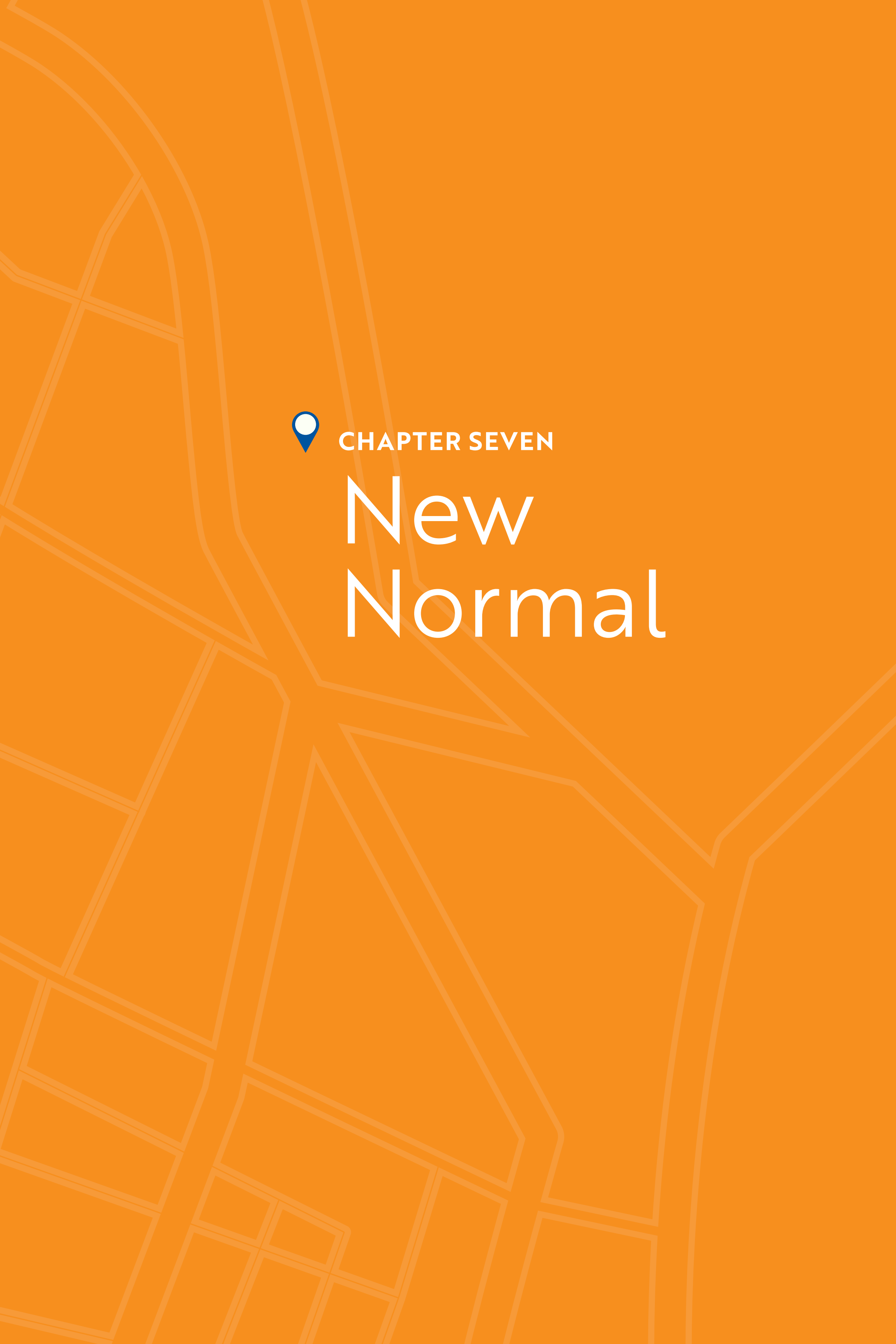

CHAPTER SEVEN

New Normal

> “*Becoming stronger physically after injury, I looked for opportunities to strengthen my life in my new circumstances; it takes energy and an open mind, but it can be exhilarating to reinvent yourself.*
>
> *- Randy Upper, SCIO Community Member*

EMBRACING A NEW NORMAL IN HEALTH, FAMILY, SPORTS, WORK AND TRAVEL

Bladder, Bowel, Skin & Sex

You will hear a lot of talk about bladder, bowel, skin and sex and for good reason as things change after an SCI. It's up to you to figure out your new normal. Your goals for independence will vary depending on what type of injury you have, your age and previous health conditions — everyone is different. This is so important to understand because, as you talk to other people with an SCI, you will start to realize that everyone manages their body issues differently.

