Finding your way forward after spinal cord injury

By Julie Sawchuk and Spinal Cord Injury Ontario
For Theo Sawchuk and all the other wonderful partners, parents, friends and family who have joined the SCI club.

- Julie Sawchuk

For all Ontarians with SCI who, every day, move from strength to strength.

- Dr. Stuart Howe, CEO, SCIO

There is nothing you can’t do, if you set your mind to it. Anything is possible.

- Rick Hansen, Founder, Rick Hansen Foundation
PREFACE BY SPINAL CORD INJURY ONTARIO

Spinal Cord Injury Ontario (SCIO) has served, supported and advocated for and with people with spinal cord injury (SCI) since 1945. Our founders returned from the Second World War to Ontario with SCI and realized there were few systems and supports in place to help patients move out of hospital and into independent living. They gathered together a community of leaders and experts that would revolutionize life for those with spinal cord injury. They built Canada’s first rehabilitation centre for people with SCI and brought about specialized medical care, improved mobility devices and increased opportunities to live full, independent lives.

This innovative, pioneering spirit characterizes the people who make up the SCIO community today, many of whom have contributed to this publication. Sharing experiences and resources is the essence of our work; it increases connections and reduces the fear and isolation that some experience after sustaining an SCI. It is the intent of this publication to do the same, to delve into the reality of learning to live well with an SCI and to tap into the power of community every step of the way. You won’t find detailed medical information here — that’s available through many other channels. But you’ll find concrete information and insights that can help you make good decisions as you move forward.

We are grateful to the Ontario Trillium Foundation for their generous funding of this publication and to author Julie Sawchuk for her extraordinary skills and commitment to the well-being of her peers. We also appreciate our community members with SCI and their supportive families and our health care partners for sharing what they know to ease the journey and strengthen the outcome of those who find their way to these pages.

We dedicate this book to Ontarians with spinal cord injury and those who work to increase accessibility, quality of care and equity in this province for all.

Dr. Stuart Howe
CEO, Spinal Cord Injury Ontario
Who should read this book?

Have you picked up this book because you have, or someone you know and love has, just become a member of a group that no one wants to join? No invitation; it just happened. Spinal cord injuries (SCI) can be complicated, forever life-altering events. They take you down a path that you have never travelled before, which is why it’s helpful to have someone help you through. You may be looking for help in understanding what is going on, who all these people are and how to get the most from them to reach the best recovery possible. We want to reduce the feeling of isolation that often occurs with an SCI; you are not alone.

If you are a part of an SCI recovery team, this book is a valuable tool. Surgeons, doctors, nurses, physiotherapists, occupational therapists, social workers, dieticians, recreation therapists or students of any of these professions: **read on**! Although you have done some hardcore schooling to get to where you are right now, this book will help you see life through the eyes of someone with an SCI.

How to best use this book:

This is a roadmap. Like most other maps, the path to where you are going is not straight; therefore, this book was not designed to be read from cover to cover (although you can if you wish), but more like a “choose your own adventure.” I say that tongue-in-cheek because I know it is not an adventure that anyone would choose to have. Read the chapters that apply to you **first** and **foremost**. Use the Table of Contents to decide what you need to read about **right now** (what is your burning issue?) and then go from there.

In **Chapter One**, I tell my story. You’ll learn about the collision that caused my SCI and how I got to where I am now.

In **Chapter Two**, you’ll read about caring for a family member who has sustained an SCI. Why did we include this? We feel that the role of the family member “caregiver” is one that is vastly overlooked – and needs to be talked about more often.
The next three sections describe the key phases of recovery after spinal cord injury:

**Chapter Three**: Acute care — weeks to months in survival mode

**Chapter Four**: Welcome to Rehab!

**Chapter Five**: Going Home — from now until forever.

Although you may have to deal with legal and insurance issues before you get home from rehab, **Chapter 6** goes into detail about these matters. **Chapter 7** will introduce you to some of the “I’m recovered” things that you may be looking forward to (like travel, recreation, family life and returning to work) and some you may not be (like finances).

Within each section of the book, you’ll find **Professional Points**. These are question-and-answer sections formatted into bite-sized interviews with the professionals you can expect to meet and work with during each stage of your journey. There are personal stories from me (**Julie’s Journey**) and other SCI individuals (**Peer Perspectives**) that I have met or spoken with along the way; those who have been through it and **come out the other side**.

**Chapter 8** contains sources of information and resources you can use to access and expand your knowledge or to obtain specific support.

Our advice is for you to read this book in any fashion that works best for you and where you are in your journey. Highlight things you want to know more about or people that you know you need to talk to.

There is a lot of information coming your way and a long period during which you may need to refer back to refresh your memory. Recovery from an SCI requires months and years.

Whether you have recently sustained a spinal cord injury, are a family member, a friend or a professional working in the field of SCI, use this book to help you find your way forward.

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ABOUT THE AUTHOR JULIE SAWCHUK

Usually, “About the Author” appears at the end of a book, but we decided that you may read this roadmap with a different lens knowing who wrote it and why.

I am Julie Sawchuk, published author, professional speaker, Rick Hansen Foundation Ambassador, designated RHFAC Professional and former high school biology teacher. I am also a member of the SCI club; I live it every day. That is why I am writing this book. I have been down the road of recovery and, at the time, my husband and I wanted a roadmap that didn’t exist. I wrote this for you.

It’s only been four years since my injury (T4 incomplete) but I’ve learned a lot about the medical system, diet, insurance and the importance of peer support. I want others to learn from my journey in the hope that they will end up on a smoother, and perhaps quicker, path to recovery.

This roadmap is written in plain language. Together with SCIO, we’ve done our best to eliminate the medical jargon and the physical aspects of recovery. We wanted to focus on how to figure out the world of SCI. Nothing here is sugar coated. I hope that you find relief and that you will benefit from knowing people who have been through it before. We will help you see some light at the end of the tunnel.

Know this: IT GETS BETTER. It does. When I look back and remember being in rehab, or how I felt the first time I came home… What a difference! Every day it gets a little bit better and brighter — sometimes you’ll slide backwards — but you’ll find your way forward again.
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When you’re in such a vulnerable and confused state after sustaining a spinal cord injury, you want a roadmap. You want someone who’s been there to answer your questions.”

- Julie Sawchuk
CHAPTER ONE

Julie’s Journey
LIKE EVERYONE AFFECTED BY A SPINAL CORD INJURY, THE DAY MY LIFE CHANGED WILL NEVER BE FORGOTTEN.

Physiotherapy has helped me recover as much core strength as possible. Here I am working with Marc Pittock and Bill Glassier at Glassier Physiotherapy in Wingham.

Skiing with my daughter, Ella. I’ve tried many different sports - it takes a lot of effort, but it is worth it every time.

This was the first time I left the trauma floor at Victoria Hospital. It was where I learned how awful the bumps in the sidewalk feel when you use a wheelchair.

I wrote Build YOUR Space - how to create an accessible home for you, your family and your future for other people to learn from our three-year journey of building a wheelchair accessible home.
JULIE’S JOURNEY: THE FULL STORY

The day it all changed

As you read my story, you will be prompted to go to other sections of the book. Please do so if, right now, there is a burning issue for you.

Like everyone affected by a spinal cord injury, the day my life changed will never be forgotten. July 29, 2015. I was 41 years old, a wife and mother of two kids, Oliver (9) and Ella (12). I was training for an Olympic distance triathlon — not for the Olympics; I was just a mom trying to stay in shape and have some fun with a great group of friends. I live in the country in rural Southwestern Ontario and so I needed to travel to train with others.

On that sunny July morning, I decided to ride on my own, a distance of 60 km from my house to Goderich and back. I rose early to beat the heat and, by 9:00 am, I was on the last leg of my ride. On a straight stretch of paved county road, a car approaching from behind hit me and threw me into the ditch. The driver stopped, as did others, and they called for help. An ambulance arrived and took me to the local hospital where I was stabilized for transport by helicopter to the trauma unit at London’s Victoria Hospital.

Considering the speed of the car (likely 90 km/h), the injuries I sustained could have been worse: seven broken ribs, a broken nose, skin split open on my chin and forehead, concussion, torn trachea, road rash on my left leg, chipped top front teeth and two broken vertebrae, T4 and L1. T4 was where the damage occurred to my spinal cord. Either on impact with the car or when I hit the ditch, my T4 shattered and a bone fragment shot into my spinal cord, cut open the dura (which protects the spinal column) and damaged the nerves within.

The trauma team, a spinal surgeon and a team of plastic surgeons, fixed me up the best they could. The bone fragment was removed from my spinal column and the dura was stitched up. My spine was fused with plates and screws from T2 to T5. The plastic surgery pulled the skin on my forehead and chin back together and the trauma team inserted chest tubes to help drain my lungs.

I was in the Critical Care Trauma Unit for six days. After that, I had a room (with a view) on the 9th floor — the Trauma Unit — for another week. During this time, I met the teams of people who had worked to save my life — specialist doctors, resident doctors, nurses and respiratory therapists/
technicians. As I came around and began to understand what had happened to me, I also met therapists, more nurses and personal support workers (PSWs) who were next in line to help me recover.

Just so we are clear, at this stage I had no movement below my chest. They call T4 injuries “nipple line” and that is where my nerve pain began, all the way down to my toes. Toes that I could not move, but did have a tiny bit of sensation in. My kids and I would play a game of “which foot am I touching?” and I got it right 50% of the time. I also had very low blood pressure, so much so that sitting upright was not possible without passing out. A lift was required to get me from my bed and into a wheelchair.

**Out of critical care**

During this time, there was a lot of talk about “going to Parkwood.” I’m sure it took me some time to understand this, but Parkwood Institute is a rehabilitation hospital (part of St. Joseph’s Health Care in London). Parkwood was next — it sounded to me like the answer. So long as I could get there, everything would be fine — they would fix me up. The problem was, of course, that there were no beds available yet for me to go there. I had to return to my home hospital until a bed became free. So off I went in a patient transport van, all the way up to Wingham where I stayed for three days and then returned to London, again.

What came next was a bed in a room with three other women (all older than me, by 20 years at least) on the SCI/ABI/Amputee floor at Parkwood. I was assigned a charge nurse and a rehab team — physiotherapist, occupational therapist, recreational therapist, social worker, dietitian, general practitioner, physiatrist, speech and language therapist and psychologist. I had no idea what I was getting into. Mostly I just cried. (Jump to Chapter Four: Rehab)

**Who are all these people?**

By this point, my husband Theo and I had met with or spoken to a lot of people, all of whom seemed to be in a position to help us: an insurance adjuster, three lawyers, our insurance agent, my employer, a peer support person from Spinal Cord Injury Ontario (SCIO), a social worker and a case manager. Too many people to keep track of. Thankfully we live in Ontario and up to this point no money was needed from us — no expenses for surgery, medications or the hospital stay.
Speaking of money, auto insurance was involved. Because it was a motor vehicle accident (MVA), it happened on a roadway and I was an insured driver, it meant that I was covered under accident insurance for medical rehabilitation, attendant care and lost wages. We, of course, had no idea about any of this; it took some time, research and speaking with others to understand what it all meant.

We learned that the auto insurer had to determine if my injury was considered catastrophic or non-catastrophic. Everyone we spoke to, especially doctors, understood that my SCI was a catastrophic injury, but the insurer had to go through a process of reviewing all my medical documentation to determine the level of catastrophe before they decided the level of coverage I should receive. If you are in this position, do not be scared by this process. That’s what it is — a process. It may seem like a complete waste of time and resources, but it has to happen.

This is why it is important to start looking for a personal injury lawyer early in the journey. You do not need to have a lawyer straight away but, if your situation requires one, don’t put it off too long. I had someone ready to help within a couple of weeks of my collision. Ask about money, do the math and understand how much it is going to cost. It is unavoidable — you will have to have a lawyer if an insurance settlement or a lawsuit is going to take place, so know that there will be costs. If you have the possibility of a $1 million settlement and are paying a lawyer 20%, know that you will pay out $200,000 plus HST on lawyers’ fees ($26,000). Although it seems daunting and intimidating, don’t be afraid to negotiate. (Jump to Chapter Six: Legal & Insurance)

**Rehab**

Getting to Parkwood was a huge letdown for me. Not because it was inadequate in any way, but because I was looking for miracles. Looking back, I have no idea what would have made that transition easier, but I know that I had very unrealistic expectations. By the end of the first week, I was set up with a schedule and I knew what to expect for each day. (Jump to Chapter Four: Rehab)

I learned what bowel routine means and about intermittent catheterization (just not on my own, yet). As a biology teacher, I felt I knew a lot about the human body and how the digestive system works, but this was a whole new
level of detail and I needed to be comfortable with my own body — not just something on a diagram or in a dissection tray!

I began to talk to nurses and my social worker. I was grieving. I could not wrap my head around my new future and didn’t understand how I would ever be independent again or able to work. I had questions about the likelihood of recovering muscle function, sensation and bladder/bowel function. I was not really getting answers other than “give it time” and “it takes time”... time was a word I was pretty sick of hearing. Because of my head injury, I was not ready to read but I did want to talk.

Before arriving at Parkwood, I was told by nurses in acute care that I would not be able to have visitors during the day while I was at therapy — only during visiting hours. They said I was going to have to concentrate on my therapy and that friends and family would be too distracting. This was misinformation — I was able to have people come to therapy with me, see what I was doing, how I was doing and give me the encouragement I needed to keep going. Before the collision, I enjoyed the challenge that came from doing workouts with other people. Either in a fitness class or on a group ride, it made me work harder, go faster, be stronger. Having people — friends, family, work colleagues — come with me to my physiotherapy or occupational therapy made me try to be that person again.

