to ensure that persons who are otherwise fit to work are not unfairly excluded where working conditions can be adjusted without undue hardship.”

Most employers will have already “invested” in the individual (e.g., to develop their skills), so although they might not be able to do their old job due to physical limitations, the employer will want to retain the skills that employee has. It’s best to have an open and honest conversation with that employer to help plan a path back to the workplace.

ALIREZA TEHRANI PROVES A SECOND CAREER IS POSSIBLE

When Alireza Tehrani came to Canada from Iran, he planned to continue to work as a dentist. After sustaining a spinal cord injury, his degree of disability just wouldn't allow it. So he switched to accounting and earned his CPA certificate. Initially, he assumed his education and background as a professional would pay off and he would find a position easily. As time passed, he realized that he needed help.

By working with SCIO Employment Services, Alireza reworked his résumé, practiced his job interview skills, learned about disclosure and participated in job fairs. He registered on Career Edge (which connects employers to job seekers facing barriers through a paid internship) and secured a four-month internship at RBC. Alireza is still on that contract. Now that he is known in the organization and has proven his value, he is confident he will eventually gain full-time permanent employment with RBC.

"The best thing I gained from Employment Services at SCIO was confidence. I had lost my first career, I was disabled and I was a recent grad. I wasn't brimming with confidence and I didn't know how to cross the divide to employment. The mental and emotional support I received got me started. I'm now experienced, capable and at the beginning of a long second career."

TRAVEL

Planes, trains and automobiles

Before you go anywhere, make sure you apply for the Disability Travel Card offered by Easter Seals. This allows you to have a free travel companion on VIA trains and other travel partners. Airlines also allow free or discounted travel companions, each with their own regulations. Always call the airline in advance of your trip to make sure they know about your wheelchair and how you transfer to a seat — do you need a lift? They will ask about the weight of it and the size. You need to ask for an aisle chair to be ready and waiting for you to transfer with. Ask again when you check in! Each airline is different and they are not equally prepared for travellers using wheelchairs. You should also ask to be bumped up to the front of the plane — way easier to get on

CMHC

Canadian Mortgage and Housing Corporation will provide funding for on-reserve housing in need of modification.

<https://www.cmhc-schl.gc.ca/en/developing-and-renovating/funding-opportunities/on-reserve-renovation-programs/residential-rehabilitation-assistance-program/home-modifications-for-persons-with-disabilities>

Local service clubs

Especially if you live in a small community, the Lions, Masons, Rotary or other service clubs may be willing and able to help out. It may be a financial contribution or it may be with people power to help build a ramp into your house, for example. If you don't ask, you won't know!

Fundraising campaigns

Major renovations can be costly, especially when they are not planned for and need to be done quickly. It's okay to ask for support; many people will understand that need and will offer up some amount of financial support. GoFundMe is a good way to start, especially if you have some friends (local or on social media) willing to help you get it going.

Peer Perspective

PETER ATHANASOPOULOS, DIRECTOR OF PUBLIC POLICY, SCIO

I have been living with an SCI for more than 20 years, after I was injured at 17 years old in a diving accident. I was so grateful to my SCIO peer mentor early in my recovery that I volunteered to become one myself. After that, I was hired to run the peer program at SCIO and now I head up the charity's advocacy program. I spend my days working with our passionate community and our government and health partners to update legislation and policy so that all Ontarians with SCI and other physical disabilities can experience greater access to affordable mobility devices, health care and medical supplies, as well as full accessibility in this province. This book is a wonderful tool in advocating for oneself after injury. When you're ready to advocate on a wider scale within our community, let us know and we'll give you another roadmap!