The other thing about bladder, bowel, skin and sex is that, as you recover and learn to listen to your body, how you will manage these things will change. You will have to be brave and experiment with different ways of using a catheter, emptying your bowels, protecting your skin and experiencing pleasure.

Bowel & Bladder

You may experience similar bladder and bowel challenges as others who have sustained an SCI, but every person has their own story, which is much bigger than their injury. Your care needs will depend on your age, level of activity, education and employment goals, relationship status, passions and desires. And any of these can suddenly change. There is no one-size-fits-all life. Look around and ask around — in the hospital, in rehab and with your ongoing care team as you become more independent, in order to ensure your personal needs for bowel and bladder care are being met daily for the very best health.

Skin

Pressure injuries can develop in just a few hours, are difficult to heal and can lead to dangerous infections. They are almost always preventable. You will be advised to perform daily skin checks to look for areas of redness on pale skin or blueness on dark skin, swelling that feels firm, or broken skin. As mentioned earlier in this book, do it!

The best ways to prevent pressure injuries are well-fitting equipment and pressure relief. You will be given detailed information and pressure relief techniques in rehab. This is one of those health issues where an ounce of prevention really is worth a pound of cure: a little work in advance saves harm and pain down the road. Also check out SCIO's resources on skin health, including a new edition of *Preventing and Treating Pressure Sores*.

Julie's Journey

TIME IS STILL A FACTOR

When I came home from rehab, I was still using a mirror to help with catheterization (in bed). My bowels needed a suppository and milk of magnesia in order to move, but I had no skin issues at all.

Four years later, I can use a catheter (without looking) anywhere — even in a car. My bowels move every day (sometimes several times a day) with just digital stimulation — no more milk of mag! I have had pressure sores from my knee touching the opposite leg just while sleeping, as well as burns! As for sex, we are still working things out — but communication really is the key.

Things change. Don't be afraid to do things differently — it will lead you to greater independence and a sense of control.

Sex and Sexuality

Our sexuality is such a personal thing. Some of us have grown up completely at ease with masturbation, talking about sex and expressing oneself sexually. And then there's the rest of us! With a spinal cord injury, it may require a deeper exploration into yourself and your sexuality to reach a level of comfort. It's an important endeavour – one that may bring up unease – but can be explored by being honest with yourself, your partner and your health care team about your goals and desires. Your new relationship with your body after sustaining an SCI will take some time to grow, and your sexuality is just as important now as before your injury. When you come to a new place of comfort with sex and sexuality, you can share and develop trust with a partner. Honest communication is crucial, both to dispel myths and to establish shared goals and expectations.

There are a lot of resources out there and more being developed regularly to keep the conversation about sex and sexuality going and provide the 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!

Peer Perspective

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!

Improved fitness also meant that I was stronger for my daily life, which made everything easier. It was a gradual process, so much so that I didn't notice until the changes were pointed out to me. Things like doing 20-30 transfers in a day, with way less effort. Doing more and being active also makes you feel better, which means you can do more!

Do you have to be into competitive sports to be involved in something like wheelchair rugby?

That day that I signed up, I didn't even know (or need to know) that there was a National Team. I was attracted to the sport because of the team atmosphere, the camaraderie and the fun that I saw that first day — it was something that I knew I was missing in my life. As I got more involved, I realized that one of the best parts was getting "taped up" (what they do at the start of the game to protect fingers and enhance grip on the ball) and going out for a beer with my teammates.