**Three Months Later**

After three months of therapy, five days a week, two or more hours each day, I was stronger. Not as strong as I wanted to be, but I was dressing myself and doing both bowel care and intermittent catheterization independently. Because of therapy, my core strength had improved a bit and, although I couldn’t sit up without support, at least I was no longer passing out.

Initially, at Parkwood, I used a power chair to get around and a ceiling lift to get in and out of bed. By the end of my inpatient stay, I was able to transfer with a transfer board and I had a properly-fitting manual chair that I could manoeuvre on my own. My shoulders and arms were stronger, thanks to many repetitions using weights at Occupational Therapy (OT). Tricep dips, tilt table, standing frame and trying to balance on “four points” had become a regular part of my daily physio. I was able to use the RT300 FES bike and “walk” with the Lokomat and in the Eksoskeleton.
Before the end of my Parkwood stay, there was a team meeting which included all my doctors, my charge nurse, all the therapists, the insurance adjuster, my legal representatives, case managers and my family. Representatives from the Local Health Integration Network (LHIN — formerly CCAC; now Ontario Health Teams) and from SCIO were also present to answer questions.

I wanted to go home even though I didn’t feel ready to go home. My team said I was ready. I also knew that I needed to go home and be with my family again. Even though our home was not accessible (110-year-old farm houses tend not to be), with help, Theo had done his best to make it manageable for me to live there while we decided what our next move would be — renovate, build or move.

Back Home

Going home meant that I needed to have a plan to continue my physiotherapy. I decided on a local clinic two days per week, as well as attending Parkwood once a week as an outpatient. For three years, I continued this therapy plan, as well as swimming twice a month with a kinesiologist who is trained in water art therapy. Of course, sometimes life got in the way of my plans for therapy, but keeping this regular schedule meant a great deal of core recovery, improved blood pressure and even a tiny bit of functional recovery in my hips.

There is no public transit in rural Ontario. Getting my licence back meant I could get to therapy and visit friends without having to find a driver. It required retraining at a licenced driver training facility (with hand controls) and getting a car modified to have space for my chair. Driving was a milestone for me; being able to get around independently was wonderful!

In the past four years, I have travelled to Jamaica, Florida, North Carolina, Edmonton, Toronto, Ottawa and Vancouver and I’ve rented three lakeside summer cottages. I’ve gone with friends, family and on my own in planes, trains, taxis and rental cars. There is a lot to learn about leaving home — a lot to get organized — but it’s doable! It’s so important to spend the time in advance to learn about where you are going, talk to people in person and make sure you have enough supplies for just in case kinds of travel.

I have not returned to my job as a high school teacher. I am thankful for the benefits that I have through my employer and from my auto insurance. Instead of returning to work in the classroom, I have been working on me.
Therapy is my work, my full-time job. Getting better, stronger, healthier and learning how to deal with pain — that is my work. There is a lot to learn about diet and the importance of maintaining a healthy weight. Pain management is a priority for many people with an SCI, along with budgeting energy. Both are very hard tasks to learn and I struggle with both.

**Change will come**

While you are still in acute care, you will have a million things going through your head. You’ll want answers from everyone and will have questions you don’t even know who to ask. For sure, one answer you want is, “What are my chances?” The thing is, everyone is different, every injury is different and every recovery is different.

The differences are not just because the spinal cord is long and the location of the injury determines (in part) the extent of the loss of function. The way the damage occurs, the speed at which medical attention is received and the effort that goes into the recovery all influence the outcome. Acute care doctors can only make an educated guess about your future. Often they are not connected to the rest of the recovery team. They have extensive training and loads of experience, but often they don’t have the opportunity to stay connected to see the long-term follow-up and know final outcomes.

While you are recovering from surgery, or other wounds, if your SCI was caused by a traumatic event, ask A LOT of questions — and ask everyone. What you will get is a variety of answers and opinions. Some will be correct and some may be off base by quite a bit. An example, from my acute care stay, was what nurses told me rehab would be like. They almost scared me off of going!

Everyone who helps you along with your recovery is working in a silo. They only see patients for so long and, after those patients leave, they likely get little opportunity to follow up and ask about the next stage in the process: “How did it go, after all?” Take in everything that your medical team tells you — most of it is going to be accurate, but only time will allow you to figure that out.

**12 is not zero**

As I left acute care to go to a rehab hospital, I asked my surgeon what the chances were of me having any kind of recovery. His answer was, “If you
have not had anything come back by now, you won’t.” This, of course, was
soul crushing for me. Not the answer I was expecting or wanting to hear. I
couldn’t sit up on my own, get my legs off the bed or control any of my bodily
functions. But that changes. It gets better and, at the early stages of recovery,
no one can say what YOUR recovery will actually be.

Some nurses told me stories of patients who worked all day long to try to
move their toes until one day they did and they eventually walked out of
rehab. I did not walk out of rehab, but three months later I left a lot stronger
and more capable than when I entered.

Four years later, I am still gaining muscle strength in my core and getting
flickers of activity in my hip flexors and glutes. There is no saying why for
sure, but I do know that the harder you work and the more you try to do,
the stronger and more capable you will get. When I left rehab, I bugged my
physiatrist to give me an answer: what are my chances of recovery? Answer:
12%. A 12% chance of recovering my ability to walk. 12 is not zero — and
that has been my philosophy ever since (on most days). So I keep trying to
get stronger, sit up taller, reach farther, transfer from this space to that. Only
you can determine how far you will get.
Though my husband’s support was important to my recovery, it was even more important for me to take the lead on it.

- Lubna Aslam, SCIO Peer Program Manager
CHAPTER TWO

Family Members
THE VITAL ROLE OF FAMILY: ONE FAMILY MEMBER TO ANOTHER

Did this book land in your hands because you are the partner/parent/family/friend of someone with a new SCI? If so, read on. You have a lot to learn. This is most likely the first time you have known someone with an SCI and there’s a chance you feel quite lost. Although we won’t have all the answers for you, as every SCI is different, we hope that you will learn a lot here and that it will help the person in your life with an SCI get on the road to recovery.

In this section, you will discover important things to know and you will read advice from people who have found themselves in the complex role of a family member of a person with an SCI.

*Family member* is how we will refer to the primary person supporting a person who is newly injured. This is the one who finds themselves right at the bedside. The family member may not actually be family, but most often is. It could be a partner, parent, adult child, family friend — someone who loves the person with an SCI and wants to see them recover as much and as soon as possible; you are attached to them! Rather than “caregiver,” which may not be accurate for this role, we’ll use *family member* throughout this publication (except where stated by those being interviewed). Family members will be called upon to make decisions until the person who is newly injured is able to do so for themselves. They will also help out, when needed, with therapy and other tasks as required. Each case is different.

Your new role as family member

This was never something you guessed would happen and now you need to be on your “A Game.” The person who is newly injured will be relying on you for help until they are able to help themselves. How long that takes depends on the level of SCI and severity of other injuries.

If you have not realized it yet, your main job is to listen. Listen to everything every doctor and nurse says and, as much as possible, write it down. Keeping a notebook as you go will help you when you can’t recall details because your brain is in a fog.
A HUSBAND’S PERSPECTIVE, PART 1

At first (until after a couple of months), I didn’t realize that I was now “the caregiver” to my wife. All I was doing was reacting to situations, answering questions that were asked by the professionals, communicating to friends and family and trying to look after our kids. I was just husband and father. But then, as time went on, I realized — especially as the nurses talked to me — I had become her caregiver.

After the accident, my life went sideways. I was a stay-at-home dad with two kids and a small farm on the side. We live an hour and a half from the hospital where she would be for four months. I had to ask for help. This was hard for me because I was the one who looked after everything and, usually, on my own. So asking and accepting offers of help was difficult.

One thing that I figured out, as the weeks went on, was to accept help and be specific. When someone offered to drop off a meal, I would say which evening of the week would be best. The same went for offers to drive the kids to their activities. Even more helpful was when people asked to help with specific things (like the gardens) and would say which day they would come.

My advice is to accept help. It won’t come around forever, and it may feel uncomfortable or inconvenient at the time, but it will be worth it. What it means is you get a little bit of relief, a meal and one less taxi ride to give your kids.
Ask for help

Now is the time to ask for help. Call for favours from family, friends, neighbours, colleagues or people from your place of worship. What you need now is for someone to “keep the home fires burning” and look after whoever is there, keeping life as normal as possible. You will also need to get in touch with the injured person’s place of work and let them know that they will not be back, likely for many months. Find out about any work or auto-related insurance your person may have.

But most of all, be by their side. They need to know you are there. It’s a scary place, being in a hospital. Seeing you will help them feel less alone and a little less scared.

A HUSBAND’S PERSPECTIVE, PART 2

We live in a small community and my wife had a lot of concerned family and friends. Her accident had been on the local radio station and in the newspaper. People wanted to know how she was and what they could do to help.

Some email and most Facebook communications had been picked up by our friend, Selena. Melissa was helping organize food drop-offs and the kids were with my parents. Farm tasks had been picked up by other friends; most things were being done without my involvement.

What I wish I had done was assigned a “point person,” someone who would get an update from me and then send the word to all the others. I was still communicating with some family and my wife’s friends via text. If you are tech savvy, use an app; if not, get someone who is. They can answer all the follow-up questions that will inevitably come from the community.

I found it all overwhelming, but connecting with my people did distract me from thinking about it all, all of the time.
If you spend your time answering the same questions from many different people (over and over), you will start to wear out. It may feel comfortable at the time, but what you don’t know are all the other communications that are yet to come. You already have to keep track of what the doctors are saying, but soon enough it will be insurance or WSIB (if it applies), then will come the lawyers, case managers, therapists, home care specialists, SCIO Regional Services Co-ordinator and the list goes on. Pace yourself.

Other things you might need to ask for help with are groceries, bringing coffee to the hospital and visiting relief at the hospital to allow you some time to go home (or to a hotel) to shower and have a nap. Are there kids who need looking after, pets to walk and feed, clients to notify? Ask someone at the hospital (like the social worker) to help you brainstorm the people that need to be contacted and list the everyday-life activities that you are going to need help with. Then, ask people to help with specific things, because people will offer and it’s best to be specific — it helps you and them.

**Find a peer**

As the newly-injured person moves from the ICU to acute care to rehab, you are likely feeling in over your head. Take a minute to find someone else who is in the same boat as you. They are a family member too, perhaps in the same situation, but likely not identical. They are the partner or parent of someone with an SCI. Reach out to that person, even for a moment, and you will find that you have a lot in common. It will be helpful for you both. SCIO can help you find a match, too, through their peer support program.

Your newly-injured person will have a different type of SCI or other injuries and will have spent a different amount of time in hospital than your peer’s person, but you can still compare notes, talk about the support you have had (or have not had) and the concerns that you have as you look ahead.

It’s important for you, the family member, to find a peer because you need help too and you can’t minimize your own situation just because someone else’s is worse. You need to talk, because on top of what you already were dealing with in your life, you now have a loved one with an SCI.

Now is the time when you don’t know what you don’t know and talking to someone who is going or has gone through the same thing will help. It will feel comfortable and it will help you get through, because you WILL get through; it just may not feel like it right now. You are in a one-foot-in-front-
A Family Member’s Story

A MOTHER’S PERSPECTIVE, PART 1

My daughter sustained her SCI when she was age 20. Being a young woman, she did not fit into the “SCI norm” and therefore there wasn’t anyone in rehab who fell into that age/sex bracket. But we have muddled through and learned a lot along the way. Number one: you (as the caregiver) did not train for this and are learning as you go, just like your child is, so cut yourself some slack.

However, you have an adult’s perspective. So be patient and don’t take their criticism of the job you’re doing to heart. You are doing the best job you can. Seek out other supporters and talk with them; we all share the same problems and triumphs and it really helps to talk to someone who is living the same life.

Remember that your child feels they have lost control of a lot in their life, so trying to control you and what you do is all they can do — don’t take it personally! If you have other children, remember to make time for them, too. They could be feeling alone and it’s easy to let your relationship with them slide with so much going on. Even if they are grown up, try to make a conscious effort to spend time with them, too.

of-the-other place.

Although you will be able to find an online forum for SCI supporters once you get home, take the time to seek out someone else to speak with face-to-face before leaving the hospital. Once you are home, you will lose constant contact with all the other in-hospital experts. Talking to someone now will give you the opportunity to stay in touch as they continue their journey, too.

As the newly-injured person transfers to rehab, you will see more people who have sustained an SCI. It may be too soon for your loved one to talk to a peer, but you can be on the look-out or let SCIO know they may be ready.
Step back, just a little bit

Rehab has the potential to go on for a very long time. It’s even more time away for the one you love and a huge learning curve for both of you. Your job is to let them learn. Of course it is important to support them, show them love and be there to cheer them through therapy, but you have to give them space to learn (and do) on their own.

Julie’s Journey

A DORM ROOM

When I went to the rehab hospital, I was grateful to be in a private room. It turned out that I was only in that room because there were no ward rooms available at the time I “checked in.” I was not at all keen to be in a room with anyone else; I wanted privacy and not to have to hear others suffer like I was.

In the end, being moved to a room of four (right outside the nurses’ station) allowed me to ask more questions, hear more information (often too much), talk to fellow SCI survivors and get help when others could not reach their call buttons. My husband didn’t feel supremely comfortable being a visitor there; he felt he was invading others’ privacy, which made him go home earlier than I wanted each visit. It meant that he wasn’t there every time I wanted his help. Maybe, in the end, it forced me to be a little bit more independent?
Seek Professional help

Returning home from rehab means that you, the family member, are really it. Hopefully you have some help coming to your home, like another family member, a professional home care nurse or a personal support worker (PSW). You will need it. Not because you aren’t capable, but because you will need a break. A break from your new situation, that is, because all the other things in your life are still happening on top of what you are doing to provide care: work, kids, home, life and now a family member with an SCI.