If you are someone who is not really interested in sports — but you want to have an active lifestyle — many things are available. Especially now that a lot of gyms are accessible. You can focus on basic fitness, or you can train for something specific. There are so many para sports! You may end up finding a sport that, before your injury, you didn't like. That's why you have to try them all; you will find one you enjoy from your chair. But, if you want to beat the hell out of people, you need to try wheelchair rugby!

There are different levels of everything — just because you play wheelchair rugby doesn't mean you have to be a Paralympian — you can be a "weekend warrior." We've got a lot of people playing who do it just for fun. They travel from Toronto and Windsor (to Dorchester) just to play on a Saturday. Many come to play at the club level; as a coach, I can accommodate all levels.

What sports are there for people with disabilities?

There's a pretty long list: rugby, basketball, seated volleyball, sledge hockey, track and field sports, triathlon, swimming, sailing, cycling, canoe and kayak, curling, tennis, archery, shooting, rock climbing, boccia, skiing (downhill and nordic), snowboarding, bobsleigh, badminton, bowling, powerlifting, table tennis, fencing and dance... just to name a few! But like I said, try everything!

What about people who live away from a city and don’t have the population base for team sports?

You can spend time at a gym (or at home) and work on your fitness; play something like tennis with a friend or you can try sports that are strictly for individuals. Integrating sport into your life means you have to be creative and committed. A sport like shooting or archery can be done alone at home, but you can still get the social aspect of it if you decide to attend competitions. Like I said before, we have people who travel long distances to be a part of the rugby club; they decided that it makes that big of a difference in their lives that it’s worth the drive.

What is your “take-away” about the importance of sports for people with new SCIs?

I remember the first rugby tournament when we “went out on the road.” People left their rooms latched open and the whole hotel became an open welcoming space and a fun environment. Sure we were focused on the court, but for me it felt similar to hockey tournaments, kind of like coming home. When we get together, we talk about all the funny incidents and stories that happened along the way, not about the games themselves.

The biggest question people have after an SCI (well, after the questions about sex) is how am I going to be social again? That’s the part of sport that is pretty important. It is how you are going to meet people and make your own stories to tell.

Each time you try a new sport it will be challenging, but the more you try and participate, the stronger you will get and the easier it will become. Ask your peers what they are doing and don’t be afraid to give it a try!

Julie's Journey

TRY EVERYTHING

There is a lot to do when you use a wheelchair. The only excuse is the one that you make. Do try — and try anything. No matter what age you are, there is something out there that you can do to be active, fit and most importantly, social.

Post-accident I have kayaked, bowled, danced, sit-skied (nordic and downhill), swum, thrown axes, shot arrows (and rifles), biked, as well as played tennis, ping-pong, snooker and badminton. I've also tried rolling on all types of surfaces — indoor rubber track, outdoor gravel track, packed trail, snow, lawn, sideroad, paved shoulder…

Some sports were easier than others; all have been wonderful. There is no need to go out and buy specialized equipment — beg, borrow or rent before you make decisions about what you like best. I first borrowed a hand bike — and getting back out on the road was a wonderful feeling! This winter, I plan to ski and have found a group of women with wheelchairs all interested in joining me!

RETURN TO WORK

For many who are newly injured, returning to work is near the top of the list of questions about the future. It will be one of the last steps you take on your way from "recovering" to "recovered." With so many other issues to work out, learning all the ins and outs of returning to work falls a bit lower down on the priority list. It is worth noting that it will happen differently for everyone. Some will, given enough time, return to the job they had before their SCI. Others will need to (or choose to) have a whole different plan of attack — a new job, working part time, starting a business or not working at all.

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.

The services you provide are based out of Toronto. Describe how SCIO helps someone with an SCI find meaningful work.

In Toronto, SCIO Employment Services offer services to help get the individual ready for work — not just people with SCI, but people with all types of disabilities. We not only help people find a job, we also screen candidates to try to make a good match and we support them with job coaching.

What advice would you give to someone looking to return to work, who lives outside of Toronto?

There are a lot of other employment service providers out there who help people with disabilities find work (March of Dimes and Canadian Council on Rehabilitation and Work, for example). The SCIO Regional Services Co-ordinator assigned to you before you leave rehab will be the place to start as they will connect you with the agency in your area. I would also suggest that they attend any type of employment training that they can find in their area.

What should employers know about hiring people with disabilities?

SCIO doesn't just work with people looking for work; we also work with employers looking for staff. We want employers to have what they need to smoothly integrate people with disabilities into their workforce. We have discussions about issues that people may not feel comfortable with yet, like how to provide appropriate accommodations for staff without overstepping personal privacy.

For some employers, hiring someone with a disability is *foreign territory* so SCIO acts to co-ordinate information between the two parties. For example, we can help a business understand their staffing issues, perform a needs assessment and then bridge the business to a talent pool that they may not have otherwise been able to connect with.

People with disabilities tend to be problem solvers, which makes them excellent employees. If they have been looking for work for a period of time, they will likely be motivated to keep that job once they get it. Employers often reconnect with SCIO because they had a successful placement with past clients, people who were dependable and reliable. Of course, people with disabilities are not all the same!

Are there particular “go to” workplaces for people with disabilities because they are known for being accessible or a good place to just get a start?

People with disabilities have all sorts of career aspirations; don’t let yourself think you should be limited. A great way to start is with something that is short term — like part-time work or a contract that runs for a few weeks. There is a lot of value in doing something for a short while; even getting personal care matters figured out in order to get to work on time can be a feat! You will also gain confidence, familiarize yourself with current workplace norms, technology, communication and increase your ability to get through a full day of work. Often those short-term placements can lead to full-time roles.

Job developers like SCIO have good connections with elections offices. They are short-term positions and are in spaces that are required to be accessible under the Elections Act. They are great jobs for those who have lost their confidence or need to get some short-term work experience. Employers like the CNE or elections offices have a hard time filling those positions because they *are* part time; they keep coming back and asking us to screen more individuals for those jobs. Working at an information desk at the CNE led one SCIO client to a permanent position with Maple Leaf Sports and Entertainment.

Like any job hunt, some things have to be seen as a stepping stone.

If I have a disability, am I required to disclose my needs at an interview?

When to disclose your workplace accommodation needs is a very personal thing. You are going to build your best rapport if you are upfront about it; the employer does *not* need to know about your disability, but they need to know what you need in order to do the best job that you can. By being upfront with them and not hiding what your needs are, your employer will be better able to judge your actual performance. It just makes sense to be open about how you can do your best work.

A job posting might say, “We are an equal opportunity employer,” in which case you should go into your first meeting knowing what would work for you. You should make sure, for example, that you have:

- Safe access and exit from the workplace (including in cases of emergency).
- Access to a lunch room/locker room.
- Ability to fully participate in that work experience. What other equipment do you need, such as hand controls for a vehicle, a lift, scooter or other mobility device specifically related to your job?

- Safe and accessible bathroom facilities with appropriate height toilet, grab bars and roll-under sink.
- Space to navigate around the work environment (wide access aisles, automatic door openers).
- Any additional resources that apply to your situation like screen readers, Kurzweil, noise-cancelling headphones, a mental health break room, height adjustable workspace, accessible parking, etc.

You should use the "Job Accommodation Network" as a reference. Although it is based on the Americans with Disabilities Act, it is a great place to do some research about your own accommodation needs, then have a list ready for when that discussion happens. Remember that you are not making "demands." It is a conversation that needs to happen for the relationship to be as strong as possible; the employer wants you to be successful. There needs to be a bit of "thinking outside the box" and understanding that most accommodations cost an employer less than $500.

There are resources for employers to help figure those things out, such as an OT who can do a workplace accommodation assessment. Larger employers, like banks, have been working hard to make their workplaces as inclusive as possible and base their workforce on federal employment legislation to increase the number of people with disabilities working in the business.

Also, remember that society now accommodates employees in the workplace regardless of their needs, such as child care needs, food allergies and scent intolerances; having a disability should not be any different.

What other job hunting tips can you share?

That is just it! You are no different than anyone else looking for work — all the same tips apply!