You are going to be doing things that you never, in a million years, would have dreamed up. If you are married and said the “in sickness and in health” bit in your vows, never did you picture this. It will be scary, exhausting, uncomfortable and sometimes just plain gross.

A MOTHER’S PERSPECTIVE, PART 2

Give your child space! If they hadn’t been injured, would they want to be around you 24/7? Not likely! And think about this: Have their interests changed just because they have an SCI? If they were not interested in playing sports, that likely has not changed. Not to say you can’t give some encouragement to try something new, but back off a bit on the “you should try…” Even if they were into sports, trying it again for the first time will not go as planned, and this can cause sadness, depression and discouragement. Some things are just never going to be the same.

People young and old often feel uncomfortable seeing someone who has been injured for the first time. Tell your child’s friends that they can still be friends and include them in their plans. It’s tricky, but you can help by having an open and honest conversation with them about it.

Nothing you can say or do will make your child do anything they don’t want to. For the most part, it will be their decision and it will take time. If you push, they will just push back. Remember: they will ask for your opinion if they want it.
**A HUSBAND’S PERSPECTIVE, PART 3**

When I met with our family lawyer, after Julie had been home for a while, he said, “Good for you.” As in, “good for you for sticking around.” In his line of work, he sees a lot of situations where this is not the case, because not all are able to. I am in no way condoning you leaving your partner, but know that you may struggle. In saying that, it was a long time before I realized that not only did I need someone to help with Julie, but I needed help for myself. It was more than a year before I started seeing a social worker to talk about me and my life. I should have found one sooner.

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**A MOTHER’S PERSPECTIVE, PART 3**

Try to see things from a teenager’s perspective. What may not bother us as adults can be mortifying and embarrassing to a child. Insist that they meet regularly with a psychologist or therapist from the very start. Although it may not appear as fear, your child is afraid. They think that people will see them as different, that they will not be attractive to potential love interests and will not be accepted by their peers.

Mostly, they are afraid about the future. Everything looks so different now — aging, health, their fragile body and their potential for independence. Talking about it, about what they can deal with in the here and now, that is how to find a way through. Seeking professional help is the best way to start this healing process.
Talk about it

Everyone recovers differently. That is why writing a resource is so difficult — because everyone’s situation is different (injury, geographical location, availability of resources, etc.), as is their approach to accommodation. Some people install lift tracks, ramps and roll-in showers; others decide to make very few changes to their home and others still go with their friends to theme parks and just tape their hands to the bars on a rollercoaster ride (true story). How newly-injured people recover is up to them. You can provide support and encouragement. You can tell them that the hard recovery work they are doing is visibly making a difference. But you can’t do it for them. The more you try, the more frustrated you both will become.

If you are concerned about progress, talk to them about it. Likely they are feeling frustrated too and it’s better to have it all out in the open. This type of communication is one thing that will keep your relationship from falling apart.

A Family Member’s Story

A CHILD’S PERSPECTIVE

It was a while after my mom’s accident when I learned something that really helped me understand her situation. One day we were going out and she told us (my sister and me) that we needed to be more helpful than usual. Then she talked about “energy points,” how she only had so many available in a day and, once they were used up, she would have to steal from the future. She said it’s called “spoon theory.” Now I get it; it’s just like health points (HP) in a video game — except it’s real. Understanding it makes a difference because now all my mom has to say is: “I’m running out of HP” and I know that I have to be more helpful, push her chair for her on hills or rough surfaces or help in other ways. She’s not just being bossy or lazy, she actually is running out of HP.
Communicate with your people

Everyone will want to know how your loved one is doing. Once they are in rehab, the improvements are not that easy to spot day-by-day, so your response will be something like “they are getting better.” Most people have no way of relating to what “SCI better” means and they will likely think that the person is learning to walk again!

One thing people will not ask is how you are doing. It will take time before you notice this — at first you’re just glad that people are inquiring about the recovery and are offering “to help if you need anything.” This, actually, is not helpful because it puts the onus on you to reach back out and ask for help. So try to act on the offer while it is still hanging in the air — have a little list ready (in your head) of things that you need help with, like picking up a car from an oil change, clearing the driveway on a day when you know you won’t be home, getting your kids on the bus in the morning or picking up a short list of groceries. Don’t be afraid to ask; most people really do want to help, they just don’t know how.

Julie’s Journey

A POST-RECOVERY PERSPECTIVE

Something that I learned more than a year after my injury was how my husband was feeling about his role in my recovery. As my number one, he really kept my life and our family going — no pressure there! One day, he told me how only two people asked him how he was doing. Only two — one friend and his therapist. That’s all. Although he didn’t realize it at the time, this hurt. So as you go about caring for your loved one, try to remember yourself in all of this. See a therapist, too, and try to be open with your friends and your family — you can even ask them to check in on you from time to time. Your energy and emotional bank is not bottomless, after all.
You cannot do this alone

As the transition happens from acute care to rehab, the health care team is still doing most of the heavy lifting. However, this will change once the transition to home occurs. Be as prepared for this as possible. Have help lined up before the discharge date. Interview people so they are in place and ready to start that first week back at home. Homecare will not do everything, so you will need backup. Family and friends will only be able (or willing) to do so much. You cannot do this alone.

As you provide care and support, you may have to do things you never dreamed of. Bowel care, for one, was not in the “marriage contract” but here you are, anyway. (See Skills To Know Before You Go Home in Chapter Four). You may have thought that learning about SCI was just about over… Sorry, but you still have a long way to go.

A Family Member’s Story

A MOTHER’S PERSPECTIVE, PART 4

We knew immediately that our life was changed forever, but what we didn’t know was that it would get better than it was in the beginning. It’s so important to get into a good routine right from the start (when you get home), but it will take a lot of patience and a lot of trial and error before you find what works for your loved one. Even with a good routine (mostly bladder and bowel I’m talking about) anything can upset it, at any given time. No matter how you try, sometimes their body is in (or out of) control, no matter what you do!
As frightening as it is to be newly injured, acute care is a powerful step forward on the recovery journey, where experts can answer your questions and address some of your fears.

- Anthony Viao, SCIO Community Member
CHAPTER THREE

Acute Care
ACUTE CARE —
DAYS, WEEKS AND MONTHS IN SURVIVAL MODE

You are now the most important person in your life.
As you start to figure out your new body, you have to look out for what is best for you. You are priority number one. Now your job is to ask questions. Lots of questions. Get a pen and a notebook, a voice memo on your phone, or any system that works for you to keep track of everything.
If you are not able to write or record notes, have someone do it for you. Ask your partner, friends, parents or someone else close to you to write everything down. Ask the nurses/PSWs to do it every time something happens or changes. Names of specialists, doctors, medications, timing of events, test results, what was said at appointments, recommendations of therapists … you will thank yourself later for noting it all down! You will need to refer back to medications that you were treated with or remember which nurse helped you out with a particular problem. When you talk to peers, you will learn things that you may not know you needed to know!

Don’t try this alone
Reach out to those around you. When you have run out of people to talk to, consult some of the resources listed at the back of this book. With the help of Spinal Cord Injury Ontario, we have put together a list of reliable websites to help you get through. Because you will get through — it gets better.

Intensive and Acute Care
This section has a series of interviews from trauma care providers. (There are a number of ways to sustain an SCI and not all require trauma or intensive care. Here we focus on those that do.) The overall message is to focus on healing, listen to what they say and know that they do have your best interests in mind. Most of all, ask questions. For a start, ask about the medications they give you, why they put you in different body positions, and how your bowels and bladder are functioning. Everything they do for you has a reason — ask why.

But first of all, who are all these people?
Your room will have a revolving door for the first while. You will see a lot of different nursing staff (RNs and RPNs) and PSWs (Personal Support Worker)
who support their work. Nurses will provide medication, monitor your urine output and check your wounds and your vitals. They will help with your bowel care (which is likely no longer in your control). PSWs will help you with your meals (if you need it) and help with your personal care (bathing and hair washing). Shift changes mean you will see many faces, some possibly only once!

You will also see doctors who are orthopedic surgeons, trauma and pain specialists and possibly plastic surgeons too. If you are at a teaching hospital, you will also see resident doctors who will wake you up first thing in the morning while doing their rounds. Keep track of which department they represent (orthopedic, trauma, etc.); then you will know who to ask which questions. It’s okay to ask for reminders of who everyone is — they prefer that to talking to someone who is not sure!

As your recovery progresses, you may also meet hospital staff who are physiotherapists. They will want to get you “up” and moving. “Up” may mean sitting up in bed or in a wheelchair. You will learn to transfer in a sling and lift or with the use of a wooden transfer board, depending on your level of injury and how much pain and strength you have.

Professional Points: Intensive Care Nursing

What should I expect in Intensive Care?

The intensive care unit portion of one’s journey is just that — it’s intended to sort out, investigate and ultimately resolve critical, life-threatening injuries. That said, although important, it’s a small piece in the grand recovery puzzle. Your care team is there to help stabilize and resolve life-threatening injuries so patients can go on to recover. When in acute care, it is truly too early to know the extent to which you will recover. The body needs time.

Who can I ask for help while in ICU?

Whether you think you need it at the time or not, seek out the department social worker. Even things such as paper work stemming from a motor vehicle accident (MVA) can feel very overwhelming on top of the injuries themselves. The ICU social workers are well versed in what needs to be done in the early days after an injury and what can wait. Many patients and family members have shared that social workers often suggest ideas and resources they may not have thought of.
Will movement cause more injury?

No two spinal cord injuries are the same. In acute care, you receive the medical treatment you need in order for your body to be stable, including your spine. At this point, ask your care providers to help you start moving. Movement is key in recovery — getting up and out of bed is important; so is dressing in your own clothes, if possible. As you start physical therapy (PT) and occupational therapy (OT), ask what “homework” you can do when they are not around, especially on weekends!

Can I have visitors in the ICU and Acute Care?

Having visitors will be determined by several things, including hospital rules. Usually only the very immediate family will be able to see you. ICU is a very busy, noisy place with many patients in the same room, only separated by curtains. Depending on your personality, injuries and coping abilities, you may or may not want people to visit. Although most guests are well intentioned, it’s important to rest and focus on you. Ask a family member or your nurse to ensure visitors minimize their visit time.

You will need to keep a person in your corner who knows you, your limits and your needs. They can advocate for you about noise levels, lighting, visitors and alone time. Remember that it is possible for some visitors to take more energy from you than they give back.

What if something else goes wrong with my body?

All SCI families and patients with injuries above T6 should know about autonomic dysreflexia (AD). Learn about the causes, how to prevent it, what signs to look for and how to alert your medical team when you feel a crisis is coming on.

Advance Care Planning is very important and applies to everyone. This can be facilitated through reflection and conversation with your nurse and social worker. It’s a way to enable your Substitute Decision Maker (person you entrust to give or decline consent for medical care in the event that you are not able to do so) with the confidence in knowing that they are enacting your wishes. It helps to know that if worst case scenarios come to pass, your wishes will be honoured. That is empowering.

How do we stay organized?

Keeping a notebook or electronic record may seem simple, but you will also find it to be extremely helpful! Keep it at your bedside; your spouse/partner/parents should keep one too. When questions arise, jot them down so when the specialist enters the room your questions are ready. It is so common for concerns to be forgotten in times of stress. Remember to record the answers you get as well.
Insights from the trauma care nurse practitioner: Amy Makish, BScN, MN, NP

“We encourage newly-injured people to have an active role in their recovery right from the beginning. Family and friends should not do everything for the patient; challenge them to do it for themselves. You don’t need to wait until rehab to start feeding yourself, getting dressed, etc. Start now. Family always wants to do for the patient, but should instead help the patient do for themselves.

Also — and this is important — don’t read and believe everything on the internet. It is good to google and learn, but then follow up with your health care team to understand what you are reading and how that relates to your situation. At this point, it is important that you know what the next days, weeks and months will look like. It’s time to ask about what the criteria are for getting into rehab and what will happen if a rehab bed is not immediately available.”

Insights from the ICU nurse: S.B., RN, BScN

“This is a life-altering event; your body will continue to heal as you leave the ICU. With time, and as the swelling is reduced, some function may be regained. Your ‘final’ answers pertaining to damage or injuries sustained might not come from ICU, but well after you leave our care. Hope is important! Take one day at a time. If that feels too overwhelming, then start with one minute at a time and build from there.”
Patients with spinal cord injuries will almost always have multiple doctors. You should ask each doctor what their role is in your care so you know what to expect. Whenever your doctor proposes a medical procedure/surgery, be sure to ask the primary reason for the procedure, what you can expect from the results of the procedure/surgery and also what the common complications are. This will ensure you are as informed and ready as possible.

What should I expect from the surgery?

The initial damage is done at the time of injury; traumatic spinal cord injury is not reversible with surgery. In many cases, surgical intervention is performed to prevent progression of the SCI. For example, if you have an incomplete injury, surgery can be performed to prevent complete paralysis. If any of your vertebrae were broken at the time of the injury, surgery may be done to stabilize the spine (involving plates and screws), without necessarily trying to improve the function.

You (or your loved ones) should ask your doctor before and after surgery for clarification to understand the primary reason for doing the surgery; understanding will allow you to have the most reasonable expectations for the outcome.

What questions should you ask your surgeons?

You will likely feel very overwhelmed, with information coming at you from many doctors. Don’t feel that you must ask ALL questions immediately after your injury. You will have a long-term relationship with your health care team and you will have plenty of opportunity to ask questions. Most doctors will continue to see a patient with spinal cord injury for several years.