- Look at all sizes of businesses. It's not just the larger employers who will make accommodations; it's the small to medium businesses who are more nimble, can be creative and are looking at a different talent pool.
- Do your homework so you know what your needs are.
- Find an employment service provider with experience working with people with disabilities.

- Remember that this is *your* job search. You may be using a job search service, but you need to put in 100% effort.
- Continuously update and customize your résumé.
- Network, make connections, look at opportunities everywhere.
- Set up informational interviews and don’t leave a meeting without getting another name to talk to; get yourself out there!
- You’ll find jobs in the least likely places (e.g., at your hairdresser); tell everyone that you are looking for work and how they can reach you.
- Work on your elevator pitch (who you are and what you are looking for).
- If your approach is not working, change it up.
- Find a peer that you can talk to or search with.

Remember, information is power!

Peer Perspective

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 and off. Being the first to board and last to get out is a drag, but it is better than having to ask people to move out of the way, so be sure to check in early.

Train travel is excellent — if you book ahead. You may even get bumped up to business class and have all the perks that go along with it. Take advantage of these offers because otherwise travel can get quite expensive. While your friends are finding inexpensive AirBnbs to stay in, you will be phoning around looking for hotels with roll-in showers! I purchased a travel commode that packs up into a suitcase with wheels. It's heavy, but it has been useful. Ask others what they have used that is helpful. A travel grab bar with super suction is another good investment.

Supplies and more supplies

I cannot stress enough the importance of having enough catheters and other bathroom supplies. You never know when your bladder will "go on strike" and you end up having to pee every hour using two to three times the normal number of catheters! In the US, you can't just roll into a pharmacy and buy them — you have to have a prescription! Medications should also be in their original bottles when you travel (although I've never had a problem).

FINANCES

Much of what you will do in the future will depend on the resources you have available to you.

Unfortunately, this might be the biggest divide that exists in the SCI community. If your SCI was not caused by an auto accident covered under the Ontario legislation, you will have to access resources, equipment and housing from the other services that are available in Ontario and Canada.

Insurance and Lawsuit Settlements

As you make your way through the process of pursuing lawsuits and settlements with your insurance company, you have to decide what you are going to do with the money. You have options.

Structured settlement

This is a way of investing your money for the long term, allowing you to have regular payouts that you decide the time framework for. This is considered the safest option for your money; it gives you a certain amount each month/year/

decade, which means you can't spend it all in one go. It also means that no one else can have access to it, if you were sued, for example. Structured settlements are set up by companies that specialize in these types of investments. You will receive interest on your investments, but these rates are not high. This option is also tax free — the government cannot tax the interest you earn. There is also a great deal of flexibility in how you can have your structured settlement set up, e.g., an annual larger sum for equipment needs, or a larger sum every 10 years to replace a vehicle.

Also the payout here is generally guaranteed for the life of the annuitant with a minimum number of years (in case of early death of the annuitant).

Investments

The second option is for you to receive the payout in full and invest it with a financial institution. This is a riskier option because you are at the mercy of the financial markets; you may get a higher return on your investments, but that income will not be tax free. You will have to pay capital gains taxes on it. If you decide to go this route, make sure you find someone reliable to help you with the investments; most of the major banks have investment specialists — just ask.

Some people choose to do a combination of both a structured settlement and some investments. Your lawyer will make recommendations to you about which will be best, but it comes down to you and your future needs. If you are young, a structured settlement is smart because it will guarantee you an income for a long period of time; the amount will depend on the amount of your settlement. If you are not young, you will want to make some return on your investments while you still have time, so you should investigate other investment options.

GOVERNMENT AND OTHER TYPES OF FINANCIAL ASSISTANCE

Support for income replacement and taxation:

Through the CRA, the disability tax credit is used to reduce the income tax paid by people with a severe and prolonged physical impairment ($8,235 in 2018).

https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html

RDSP — Registered Disability Savings Plan

If you are eligible for the Disability Tax Credit and are under the age of 50, you should open an RDSP. Making contributions yearly (up to age 49) also makes you eligible for matching government grants up to $3500 per year. This means that the Government also pays into your RDSP to help you save.

The Canada Disability Savings Bond is money the Government contributes to the RDSP of low- and modest-income Canadians. If you qualify for the Bond, you can receive up to $1,000 a year, depending on income up to the age of 49.

Speak to your banking representative to get this going as soon as possible. The RDSP is designed to encourage people to save money for more than 10 years. If the money is withdrawn before the 10-year mark, all grants and bonds must be repaid to the government. Special considerations exist for those with proven shortened life expectancies.

https://www.canada.ca/en/employment-social-development/programs/disability/savings.html

CPPD

CPP-Disability can support those who are between the ages of 18 and 65 and have what the Government considers to be a "severe and prolonged disability" which "regularly stops you from doing any type of substantially gainful work" and is "of indefinite duration."

https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-disability-benefit.html

ODSP

Ontario Disability Support Program supports those with demonstrated financial need and falls under the same qualifications at the CPPD stated above. For those in a low income situation who may be receiving CPPD, ODSP can "top up" income and can also provide benefits for supplies and equipment.

https://www.mcss.gov.on.ca/en/mcss/programs/social/odsp/income_support/IS_Eligibility.aspx

Private/workplace insurance

Disability insurance can be claimed if you qualify through your employer's private insurer. Short-term disability insurance is usually paid for up to six months. Long-term disability insurance can replace between 60 and 70% of your normal income once your short-term claim is up and can last for up to two years or longer. Speak to your employer's Human Resources department.

EI (Employment Insurance)

EI can pay up to 15 weeks once you have exhausted all your employer income insurance and if you qualify.

https://www.canada.ca/en/services/benefits/ei/ei-sickness/eligibility.html

Support for caregivers or receiving care

Get as much help as you can for as long as you can. There are resources available for you to pay for a PSW. Check the following resources to see which you qualify for.

Direct Funding

This service provides adults with physical disabilities the ability and funding support to become employers of their own attendants.

https://www.dfontario.ca/

Family Caregiver Benefit

The Family Caregiver Benefit can assist those who look after an injured or ill family member; you may be eligible for 15 weeks assistance.

https://www.canada.ca/en/employment-social-development/programs/ei/ei-list/ei-employers-maternity-parental-benefits.html

Ontario Works

Ontario Works can provide financial, employment or emergency assistance to those who live in Ontario and are in need due to caregiving responsibilities or because of injury/illness.
https://www.mcss.gov.on.ca/en/mcss/programs/social/ow/

Home and Community Care

Contact your Local Health Integration Network (LHIN) (or Ontario Health Team) to find a caregiver that will come to your home, with fees covered by OHIP. Be sure to connect with your local team for an intake interview before you leave rehab.

http://lhins.on.ca/

Discretionary Benefits

Discretionary Benefits are provided to individuals in receipt of benefits under the Ontario Works and Ontario Disability Support Plan (ODSP) for the purchase of health related items.

https://www.mcss.gov.on.ca/en/mcss/programs/social/directives/ow/7_1_OW_Directives.aspx

Prescription Drug Benefits

Ontario Benefit Drug Program helps pay for drug coverage for those on ODSP or Ontario Works.

https://www.ontario.ca/page/get-coverage-prescription-drugs#section-0

Cost of equipment, supplies and medication:

ADP (Assistive Devices Program) — Those with a long-term physical disability can apply for funding for equipment (wheelchairs and hearing aids) and supplies (like ostomies). Income is not considered, but there is a specific list of equipment/supplies that are covered (to a maximum of 75%).

https://www.ontario.ca/page/assistive-devices-program#section-0

Trillium Drug Benefit is for people who spend approximately 3 to 4% or more of their after-tax household income on prescription drug costs.

https://www.ontario.ca/page/get-help-high-prescription-drug-costs#section-0

Home or vehicle modification:

March of Dimes will assist residents of Ontario who demonstrate financial need and require modifications to their home or vehicle because of a disability that impedes mobility.

https://www.marchofdimes.ca/EN/programs/hvmp/Pages/HowtoApply.aspx

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!