What is my prognosis?

Do make sure you ask your doctors about the preliminary prognosis. Your doctors will likely inform you that traumatic injuries are unpredictable; however, they should be able to offer you an educated opinion as to the expected long-term outcome. Their ability to provide you with an accurate prognosis improves as more time passes, so continue to ask.
Insights from the Surgeon:
Parham Rasoulinejad, MD, FRCSC, MsC

“Patients who have a spinal cord injury often underestimate what they will be able to do independently. You will have many resources over time that will allow you to live a happy and fulfilling life as a contributing member of your family and society. The journey to recovery will be very long and challenging, but with every challenge comes a new discovery of inner strength and perseverance.”

Respiratory technician

If you had chest tubes post surgery, be prepared to be followed by a respiratory tech. You are going to have to relearn how to cough in order to clear your lungs. With reduced core muscle strength you don’t have the same “umph” needed to get phlegm up and out. The respiratory tech will help you with this. Wait until you sneeze for the first time — you’ll look around and say, “Whose little sneeze was that?”
Who can I go to at the hospital to ask for help?

You are not in this situation alone. The ICU and trauma team will have a social worker for you to talk to. The patient is not the only one going through something awful. The family and loved ones are too.

Who should we involve in our team at this point?

In the acute care stage of recovery, you mostly just need hospital staff. You and your family are in control of your team and at this stage there is no need to involve outside case management, legal or insurance people in family meetings. This is a very personal time where diagnosis is still being discussed. Things will change when it comes time to go home, but that is not now.

It’s not just the patient that needs help

You are not alone in this situation. Every step of the way, change is happening to everyone — children, partners, parents, etc. Everyone should access help, not just the injured person. This is often hard for families to do because they minimize their experience compared to what is going on with their loved one.

Families will need to look at their normal coping strategies while dealing with stress — exercise, journaling, talking to friends or professionals. Ask if those coping strategies are working and what else you can do. Children, especially, will seem resilient, but should be monitored over the long term because everyone’s stress will affect their view of the situation and of their own life. Many families have never had to cope with something as major as a spinal cord injury and sometimes those families need the most help.

How do I cope when coping seems impossible?

Believe it or not, you will build resilience in yourself and in your team as time goes on. Yes, this will shake your belief of security in the world and create a feeling that you are not in control of your life. It may take your stress levels off the charts, but you are in control now. What happened to cause your SCI is over. Now you need to focus on each day and not think too far into the future.

Some of the things you are telling yourself may not be true (like about how you’re going to cope), so talk about them, write them down and examine each thought by shining some light on it and asking: Is that actually true? Do I need to have this worry? It may not be true. Have this conversation with your social worker or psychologist and take control of your thoughts. Act on the thoughts that are true, shelve those that are not.
What about money?

While in hospital, everything is covered by OHIP if you are an Ontario citizen.

How do I deal with offers of help?

This is NOT your job. Yes, you will need help, but delegate someone else to manage those offers right now, if you can. People genuinely love to offer help and, in turn, it helps them feel better about your situation. Navigating the aftermath of a family tragedy often involves food; neighbours and friends will want to bring it, so let them. Your delegate can label it and put it in the freezer, as there will be days where nobody can cook.

Your delegate can also have a list of other tasks that need to be done. Welcome the help of others (such as church or work communities) to get things like gardening, snow clearing and child care, looked after. Hospitals are scent-free and, unfortunately, flowers often aren’t permitted. Consider asking instead that money go toward parking or a coffee fund for those sitting beside your bed.

Insights from the Acute Care Social Worker:
Bev Lewis, MSW, RSW

“Most of all — don’t panic. Don’t minimize the situation either, but panic will not help. There will be a lot of help to manage every step of the way. There is a lot of evidence to support that people can manage more than they think they can and can make more adjustments than you thought were possible.”
What else should I expect during acute care?

Expect people to visit without an appointment, including legal and insurance people, friends and strangers. If your SCI was the result of an insurable accident (MVA or WSIB), you will, for sure, be visited by someone from the insurance company. This is the insurance adjuster and they will want every last detail. Also, keep in mind that material offered by law firms might not be unbiased.

A peer-support mentor (a trained volunteer who is living their life with an SCI) may also come to see you. Keep in mind that it may be too early for you to comprehend your future circumstances and the peer support conversation may best be had between peer and family/loved ones — it offers support and hope for families. Collect whatever information they have to offer, as peer support will be helpful when you are ready for it.
You ask yourself a lot of questions in rehab: How strong can I get? How do I do better? Do I need help to progress today? It can also be quite a social environment where you connect with new friends.

- Ivan Rendulic, SCIO Peer Program Co-ordinator
CHAPTER FOUR

Rehab
WELCOME TO REHAB! ... REALLY??

Staying in a rehabilitation hospital (specializing in spinal cord injury recovery) is just a stop on your way back to a full life. Your recovery will continue once you get home and will go on for as long as you force yourself to learn how to be more independent. For now, you are learning about your new body and how to handle it.

Up to this point in the Roadmap, the concept and the place we call “rehab” has not been completely or thoroughly explained. If you read “Julie’s Journey: The Full Story,” you will have a sense of what happened in my case, but it is not the same for everyone. Let’s get you comfortable with the idea and the place of “rehab” before we go any further.

In the Province of Ontario, there are six rehabilitation hospitals that specialize in spinal cord injury care and rehabilitation: Lyndhurst in Toronto (part of University Health Network), Parkwood Institute in London (part of St. Joseph’s Health Care London), Providence Care in Kingston, Hamilton Health Sciences Regional Rehabilitation Centre (located at Hamilton General Hospital), the Ottawa Hospital Rehabilitation Centre and St. Joseph’s Care Group in Thunder Bay. It is also important to note here that all of these facilities also have people who specialize in caring for Acquired Brain Injuries which often, but not always, occur when the SCI has been caused by a traumatic accident.

Having been diagnosed with a spinal cord injury, your physician may refer you to the closest rehabilitation centre. As Ontario is a very big province, for some, this could mean making the decision to be far from home (for what could be months) in order to support recovery. This is not an easy decision to make — and yes, you do get to decide. Wait — what? Yes, you have a choice to go or not go. READ ON so that you know how important it is to go to, stay at, and put all you have into your time at rehab. The benefits will outweigh the challenges posed by the distance from home.

One thing is for sure — and I think you have a sense of this already — it is not going to be easy. Rehab is one of those times where “if it’s not hard, it’s not helping.” The other sure thing about rehab is that you are going to be a completely different person when you leave compared to when you first roll in. And by completely different, I mean better. Not “better” as in you are
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.

**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.
Being away from home is never easy. Being far away from home is going to be challenging, but not insurmountable. Communication technology will help you stay connected to those back home and you will develop relationships with those who are going through the same thing that you are. Often these are the people who end up making the most difference in a person’s recovery.

Get comfortable. This is where you are likely going to spend a lot of time, possibly months, so make it feel like home. Have your family members bring or send pictures, comfortable blankets, stuffed animal friends, snacks, a device and a headset. Oh, and don’t forget earplugs!

Your level of injury and any other complicating health issues, including your age, will determine how much time you spend in rehab. You may be able (once you are strong enough) to go home for a weekend/home visit. Get as much out of your care team as you can — they are there for you. You will be a different person when you leave.
You’ll meet many, many nurses; however, you are likely going to have one primary nurse who is assigned to you. This is the nurse that you will spend a lot of time with and you should use as your “go to” person. Ask all your questions and learn as much as you can. Ask them to show you exactly what they are doing and why. When they are not around, write down the questions you have so you remember to ask the next time they are on shift. You will also see registered practical nurses (RPNs) and personal support workers (PSWs) while in rehab. Ask their names and what level of qualification they have because they may not always wear name tags.

Your nurse will be doling out your medications, monitoring your urine, measuring your vitals and, to an extent, helping you through your day. They will help you establish a bowel and shower routine and will talk to you about your pain. They can be the connection between you and your doctor by relaying messages to them for specific medical concerns. There will usually be a nurse who is the Unit Lead — if you think you are not getting the care you need, ask them for help.

**Why are the nurses not doing everything for me? I’m paralyzed!**

If they are a good rehab nurse (Certified Rehabilitation Nurse in Canada), they will make you do everything you can as soon as you are almost capable. Trust me, this is for your own good! It is their job to help you learn to be independent with your own care. Your spouse, parent or professional caregiver may not always be there when you need them to be. You have to learn what you can do by yourself or, if due to a high level of injury and you are not able to, you will learn how to direct your care providers.

**I don’t want to do that!!**

You will learn (whether you want to or not) a lot about your body — much of which you have never thought about before. For some, the intimacy with which you will need to know your anatomy will be uncomfortable, but you really have no choice.

There’s the easy stuff like how to do your own skin checks — those parts of your body that you cannot see easily and can no longer feel. You need to make sure you have no areas that are receiving too much pressure from your wheelchair or mattress. Transfers from one place to another can cause skin irritation, cats have claws and toilet seats can pinch! Pressure sores can develop into extremely serious, even life-threatening conditions, so it’s important to learn how to check and position yourself to prevent them.

Then things get more personal.
I have to do what??

Your bladder needs to be emptied regularly (perhaps up to 10 times a day) and, if you have lost bladder control, it must be done with a sterile catheter. People with high level injuries and little hand function often use in-dwelling catheters, but for those who are able to, studies show that in-out catheters result in better bladder health. You will learn about medications that help with bladder spasticity and other ways of managing bladder health like supra-pubic ports and botox. Unfortunately, you will also learn about urinary tract infections.

Urinary tract infections (UTIs) may plague you for the first part of your new life. First, and most importantly, learn your signs. You will see changes in urinary function such as cloudy/foul smelling urine, incontinence (more than usual), fever (moderate), headache and fatigue. Most people also generally feel poorly. There are many non-scientifically proven methods for preventing UTIs. The proven ways to prevent UTIs are good hygiene, drinking lots of water and making sure you empty your bladder regularly with a sterile catheter.

Initially, your bowels will act like a beast that cannot be tamed, but eventually you will get those intestines under control, even routined, too. Depending on your type of injury, there are different ways of managing bowel movements. You’ll learn the importance of wearing gloves, using personal lubrication, suppositories, milk of magnesia and digital stimulation. If you are not able to perform your own bowel care, nursing staff will help you learn how to direct your care in order to have an effective bowel routine.

The sooner you learn to manage your bladder and bowels, the sooner you will be able to wear your own underwear again! There is no need for you to continue wearing an incontinence brief if you are able to go accident free for several weeks in a row.

So what about sex?

Sex is on the minds of patients more than health care providers ever realized. Now, nursing staff understand the importance of talking about it. So ask lots of questions; after all, you have to learn a whole new way of being intimate with your partner and with yourself. Ask about position, lubrication, toys, aids and side effects. What people may not realize is that sex can lead to Autonomic Dysreflexia — not the outcome of an orgasm that you are after! A healthy sex life is indeed possible with an SCI and there are lots of places to find information and supportive resources for when you’re ready. Read more on sex in Chapter Seven.
Who’s in charge here, anyway?

Although it may seem that the nurses are in charge of your recovery, it’s your body and you are the one in control of what happens to it. You need to listen to your body — and you need to help your care providers to listen, too. You have to advocate for your needs; try saying, “I know this is your job and you are telling me what you think is best, but my body is telling me… Can we try this… ?”

It’s not so much a science as an art form. Learn about all the other options that are available for whatever issue you are having — someone, somewhere will have tried something different.

What do nurses really want families to know?

The nursing staff wants families to know that you also have a job to do. Your role in rehab is to step back, be a cheerleader and let the patient be in charge of their care. Let your loved one have the control — especially in cases where the patient is older or younger, children of seniors or parents of teenagers tend to interject. You need to let them make the decisions, ask the questions and do the talking. If you feel that your loved one is making the wrong decision, talk to the staff separately and say, “Is this appropriate?”

Especially in a traumatic event, where survival may not have initially been clear, you need to let them get as far along as possible — on their own. Often, families end up taking away the control, even though they are trying to help. Nurses are not always going to be there to help and neither are families. Step back and let nurses do their job of teaching. SCI will mean struggle; trial and error is how people learn.

Another reason to give space is because if you, a family member, are always hovering, the patient may not be comfortable to ask nurses questions, rest or just do what they need to do. So let them be. Allow them to struggle. Life is going to get to a new normal, eventually.

Insights from the Rehab Nurse:
Elizabeth Fox, RN, CRN(c)

“I don’t get paid to do it for you, I get paid to watch you do it. Welcome to rehab!”
BLADDER & BOWELS

I distinctly remember being in my hospital bed in the trauma unit and watching the urine as it left my body through a tube connected to the catheter bag. I realized that if I took a deep breath I could actually “move” the urine to go down the tube faster. I thought that was pretty cool, but I’m a biology teacher, so I think words like “sphincter” are cool.

But my point is that I was getting to know my body in a new way. Before the collision that caused my SCI, I had a pretty good connection with my body; I knew when I was hungry, tired, hormonal, pregnant...

My SCI has required that I learn about my body in a whole new way — and be comfortable with it at the same time. Pre-SCI, bowels and bladder stuff happened without too much thought or organization. Now, dealing with it has become incredibly intimate, something that has required a whole new mentality.

While in rehab, the nurses were very excited about the possibility of teaching me how to use a catheter on my own. For a long time, I was not at all thrilled about it and put it (and them) off for as long as possible. But learning to do intermittent catheterization (pretty much anywhere now) has given me the independence to go almost anywhere, except for the odd house that doesn’t even have a closet big enough for a person in a wheelchair to get some privacy.

The bowel stuff is a bit tougher to manage, but you will get there. It won’t happen overnight; in fact, it will likely take months to get into a routine that you (and your bowels) are comfortable with. Shit happens. And at the beginning, in places and ways that you would not wish on your worst enemy.

But it gets better when (not if) you get more comfortable with your body. Pay attention to little signs, things that your body is trying to tell you, like foods to eat in order to avoid delays, how much (or what) to drink and medications that change how your body functions (like antibiotics).

Trust me, you are going to be sticking your (gloved) fingers in places you would never have imagined before. You may need the assistance of a nurse, or a professional caregiver; the more comfortable you are with your body, the easier it will be for them to help you. But you will get used to it, you will get better at it and you will start to develop the freedom you need to carry on with your life.
LOA: Leave of Absence

Speaking of struggling… Everyone struggles the first time they go home. An LOA is a way to learn what you don’t know and yet have the ability to go back to rehab and say to your therapists/nurses, “What about…?”

You likely won’t have nursing care 24 hours a day when you are home for good, so an LOA will help you “practice” being home. Some rehab hospitals have units that are designed for an LOA (called Independent Living Units) and you can ask to go home for a weekend, too. You will learn about the impact of travel (in a car, often for the first time), getting in and out of bed and just the mental stress of adjusting to the next phase of your recovery. You have to go home eventually, so why not practice that, too?

Julie’s Journey

GOING HOME

Two months into my four-month hospital stay, I came home for a weekend. My husband and his friends had moved our bed to the main floor to make a new bedroom out of the former dining room. Other furniture had been moved to give me space to get around, but it was tight. Aside from all the physical discomfort I was still experiencing, the emotional toll of coming home hit me hard. I would never be able to walk around our property independently, enjoy the trees and help out with our large vegetable and fruit gardens. Even travelling up and down the long gravel driveway would forever depend on the season and the weather. Going home should have been joyful, but instead it really hit hard.
A physiatrist is a doctor who is a rehabilitation specialist. They will have expertise in neurotrauma (SCI specifically) and acquired brain injury rehabilitation. They are the doctors who will have the most information about spinal cord injuries and will be able to answer all (or at least most) of your questions. They will stop short of any type of recovery prognosis, but they will give you their best opinion. While you are in rehab, see them as often as you can. Stop them in the hall and give them an update on your progress in therapy. They will also be one of your cheerleaders!

When you leave rehab, they will keep you as a patient for as long as you need their assistance. Keep a running list of questions that you have so you can make the most of your time at each appointment. You will need to talk about pain management, UTIs, bone density, blood pressure, physiotherapy, medication, emotional support and whatever else you want answers for.

Your physiatrist will have a lot of connections in their rehab community and they may be an excellent person to ask for recommendations. They will know from other patients what people have done who have had the most success and therefore they will be able to guide you in that same direction. Ask for recommendations by speaking to other patients as well; those who have had success (including legal) will be the best to talk to. Ask your physiatrist to connect you to others so you can build your community of peers.

**Insights from the Physiatrist:**
Keith Sequeira, MD, FRCP(C)

“Be sure to think about the long-term consequences of your actions. As you start your recovery, have goals for being active, maintaining your weight, managing bone density, shoulder strength, cardiovascular and general health. Making choices to play sports will be beneficial for your social life and your mental health, but think about the future and how you will maintain your fitness and your everyday life should you become injured. Investigate all types of treatments for physiotherapy, dealing with nerve pain, or if nerve transfer and tendon reconstruction would be helpful.”
HBP IS AD IN SCI FROM UTI

One of the physiological anomalies of an SCI is the effect it has on blood pressure. Blood pressure regulation can become difficult if you have an injury of T6 or higher. You may experience low blood pressure (90/55) due to the lack of messaging to your lower body. No messages to the muscles means they can’t contract to help push blood back up to the heart and head. This often causes dizziness, feeling of lightheadedness and blurred vision. Although all of these symptoms are uncomfortable, they are not necessarily deadly.

The opposite is true of high blood pressure in SCI patients. This is what is known as AD — Autonomic Dysreflexia — which is caused by discomfort or pain that the body cannot sense or respond to. AD causes elevated blood pressure, which can lead to stroke, cardiac arrest or other deadly conditions.

It was three and a half years post injury before I really experienced the true effects of AD. It happened when I had one particularly awful UTI. The infection had caused my bladder to produce blood which, in turn, had started to clot. The blood clots blocked the catheters I was using and I was not able to empty my bladder. Of course my body did not like this, my bladder getting fuller by the minute, and I started to feel the effects of AD. My blood pressure was increasing, I was red in the face, starting to sweat and getting a really bad headache. By this point we were on our way to the hospital; I knew I needed help to get the clots out.

This was a scary time for me. At the hospital, I quickly explained my situation and they brought me into an exam room where they proceeded to use a number 18 three-way catheter so they could flush my bladder and suction the clots through the catheter at the same time. It took a serious amount of suction from a large syringe to get the clots out. It also took a couple of days (and some killer antibiotics) for everything to settle back to normal. Do not mess around when AD happens. Figure out the source and get it looked after ASAP.

Carry a card in your wallet, one that explains AD, since not all emergency staff will understand the condition.
**General Practitioner (GP)**

The GP is your family doctor while in the hospital. Ask them your medical questions; they will manage your medications and help with the diagnosis of any secondary complications (like UTIs and skin breakdown). Together you, your physiatrist and your GP can determine which route(s) to take to help manage your pain.

**DIET MATTERS**

Now you need to prepare your body to be ready for what comes next — rebuilding. How much you will recover is anyone’s guess, so you have to provide your body with the nutrients it needs for the best recovery possible. That is where a dietitian can help. Hopefully, you will have the help of a professional while you are in rehab, so ask all the questions you can.

**How much should I be eating?**

As you move from acute care to rehab, your body is likely still in a “hypermetabolic” state. This means that your energy needs are higher than usual because the cells and systems of your body are trying to repair the damage that has occurred. BUT this doesn’t mean you can eat whatever you want; this is when every calorie you eat counts and those calories need to be high quality nutrients.

There will come a time in your rehab where your choice of calories can mean the difference between weight gain and muscle loss. Weight gain leads to increased stress on joints and makes recovery more difficult. If you gain weight when you have paralysis, it means you have more body mass to move around using just your arms and shoulders.

**Does what I eat affect the pain I have?**

There is a lot of new research showing that there is a connection between inflammation and pain. Often, inflammation in the body is connected to food choices. Your diet could very well impact the amount of pain you are feeling. Nerve pain is something that is very difficult to overcome — you need to do whatever you can to make a difference. If changing what you eat can reduce your pain, why wouldn’t you try that?
**How does my diet affect my bowels?**

While in rehab, you will be figuring out how your bowels work and what routine works best for you. Your rehab dietitian will help you understand what types of food (and fibre) you need to eat and they will also be able to help you determine what types of medications you might want to talk to your doctor and dietician about.

Before your injury, you likely knew to “eat your fibre for good gut health,” but now it really makes a difference. Eating foods that are high in both soluble and insoluble fibre will help move material through your intestinal tract — and this is what you really need now that your intestines don’t work the way they used to. Ask the professionals that are working with you for help — specifically, what are the foods that will help your bowels? Remember that every SCI is different, so what you need to eat may be different from that of the patient in the next bed.

**What is the connection between skin health and diet?**

Due to reduced circulation (caused by paralysis), your skin will receive fewer nutrients and less oxygen. If a pressure wound occurs, even less oxygen and fewer nutrients are delivered to the area and essentially the skin is dying. This is why putting high-quality nutrients into your body is so important. Healing skin requires more than just relieving the pressure to the area; you have to optimize the quality of fluid and nutrients getting there.

In order to fill that hole in your skin, you need the raw materials of proteins, vitamins and minerals and you want those to come from your diet, not from what is stored in your body. Muscles are already being broken down, impacting recovery and strength. Think of it like a pothole; if you fill the hole with sawdust and cover it with duct tape, it will be closed, but you know it won’t stay that way. The raw material needed to fill the hole must be of good quality. Research shows that the strength of skin two years post pressure sore is only 70% the strength of the skin prior to break down — and that is when it heals under ideal conditions. So remember, garbage in, garbage out.

**But this should be the time for comfort foods, right?**

No. Although you may crave comfort foods, every calorie you eat should be of high quality. Salt, sweet and fat feel better in your mouth and to your brain, but they don’t help your body. You can’t afford wasted calories. Focus your eating on nutrient-dense foods. They should have high protein, good fats and lots of antioxidant qualities. Eat nuts, fish, eggs, seeds, berries, leafy greens and colourful vegetables. Although you may spend most of your time thinking about walking again, getting there requires high-quality foods.
Insights from the Dietician:
Chris Fraser, RD

“Most patients are focused on therapy and how to get home. They tend not to think about the food that they are eating, especially because comfort food can feel so good! During rehab is the time to think about what you need to eat and to ask for help. Start planning and talk to your people. They will want to bring treats for you to ‘feel better,’ but you need to be firm and ask for their support in changing how you eat. You need to fuel your recovery — your skin, muscles and bones need as much help as you can give them!”

MENTAL HEALTH

Professional Points: Psychologist

Some people will be more comfortable than others when it comes to speaking with a professional. Whether you realize it or not, your life has been turned upside down. Talking about it, learning relaxation techniques like meditation and, most of all, talking about feelings is more important than ever. Depression is a reality for many people with an SCI. Not being able to do many of the activities that you used to do will take some adjustment, so discussing ways of coping will be very helpful. Even though you will have spoken with a psychologist at least once while in rehab, don’t think you are done — talking can sometimes be the best medicine. Your mental health is so important and depression can lead to increased pain. Being reminded that what you are going through is difficult is often helpful to move closer to acceptance.

Your discussions need to be open, honest and in a place of trust that allows you to feel vulnerable. That is why your choice of therapist needs to be carefully considered. While in rehab, you likely had a psychologist on your care team, but heading home you will need to find one in your community.

Do I need therapy?

Many people have found it a crucial step in their recovery. Suffering an SCI is a loss. Not only a loss of physical mobility, but it can also be a loss of self, roles, relationships and independence. The process of going from walking to not walking is akin to other grieving processes. Grieving is not a linear process and emotions will come and go; remind yourself that this is normal. Expect to have a fluctuation of emotions: hopelessness, fear, anger, determination and devastation, to name a few. Talk to others who have experienced SCI about these emotions, as a way of learning that these experiences and emotions are normal. Feeling isolated and alone can be one of the worst parts of
experiencing loss. That is where talking comes in. A professional therapist can help you find ways to adjust to your new life, your emotions, thought processes and can help you problem-solve about how best to adjust to your new life and relationships.

**How do I find a psychologist or social worker once back home?**

Start with your family doctor. If you are in a Family Health Team, then most likely you will have a therapist on that team. Your doctor may recommend you start there, see how you connect and then decide if you want to continue to see them. It should not take too long for you to decide if you want to work with them (maximum two sessions). If you are not comfortable, feel you don’t connect or relate to that person, try someone else.

**Does my therapist need to have experience with SCI?**

It is not essential that your therapist have experience with SCI, but it would help. Having an SCI places you in a new culture, one where terms like *bowel care* and *injury line* are new. Experience with SCI also leads to an understanding of how “excuse me, I have to pee” means that it has to happen now and that a supposedly accessible washroom often is not. The experience could be with former patients who had an SCI or it could mean experience in a rehab facility. All this background knowledge will help move your therapy along more smoothly, with less need for explanations from you.

**How do I pay for a psychologist or social worker?**

Fees for services can range depending on where in the province you are located, but the average is $125/hour. If your injury is the result of an MVA or WSIB, then insurance will cover this expense until you settle with the insurance company. If you have work benefits, they should also cover most, if not all, of the cost. If you have neither option available to you, **DO NOT GIVE UP.** OHIP will pay for the services of a therapist who is a member of a Family Health Team. Again, ask your doctor.

**Should my partner/Family Member also talk to someone?**

Your immediate loved ones can benefit from connecting with a psychotherapist or social worker as well. This loss is also theirs. They are experiencing many changes in their lives because of your SCI and you are not the person to guide them through these experiences and emotions. You are too close to the situation to be able to support them in an appropriate and healthy manner. Family caregiver fatigue is a real thing; emotional support from talking with a therapist is one way to help prevent this from happening.
What will we talk about?

Each person’s journey will have unique challenges and aspects that should be addressed; however, there are a few core areas that you should cover with a therapist to ensure optimal emotional recovery, including relationships, emotions, sleep, body image and returning to work, to name a few. Because SCI and acquired brain injury (ABI) often go together, your therapist should also be informed of any ABI symptoms in order to address them during therapy.

Insights from the Psychologist:
Erin H. Ross, PhD, CPsych

“Make sure you are monitoring your sleep. Sleep aids in physical and emotional recovery and can be the difference between feeling determined or feeling devastated about progress and setbacks. Nutrition and movement are also powerful in terms of their impact on our mood. Recovery will have many physical demands that require our bodies and minds to be as healthy as possible. In addition, socialization is key to emotional wellness. Loss and physical changes too often result in isolation from friends, family and other social interactions. We are social beings. We find meaning, happiness and a sense of calm through our interactions with others. You will need this more than ever during recovery (and adjustment to your new life). In short, eat well, sleep well and be social.”
While in rehab, you will have a lot to talk about. Your social worker will help you figure out what you need for discharge, for your physical surroundings and also the people to involve in your at-home rehab. They will also just be a good person to talk to.

**Why do I have a social worker?**

Aside from the nurses, the first person you need to talk to is your social worker. Rehab inpatients are assigned a social worker as a part of the team. Even if you don’t have any specific questions, all you have to say is, “Where do I start?” or “What do I need to know?” That is the job of the social worker — to help you figure out what the puzzle pieces are and how to start putting them together. You need to learn how your life has changed and what it is (likely) going to look like when you leave rehab. This way you will be as prepared as possible when the time comes to leave.

**How will I manage finances?**

Unless you’re independently wealthy, you will need money to buy equipment, supplies, pay for physiotherapy, maybe renovate your home, buy a new car and purchase clothing that is wheelchair friendly. If your SCI was the result of a motor vehicle accident (MVA), a workplace accident (WSIB) or another kind of accident covered by insurance, after lots of paperwork, insurance will pay for many (if not all) of your expenses. Your social worker will help you navigate the beginning of this system; it is one that will continue long after you leave the hospital.

If you don’t have insurance, your social worker will help you understand and start the process of getting help from a case manager, Community Care Access Centre (CCAC), work-related insurance, Ontario Disability Support Program (ODSP), Employment Insurance or Ontario Works assistance. Help does exist. They will help you with the applications and the paperwork — it’s a great idea to start keeping a binder!

**Help me with housing!**

You may need to get creative when it comes to finding housing. If your SCI means that you will be using a wheelchair, chances are that your current living space is not very accessible. There is a very serious lack of accessible housing in every community, so if your goal is to be independent, you are going to have to choose — renovating, moving or considering some kind of long-term care facility until other housing becomes available.
How to find social support, community support and advocacy

You are not alone. Your social worker is there to listen. Talk about how you feel and how angry you are — it is a necessary part of recovery. You are going to need to grieve your loss, regardless of what happened to cause your injury. Having an SCI will likely be the biggest adjustment you will have in your life and you will need a sounding board to voice concerns about your future. Your social worker will listen and will be your advocate. They will help you find the resources you need and help you speak to your doctors or therapists so you are all on the same page. Your social worker will also help you connect with the community partners that are there to help you with your needs. Family members and friends are also grieving your loss. They will need support as well and should not be afraid to ask your social worker how they can get help.

What is a team meeting?

Your social worker will set up a team meeting with anyone involved in your case — your doctors, nurses, therapists, case manager, family and social support (perhaps even legal and insurance personnel). Everyone at the team meeting has the same goal in mind — for you to gain as much independence as possible and be ready (with funding in place) to leave rehab when the time comes.

**In cases of WSIB, your WSIB Social Worker will set up the team meetings, prepare medical reports and liaise with WSIB to get as much organized as possible before you return home. WSIB has a specialized team that is accustomed to working with people who have had catastrophic injuries.**

Insights from the Social Worker:
M. Jean Sommerdyk, MSW, RSW

“My role is to help patients find what they need. Whatever the situation, even when it seems complicated, we will help find the community supports required for when it is time to leave rehab. Ask for help; you do not have to go through this alone.”
In rehab, you will have many people come and go — nurses and nursing students, visitors, specialists — but the one constant will be your therapists: physiotherapy (PT), occupational therapy (OT) and speech-language pathologist (SLP). You will get to know each other well. Trust them; they have your best interests at heart. Confide in them — your concerns, questions and fears. They will have the experience to help you or will know how to find what you need.

**Professional Points: Physiotherapy (PT)**

You may have already started doing some physio in the acute care hospital (like trying to sit up, or working on hand flexion), but if you were there only for a short time, this may be your first introduction to what physio is all about. At rehab, you will likely see your physiotherapist five days a week for between 30 minutes and an hour. You are going to get to know each other well!

**How is physiotherapy going to help?**

You won’t always enjoy it, but deep down you know it is the right thing to do! Your PT will help you learn how to work on your mobility gently, prevent further injury and gain strength and balance. You’ll learn how to stretch muscles carefully and reduce contractures in your joints. Physio also helps with blood circulation. You will start with conversations about the activities you did pre-injury and your PT will help you understand the process of working through many different stretches or exercises to reach milestones. Specifically important to work on are core strength and posture — being seated all day requires this.

**What is Activity Based Therapy?**

Hopefully you will get opportunities to do Activity Based Therapies. These activities work to mimic and reinforce normal movement patterns such as walking or cycling. Technologies like robotic exoskeletons were created to allow repetition of normal muscle action, with the hope of reinforcing that movement.
ROBOT GOALS

From the very first day I rolled into the physio gym at rehab, I knew I wanted to get into the Lokomat. There was a young woman up and “walking” in it and she looked so happy. I asked my physiotherapist assistant (PTA) about it and once I learned that it was not something that I could just get up and do, that robot became one of my goals. Before I was able to be up in that machine, I had to learn how my body managed blood pressure as well as muscle spasticity — I got “trained” on the tilt table. Along the way, though, I came to understand the benefits of robotic therapy — it wasn’t just for the fun of being upright. There is a great amount of research and understanding about the physiological and psychological benefits of robotic therapy. It doesn’t just make you look cool. It feels fabulous to stand upright, it’s good for your bones (weight-bearing activity) and you can give and get a hug while standing.

What is FES?

FES stands for Functional Electrical Stimulation, a technology you should try to get access to. FES stimulates muscle groups (similar to a TENS machine) through the input of electrical stimulation to the nervous system. Many pieces of FES technology (typically cycling ergometers) can also be purchased for home use, which allows for more opportunity to use it. Typically, FES is used for leg, buttock and abdominal muscles, but is also used for arms and shoulders. FES may help with bone density, as well as maintenance of (or even an increase in) lean muscle mass, decreased fat deposits, improved circulation and cardiovascular conditioning. Some people also report decreased spasticity. If you have insurance, your company should back the purchase of FES — don’t accept “no” as an answer to your request.
T4 SISTERS

I was lucky to be able to attend rehab as an outpatient. Parkwood has a gym that has very reasonable membership rates that include use of the FES bike. With four bikes in a row and an hour of literally being stuck there, you have time to make conversation and get to know one another. It just so happened that my Thursday time slot coincided with three other women who also had T-level injuries. We were the T4 Sisters; meeting weekly to share what was new, give and take advice. It really was one of the best things to happen to me. Over time, even though I had an FES bike at home, I still went to Parkwood to ride there. It was more than just the physical therapy; it was the social time, advice and camaraderie that made me do the three-hour drive (round-trip) almost every week. It became an essential part of my therapy.

Should I continue physiotherapy when I go home?

Your body still needs lots of help as it heals. At this point, it is important to remember that YOU are still the most important person in your recovery. You have to be comfortable with the therapist you choose. Once you get home and are settled, you will need to make a new routine for your physio. No longer will you have someone setting up your therapy time and writing it on the board beside your bed. Physio, once you are home, is even harder than in rehab because now you have to make it happen. You have to find a therapist, arrange to get there as often as you can and work hard.

How will physiotherapy continue to help me?

Physio is your key to recovery — because you will continue to recover. Your balance will improve, which means you will be able to reach closer to the floor and feel comfortable doing so. Your manual dexterity may improve and you may be able to fold laundry. Your blood pressure will level out more quickly and you’ll be able to stand in a standing frame for longer. Your upper body strength will improve so you can do transfers that you may have not thought possible. Every little bit will make a difference. Given even a small chance that your neural pathway will be restored, making your body try to work is the only way to know how much recovery you will get. You have to try.
How do I continue to do physio when I get home?

Finding the right physio clinic is key to this success. If you live in a larger centre with multiple clinics, spend some time asking around. Who has experience working with an SCI? Who has had positive experiences with the people at the clinic? Who has been able to see results in terms of recovery? Ask everyone! This will be one of the most important decisions you make about your recovery. You don’t have to stick with a certain clinic or therapist if it doesn’t feel right. You can also have a kinesiologist visit you in your home to help you with your exercises or they can meet you at a community pool. Water therapy is also very valuable, to both mind and body.

Once home, use what you have learned in therapy — such as posture, body alignment, the proper way to roll or transfer etc. — and implement them in your everyday life as much as you can. Try not to allow yourself to do things the easiest or quickest way if you know it’s not how your body would typically move. Your nervous system is constantly learning and changing — you have the best chance for your system to relearn the proper patterns if you are practicing them more than just during your therapy sessions. This can be exhausting and frustrating, but it is important.

What type of physio equipment do I need?

Although physio is your key to recovery, this does not necessarily mean it will get you up and walking. But there are many ways to keep recovery happening — and they don’t have to cost a lot. Strengthening your core, shoulders and arms will be your means to be as independent as possible. Start with a stretchy band and set up a plan to use it every day. If you can get out of your chair, do exercises on a mat or physio bed. If possible, start out using light hand weights and pulleys. All these things will help you with transfers, dressing and even cooking. Having access to a standing frame is a good idea (at home or at a physio gym). It will help with joint loading and some people report improved bladder/bowel function. Standing on your body weight also can help with bones and bone density.
FOUR YEARS AND STILL WORKING ON IT

It’s been four years since my injury. In those four years, I have been lucky to have physiotherapy at least one day a week. Some weeks I have had energy to work hard, others, not so much. But, every once in a while, I get to say to Marc and Bill, “I wasn’t able to do this before, was I?” Some things seem very trivial, like putting two hands out in front without falling forward. But others lead me to think that there is more to come. Which makes me want to tell you not to give up. You don’t know what you are capable of until you try and try again. No matter what doctors say, you won’t know what your body can do (or re-learn how to do) until you make demands and have higher expectations. I plan to continue my weekly therapy so that I am as strong as I can be in my core and shoulders — it makes everyday tasks (like transfers) easier.
Insights from the Physiotherapists:
Bill Glassier, BSc, PT & Marc Pittock, BA (Kin)

“There is therapy is hard. There will be days that you’re not going to want to do it and days you feel defeated and exhausted or are afraid that you’re never going to improve. It’s okay to have a pity party (for lack of better words) for a little while, but then get back up and keep trying. Therapy is meant to be challenging. If it doesn’t challenge you, it won’t change you.”

Insights about robotics therapy:
Stephanie Cornell, MPT

“There are a lot of pieces of equipment available that promote walking and enhance mobility post SCI. Find out what is right for you. Your therapist will make recommendations based on the evidence of the recovery of your nervous system. Early on in recovery, it is important to focus on flooding the nervous system with deliberate, meaningful sensory information.”
Julie’s Journey

JUST KEEP SWIMMING

For me, being in the pool was the most freeing experience. It got me out of my chair and I didn’t have to rely on someone else to be active and try to move my body. I was a swimmer before my accident, but you don’t have to have been to try it out. Ask your therapist to help you. Many rehab locations will have a pool and someone certified to do pool therapy. It’s hard to say for sure how much, but a lot of my muscle recovery is from being in the water. You will be able to do things in the water that you can’t do on land — yet. That is the surprising thing; if you can move this particular muscle in the water, then you can work on getting it to move on land. Swimming is also a fabulous cardiovascular activity and you won’t overheat while doing it!
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!

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.

Peer Perspective

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No matter what level your injury is, OT will also assist you with pain management through stretching, range of motion, strengthening, acupuncture or acupressure (using fingers on pressure points) and body positioning (such as in your chair or in bed). As you improve and gain strength, your therapy will be altered to work on becoming independent with activities of daily living (ADL).

What are ADLs?

Activities of Daily Living. As mentioned before, you will be learning how to do all the things that you learned when you were a child, like getting dressed, brushing your teeth or eating. There is a real knack to learning how to pull up your pants while sitting on them! You may need to learn how to hold a stylus or a spoon for cooking. Transferring into your car (or the tub) is also a big task to work toward. The more you can learn in rehab, the better off you will be when you are discharged to go home. In addition, you may be prescribed an aid or piece of equipment that will help you achieve your ADL.

Life at home

In OT, you will learn what equipment you may need to have at home. You will need to evaluate your home access, sleeping area, kitchen and bathroom. Knowing what support you have at home and your level of function will help your OT know what you need to work toward. If your rehab hospital has an Independent Living Unit (ILU), you should take the opportunity to try to live on your own for 24 hours. This will give you insight into what you still need to work on.

Pain and skin education

While you are an inpatient, you will be taught various techniques for pain management and for monitoring your skin. There is a lot to learn about pain management and everyone’s experience is different, but it’s important to talk about it regularly with your medical team.

For skin management, get yourself a small mirror that you can use to look at the parts of your body you are sitting on. Daily monitoring with a mirror is important; be aware of ankles, seams on clothing, pressure points from bony protrusions of your body and changes in routine which can all lead to pressure sores. Protect your skin at all costs. Pressure sores can easily become infected and, because of decreased circulation (due to your SCI), healing takes much longer than normal and can lead to more serious conditions. SCIO has produced an excellent publication on this subject: Preventing and Treating Pressure Sores.
Do I need OT once I’m at home?

You may need a different OT once you are back at home. It is the job of this OT to assess your home and help you realize what appropriate goals are once you get home. Some people dream big and want everything to happen at once; others don’t realize what they might be able to do. Safety is key; once you are home, you will want to be as independent as possible and that can only be accomplished if you have confidence and strength.

Not everyone needs or can afford an OT. If you have one once you’re home, make sure you are clear about the skills you want to learn: cooking, driving, working, playing with your kids — your OT will analyze the activities you want to do and teach you modifications so you can be successful. Once you are settled back into your home, your OT will help you make plans for returning to work or school. They will also have resources for parenting with an SCI, coping and time management skills and helping develop healthy habits such as skin checks, regular exercise and a healthy diet.

Choose an OT who is familiar with your type of case

Your OT must be familiar with the systems where you need to get funding; for example, if your only option is OHIP and government-funded programs like the Assistive Devices Program (ADP), make sure you have an OT who knows how to access these services. They must also be able to write persuasive application letters to programs from which you need help. Alternatively, you want to make sure you have an OT familiar with the Statutory Accident Benefit Schedule (SABS) and insurance processes if you were injured in a car accident. Your OT will be a big part of writing your treatment plans for insurance purposes.
**STURDY UNDERWEAR**

When I was in rehab, my Occupational Therapist was a highly knowledgeable, strong and soft-spoken man. I distinctly remember a conversation about clothing choice. We talked about comfortable pants that don’t have seams, shoes that don’t dig into feet and sturdy underwear. Sturdy underwear?? I had not really understood what that meant or why “sturdy” was the adjective chosen. But now I know. When it comes time to use a catheter on the toilet and you have to pull down and up your underwear while sitting on it at the same time, you will understand that sturdy is what it needs to be; otherwise, you’ll put your thumb through the lacy bits and they won’t last long at all!

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**Insights from the OT: Gary Lee Tai Fuy, BSc, OT**

“Do not compare yourself to your roommate or anyone else in rehab. Wondering, ‘When can I achieve that?’ and ‘Why can’t I do that?’ will only get you down on yourself. People will have more or less severe injuries and different American Spinal Injury Association (ASIA) scores. Age, previous fitness level, other injuries and medical conditions will complicate your achievements in therapy. Making comparisons can cause you to become angry and lead to depression. Keep a list of your own achievements and watch the list grow!”
Recreational Therapist

More than likely, you will have to find a new and/or modified version of the recreational activities that you did pre-injury. Many things can be modified like cycling, hockey, skiing, bowling and tennis — it is just a matter of finding the right person to hook you up. Your recreational therapist will show you variations on different sports and will try hard to help you find something you enjoy. Remember that, as you recover and gain strength, a greater variety of activities will become possible.

For people who participated in sport before their accident or injury, going home can be a reminder of all the activities they are not able to do any more. The soccer cleats may be where they were left and the hockey equipment still laid out on the floor in the basement. Everywhere you look, there will be stuff from your old life. In time, you will be able to deal with it and you will. Nothing will be the same as it was before, but you will find a new normal.

Speech-Language Pathologist

A Speech-Language Pathologist (SLP) may become a part of your care team if you had a head injury. Concussions often lead to difficulties (slowed speech, word recall, etc.) that can be tackled with therapy. Educating patients and their families upfront about the potential of a co-existing acquired brain injury (ABI) is important because family members may see changes in their loved one and not know why. You may be advised to have cognitive communication testing and subsequent therapy to help mitigate the effects.

PEER SUPPORT

The importance of finding a peer (or several) cannot be overstated. Spinal cord injuries are unique to all others and the need to connect with someone who has lived through it is SO important. Whether you find a peer on your own or are connected with one through an organization like SCIO, you will benefit from the knowledge of what they have already been through.

Why do I need a peer?

It’s not just the knowledge that will be shared that is important, it is also paramount for your mental health. Just talking to someone who has been there lifts a weight off your shoulders.
How do I access Peer Support?

Peer support is invaluable. When you find it, you will have the opportunity to talk candidly with someone who has “been there.” They can relate to what you’re going through. It’s important because you will meet people who have sustained an injury and gone on to live a fulfilling life.

A Peer Program Co-ordinator from SCIO will help match you with an individual who can share personal experiences, help you gain more confidence and understand the little details and the big picture of living with a spinal cord injury. SCIO will help you make arrangements to meet with a peer support volunteer in person or over the phone. If the match doesn’t feel comfortable, they can help find you another option. If you are not currently an SCIO community member, it is easy to register on their website at www.sciontario.org/join. Not all personalities and circumstances align. Do your best to find a peer before you leave rehab, because there is a lot to talk about before you go home.

SUPER DAVE

I met Dave Willsie when I was about a month into my rehab at Parkwood. He had been asked by a mutual friend to stop in and see me, so I was not expecting him. It turned into the most memorable visit of my whole time in recovery. Dave was a guy living his life with a C-spine SCI (C6 Incomplete), using a manual wheelchair and running his own lumber business with his brothers. Did I mention that he was the team captain of the Canadian Wheelchair Rugby Team?

But it wasn’t the celebrity that I remember most. It was Dave, just a guy in the same boat as me. We had only just met, but we talked about everything — nothing was off the table. He made me feel comfortable and I knew I had to be brave in order to ask some questions about stuff I was concerned about. Catheter stuff, bowel routine, going home, work, relationships, sport and the importance of peer support — we talked about it all.

Dave was injured when he was 27. He learned everything he needed to know about living life with paralysis from his rugby teammates. They played together, rode roller coasters together and travelled on all the “accessible” airplanes, staying in all the “accessible” hotels around the world. There is a lot to be said for team sports.
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.
SKILLS TO KNOW BEFORE YOU GO HOME

Going home means, essentially, that you are on your own. It’s going to be challenging, no matter how you look at it. But it will be less so when you know how to be prepared. Here are some things to know, ask about and work on before you leave rehab. Have an honest conversation with those you are going home with — the list is long, but by this point in your recovery you will be able to answer a lot of these questions.

Do not read this list until you are ready; otherwise, you may find it overwhelming. As you start to talk to SCI peers, these are the topics you want to ask them about.

Transfers
- You will transfer often, more often than you think!
- You will go from chair to: bed, toilet, shower/tub, commode, car — and back again.
- Do you need a transfer board or lift?
- How much assistance do you need to transfer?
- How will you get up off the floor? This will happen — what is your plan?

Dressing
- Some people dress in bed, others in their chair or on the toilet.
- Choose stretchy clothing whenever possible!

Medications
- This will take up more time/brain power than you would expect, so plan on using a system when you get home and stick with it until you are comfortable making a change.
- Where will you keep them, organize them, keep track of what you have taken and when?
- Do you have a system for re-ordering and getting them to your home?
- Do you have a plan for days when pain increases and you need to keep track of any increase in medication you take?

Eating/drinking
- Shopping, food preparation, eating, clean-up, carrying hot food/
beverages — what do you need help with?
• What to eat for weight management/bowel health?
• How much fluid to drink?
• How to deal with swallowing difficulties?

Grooming
• Washing, shaving, hair care, cutting finger and toe nails. Can you do these things independently?
• Who will help you as you are learning how to manage on your own?

Bowel care
• Requires transferring to the toilet/commode, bowel manipulation, clean-up (wiping).
• What is your plan for bowel accidents (which will happen when you get home)?
• What equipment/supplies do you need and where will you get them from?

Catheterizing
• How do you position yourself for this? (bed, toilet, chair…)
• What equipment/supplies do you need and where will you get them from?
• What is your plan for getting urine to the toilet if you use a collection jug?
• Getting pants back up (down is easy!) — have you learned this skill?
• How to progress to more independent bladder care (e.g., what’s next so I can: leave home, shop, travel)?
• Can you tell when your bladder is full? Do you have a schedule?
• What are the signs that you have an infection?

Skin
• Can you check your own skin for scratches, sores or redness? All of your skin?
• Can you reach your feet to look at your toenails or cracks between your toes?
• What is your plan if you need help with this?
• Do you have an assistive mirror?

**Mobility & Transportation**

• By wheelchair: can you wheel yourself around in your manual chair?
• Do you have the strength/balance/co-ordination?
• Do you need help when you leave home?
• Can you safely operate your power chair and recharge it?
• Can you examine your chair for damage and inflate your tires?
• Do you have access to public transportation and can you access it independently?
• Do you have a car/driver? Can you (or do you plan to) drive on your own?
• Have you applied for a parking permit for your vehicle?

**Communication**

• Do you need assistance communicating to family/friends/medical staff?
• Can you make your own appointments and remember/record what you discuss?
• Do you have a method of recording and being reminded of appointments or other events (even bowel care/catheterizing)?
• Who will you speak to when you need help with your mental health and emotional well-being?
• Do you need help dealing with legal/financial assistance/returning to work? Who will you speak to?

**Housekeeping**

• In your living space, do you have a plan for cleaning, laundry, changing sheets, vacuuming, organizing, getting the mail, yard care/snow shovelling?
• Do you need help with pet care?

**Autonomic Dysreflexia (AD)**

• Have you learned about Autonomic Dysreflexia?
• Do you know what to look for when it comes to AD-related changes in your body?
• Have you noted how to describe your “normal” appearance (such as your normal blood pressure), so when changes happen you have a basis for explaining to medical teams how things are different?

**Sex**

• Have you talked about sex with your therapist or nurse/doctor?
• Are you talking to your partner about it?
• It will happen; be prepared for figuring things out.
• Do you have access to resources and information about sex and SCI? Ask before you leave rehab.

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**Julie’s Journey**

**CATHETERS**

*Most pharmacies do not regularly carry catheters (especially small town pharmacies). There are so many different sizes and types that they would need a whole wall and, let’s admit it, they would not make a great display! If you know exactly what you need — the style, size and brand — then your pharmacy will usually special order them in for you. Otherwise, the best advice is to order online. Find an online retailer that delivers free of charge — most do so within a day or two of ordering. You will likely get to try several different kinds while in rehab, so be sure you do before you get stuck on one brand. They vary in price and quality, so make sure you are happy with them before you are stuck with 99 more catheters that you don’t really like!*
Finding the right resources to build the kind of home life you want is important. And often the more help you ask for, the more independent you become.

- Crista Henry, SCIO Community Member
GOING HOME – OR MAKING A NEW ONE

Being Home
Moving home will evoke a huge range of emotions from happiness to fear. Planning to return home needs to start well in advance. Have a partner, family member or friend help out with this planning. You may have an OT or social worker on your team who will be able to assess your needs for managing in your current space or finding a new one. An SCIO Regional Services Co-ordinator can also help you plan for what you need. Getting your physical space set up and ready for your return is one thing, but remember that returning home will take a toll on your emotions.

How do I start planning for going home?
There are several options that you will need to consider before going home. Do you need to renovate? These may be big (long-term) or small changes just to get you comfortable in your current home. But big or small, both take time, so be sure to plan for that.

Maybe you need to consider moving? If your current home is not going to work, you’ll have to look elsewhere. Options include a rental space (apartment) or something like a long-term care facility or supportive housing.

Julie’s Journey

SLEEPING IN THE DINING ROOM

Because I was living in a 110-year-old two-storey farmhouse at the time of my accident, installing an elevator or stair lift was not very practical. All the bedrooms were upstairs, so we made some changes to our living arrangements. The dining room was large enough to become a bedroom for my husband and me, so we put the dining table into the kitchen. We left the piano to act as a divider, so looking through the door you saw it instead of our bed. Our bookshelves were emptied and became closet shelves — open, mind you! We put lights up on either side of the bed and placed pull-down curtains in the windows. For hanging clothes, we put a small clothing rod on the wall to add to our “open concept” closet. We made do — but how I missed being able to tuck my kids in at night.
If building a new home is on the radar, you have A LOT to think about, but you’ll still have to look at the first two options because you will be told by your rehab team that you are going home and there is not much you can do to stop or delay that discharge date. So go back to thinking about making some changes to your current location for the short term.

**What are the essentials for moving home?**

1. **Access:** First priority is the obvious one — getting in. But the not-so-obvious thing is being able to get out in an emergency. If you are building a ramp or installing a lift to access your home, this means you have elevation to consider at more than one entry. If a fire were to block that exit, you can’t exactly crawl out the window. Plan for an alternate door, such as a lift through the garage or out onto a deck. You can get an escape chair to use down a set of stairs, but keep in mind that you may not be able to operate it on your own. Before you start, measure the width of your chair so you can compare it to your doorways. Add a couple of inches on either side to give room for your knuckles.

2. **Bathroom:** There is a lot to consider for one small room. Door width and clear floor space — is there enough for you to manoeuvre your chair (and a showerchair) and close the door? You will need to install a grab bar or two but, before you do, make sure you have solid backing to screw them into. You need a minimum of two attachment points into each wall stud or ¾ inch plywood or it will not be safe. Consider all the showering options before you start to renovate. Is it possible to make your current shower accessible — can it be changed to a roll-in? Is there room for a commode or shower bench across the tub? Is there room to store the commode/shower bench when not in use? In an ideal situation, you should be able to get your knees under the sink and your chin over the sink. “Side saddle” can be done, but over the long term it’s annoying, uncomfortable and energy consuming. There are also a lot of safety aspects to consider when planning a bathroom. Temperature-controlled water, wrapped pipes and the possibility for slippery floors are also important.

3. **The rest of the house:** Of course you will also have to consider where you are going to sleep and eat. If there are multiple levels (even one step), small
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.

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**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!
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
so large and varied when it comes to medical and rehabilitation services, the Co-ordinator in your area will have the “inside scoop” on what is happening. For example, there may be a local physiotherapy clinic that has university students run rehab clinic days. They will also be able to tell you about local accessible transportation options and means of accessing equipment that has been donated or is for rent.

**Medical Home Team**

Keep in touch with your rehab physiatrist, find a psychologist and/or social worker, PT and OT in your area, but most importantly get access to the following:

**Family Health Team General Practitioner**

You need a GP — your family doctor. If you don’t have one, *find one*. They often have experience working with people with SCI but, if they don’t, it is your job to help them learn everything that you have learned about your new body. Your biggest issues will likely be continued pain management, as well as bowel and bladder issues. When you speak to the receptionist, clearly identify what your needs are and how soon you need to see/speak to someone. You can ask to speak with the nurse; sometimes problems can be solved over the phone. Family Health Teams also may have a Nurse Practitioner who can help you. Ask for them if you can’t get to see your doctor.

The nurse will need to know all of your symptoms and all the questions that you have for that visit. They will keep tabs on your blood pressure/heart rate and medications; keep a list at all times. Be sure you tell your nurse/GP if you have stopped taking any of your medications. When you suspect that you are fighting an infection, you likely are. You know your body best — you have to convey that in order to get the help that you need.
PAIN MANAGEMENT

After four years, I have yet to figure out how to turn off my pain. Certainly it is less than it was at the beginning and I have learned some triggers, but unfortunately what works for some does not work for others. I have tried meditation, massage, medication (including narcotics), medical marijuana and acupuncture. I seem to have found a balance now, but I also have identified some things that intensify pain. First — infection. UTIs cause pain to be unbearable, like, go-to-bed-and-stay-there pain. Second — fatigue. Overdoing it never helps. Third — diet. Some foods seem to trigger more pain events. My advice? Keep track of when your pain rating is high; if you can pay attention, maybe you will learn what your triggers are.

Professional Points: Personal Support Worker (PSW)

This person (or these people) may very well become the most helpful in your new life. Depending on your needs and who you hire (either privately or through a public health care company), they may be able to help you with everything from stretching and bathing to laundry and cooking. It is their job to help you do the things that you used to do, but are not able to do yourself, yet.

What is Attendant Care?

The OT assigned to your case will assess your need for attendant care, which includes assistance from a trained Personal Support Worker (PSW) or “Attendant” for Activities of Daily Living, such as showering, getting out of bed and bowel routine.

If you have insurance (from a Motor Vehicle Accident, for example), this will be referred to as attendant care. Insurance will pay the wages of this person so long as you have been assessed as needing this type of care. At this time, the insurance company may send their own OT to reassess. If you do not have insurance, there are agencies in Ontario that provide attendant services on a government-funded or a fee-for-service basis, which you can register for.
How do I make the best of PSW time?

In matters of care, YOU are in charge. This does not mean that you have to be bossy, but you do need to establish what is expected of the PSW in terms of responsibilities and timing; for example, if they are there to help you with your personal care and showering, make sure they understand other things that they can be doing while you are in the bathroom (e.g., making lunch, changing sheets, doing laundry). Be honest and upfront right away about your expectations. This makes it easier for the PSW to know what you want and need. Prioritize your day by listing (in writing) what is most important to have done that day.

How do I find a PSW?

There are a few options for finding the right PSW for you. It is easiest to start with a government-funded program. This way you should be able to start with a PSW right away. You will receive an assessment and create a schedule/plan of what the booking will entail. The emphasis is on directing your own care and being very specific around your needs, such as saying, “Place a dime-size amount of shampoo on your hand and massage it into my scalp.” Government-funded PSWs will not perform many homemaking duties as the focus is on personal care.

If you have insurance or other means, you can also hire someone privately — this means that they are their own boss; they do not work for a larger company. This will give you the most flexibility in terms of time and the type of work that they can do for you. They will have hours that are more flexible and, once you establish your needs, they will work with you to help you accomplish them.

It is also possible to hire a PSW through a firm where you say which hours you need help and they will send someone. It may or may not be the same person each time, depending on availability. Rates will vary depending on a private hire or through a company. Word of mouth is the best way to find a good private PSW; ask your other therapists, as some keep a file of PSWs available to help. Remember, not all people are the right fit. Don’t feel bad if you don’t “click” or are not comfortable with who is sent to work with you; call and ask for someone different to be sent next time.

Insights from the PSW: Elaine Delisle

“Remember — it is your body, your family, your home. Never be afraid or ashamed to ask for anything you like or do not like. The PSW is there to work for you and you deserve the best care possible.”
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.
The assessment looks at your cognitive (brain) function, your knowledge of road safety, upper body strength and ability to control your hands. If you pass the assessment, then a report will be sent to the Ministry of Transportation to get a temporary driver’s permit. You will then be able to take lessons in a modified car (e.g., with hand controls or other modifications), provided by the driving instructor.

Those with higher levels of injury will require a more in-depth driving assessment at a specialized driving assessment centre. It is still possible to drive with a “zero effort” steering wheel and a joystick style gas/brake.

After completing your lessons in a modified vehicle, you will need to be tested by an MTO (Ministry of Transportation Ontario) assessor. When you pass the road test, the paperwork will be completed by the assessor and sent to the Ministry. In time, you will receive a new licence (class G restriction 2C) in the mail. Once this is completed, the OT will write you a prescription for hand controls. Be patient — the medical review and re-licensing process is not fast.

Take your hand controls prescription to a business that installs them. If you need to purchase a new car, be sure to ask around or attend a “modified car” event at your rehab hospital so you can see what most people in your situation are using.

The wheels you choose — well, that is personal! Do you want a truck or a van? Or maybe you prefer a small car? All your decisions should be based on where your chair is going to go. Are you driving yourself places or will someone take you in your car? Can you transfer from your wheelchair to the driver’s seat? You will progress with your abilities as you recover and, therefore, your ability to get your chair in and out will also change. No matter what, if you were driving before, you will want to drive again. And it feels great!

**EQUIPMENT & SUPPLIES**

While you are in rehab, it will seem like there is an overwhelming amount of equipment that you may use during your recovery. Take a deep breath and do not rush to make purchases, as most equipment can be rented (even hospital beds). Renting or using second-hand equipment is a great way to give yourself the time to decide what kind of equipment you need. In time, you may have more and more function. You may find that as you recover some strength,
core stability and your blood pressure stabilizes, things like lifts or elaborate commode chairs may not be necessary. If you have the means, you can rent, see how you like it and then go from there.

There are other medical supplies, such as catheters, that you may require on an ongoing basis. You’ll get an understanding of your needs and options in rehab, with samples to determine what works best for you.

**Julie’s Journey**

**ON THE ROAD AGAIN**

It took me a full six months to get back behind the wheel. Both of our cars were manual, so we had to buy an automatic. We purchased a Mazda 5 — it was by far the most popular vehicle driven by people with the same type of injury as mine (T4). What is great about it is the sliding back door and the height of the driver’s seat — no need for a lift, just a transfer board. I opted not to have the robot arm that puts your chair into the car; it takes up space and is permanent. I wanted the option of putting that bucket seat back in and I needed space for my two kids and their friends.

Learning to drive with hand controls was pretty easy. After my cognitive assessment, the instructor showed me how the controls worked. I transferred into the driver’s side of an instruction car and off we went! Get on a list as soon as you can; this means getting permission from your doctor to begin the process. There was a wait list for driving lessons at my rehab facility, so that, combined with winter weather and the MTO wait time, meant it took me six months!
Mobility devices

By far, the most important piece of equipment (potentially for the rest of your life) is your wheelchair. Your chair becomes your legs. Your wheelchair assessment (done by an OT and PT combined) will look at your strength, mobility, balance, posture, blood pressure and dexterity. You will look into a power or manual model and you will talk about where the money will come from — it is a big expense! You may have good arm movement, but longevity also needs to be considered; it is a fine line. Your doctors will be consulted to help with the decision, but ultimately you decide.

While in rehab, you will start the process by being measured by your OT/PT. Those measurements will determine the size of your wheelchair — body position, shoulder issues, need for pressure relief, type of seat cushion, backrest, foot placement and angle, size of front casters, with or without armrests, type of brakes, push rims, colour — there is an extensive list of decisions to be made.

How do I choose my “vendor”?

You will need to decide where your chair will be purchased and maintained; hopefully, they will give you the option of trying different types of chairs before you have to place an order. For both of these decisions (vendor and chair type), ask around. Those who have been at your rehab hospital as outpatients will be a good place to start. Your OT/PT can give you advice and they can suggest people that you should talk to about their experiences, but they cannot make that decision for you. These are important decisions to make because it will be another five years before you will be eligible for ADP funding for a new chair. The better your chair fits, the greater your manoeuvrability will be. Small front casters mean tighter corners, but they also get stuck in bumps more easily. How your chair folds (or doesn’t fold) will be something to think about when it comes to getting it in and out of your car. The more gadgets you have on your chair, the heavier it will be to push around.

How do I choose seating?

There are several options for seating (cushion and backrest); hopefully you are able to try them out. There is also custom seating available. Ask around about people’s experience with custom seating and you will get lots of different
answers. Some say it works for them and others say that they wished they had waited. Custom seating is made by molding the materials to your exact shape. Some people find that their shape (posture, muscle tone) changes as they recover, making custom seating not the best option. Custom is also quite a bit more expensive than an “off the shelf” option.

Shower chair, shower bench or commode

What you choose will depend on your bathroom situation and posture. You may start with a shower commode and later on decide that a fold-down shower bench is more convenient. Ask your OT what will work best in your bathroom. What you need to think about is your ability to transfer safely and protect your naked skin. Be sure that the surface you choose is well padded and has no rough edges. When you have a new piece of equipment, like a shower bench, practice using it with help from someone else — be comfortable with it before you try to go it alone. Of course your equipment and processes will be determined by your level of injury and whether you have help in the home, among other factors.

Lifts and transfer boards

Your needs will change as you recover. At the beginning, getting in and out of bed and into the shower will be the biggest challenge. A lift on a ceiling track can be installed, but will require proper reinforcement to the ceiling joists. Other lifts are portable (like a Hoyer) and can be taken while travelling.

A wooden transfer board is a convenient tool. It allows the person to transfer their weight from one surface (bed) and slide across the board to the other (chair). The length of the board depends on how far you need to travel from one seat to another. There are many different styles, materials and shapes of transfer boards to fit specific uses. Have several in strategic locations in the house and always keep one in the car.

Do your research

Other types of mobility equipment exist, like hand bikes and attachments that turn your manual chair into an electric motorbike! Ask your vendor to help you try them out to see if they are right for you. Hand bikes are a great way to get back outside and there are several types of offroad devices. Again, ask around and see what others in your area use and take them for a spin. Travel commodes are essential if you want to be comfortable when you leave
home. Pool chairs and lifts are available too — varying in expense — so do your research.

**Supplies**

While in hospital/rehab, all of your supplies are managed for you. When you return home, you will need to order and pay for them yourself; Ontario Disability Support Program (ODSP) can be an important source of funding. If you have a nurse/case manager, this may be one of their responsibilities. You will need some or all of the following:

- bed pads to protect your mattress (washable or disposable); at least 4 (if you are washing them) — sometimes laundry cannot happen fast enough
- urine collection bottles, 2 - 4
- adult diapers (aka “fancypants”)
- gloves, lubricant and suppositories for bowel care
- catheters (you should be able to try a variety of catheters while in hospital)
- leg bag, elastic straps and in-dwelling catheters (for travelling); make sure you learn how to do this before you leave rehab
- baby wipes — convenient for bowel care and other clean ups
- Voltaren (or another brand of pain relief cream)
- antifungal cream (for dealing with athlete’s foot when/if it appears)

These are just a few supplies and you may find your situation requires others. What’s most important is that you understand what you need for your care and ensure you have a plan/vendor in place and a way to fund these things before discharge.
A fact of your new life is that your bowels and bladder will not always co-operate. While in rehab, I had the experience of rolling from the cafeteria all the way back up to the 4th floor with a trail of urine behind me — little did I know I was sitting on a very wet seat cushion. When you get home, this type of event becomes even more inconvenient. The best way to make sure you keep your pants dry and clean is what I call “fancypants.” They are really just adult-size diapers, but my husband came up with the term fancypants because I was not at all happy calling them diapers. It won’t just be your bladder that doesn’t co-operate — your bowels will turn against you at times as well. Developing a routine takes patience. Don’t be afraid to wear fancypants. It will give you peace of mind and maybe there’s a bit of Murphy’s Law involved — if you are wearing them, then you won’t have an accident; it’s when you are not that you will. It won’t be for the rest of your life and everyone is different, but you’ll need to be patient with yourself sometimes.
Medications

Even if you are only taking one medication, using a pill sorter is a good idea. They allow you to check and make sure you have taken your meds for that time/day. Not taking them can cause spikes in pain or plunges of mood, neither of which you want. Be sure you renew your prescriptions well in advance of running out — being caught without (especially if you live far from your pharmacy or it’s a long weekend) is never a good thing.

As you progress through your recovery, you will find that you change medications or stop using them. Never throw them out. Take them back to the pharmacy where they will dispose of them properly. Keep records of the prescriptions you take, especially antibiotics, and be sure to take that list with you every time you see a doctor.
Not every injury is associated with an insurance claim or settlement, but understanding your legal and insurance options is extremely valuable.

- Peter Athanasopoulos, SCIO Director of Public Policy
CHAPTER SIX

Legal & Insurance
LEGAL AND INSURANCE MATTERS

The following section only applies to you if you were involved in a motor vehicle accident or some other “at fault” type of incident, or had a workplace accident and require WSIB coverage. If this is not the case for you, please refer to the section about SCIO’s Regional Services Program. Your Regional Services Co-ordinator will be able to help you problem-solve for your own specific situation.

This process may start before you get settled into rehab — don’t be surprised when you have people knocking at your door. It’s really important to know who they are before you talk to them. Keep records and don’t sign anything without getting another opinion. It is so important to get a free legal consultation from a lawyer who has been researched/recommended by someone you trust. We strongly recommend that you employ a personal injury lawyer (if your situation demands one).

Professional Points: Case Manager

What is a case manager?

You are now part of a team. With a team, there is always a coach and a manager. Your case manager will be both. They may or may not have a background in nursing, but they will have had experience in the medical field. They also will have an understanding of how both the legal and insurance fields work when it comes to personal injury.

Why do I need a case manager?

The case manager will assist with many tasks such as paperwork (and there will be lots), purchasing of equipment, finding the right physio clinic and being the intermediary between lawyers, insurance adjusters and therapists. While you are in hospital/rehab, they will work with your care team to establish your goals and help you start working toward them.
How do I hire a case manager?

Choose a case manager who is from your region — someone from the city is not ideal when you live in a small town, for example. You need someone who knows the area, the people and the services that they provide. The most important part of the decision about who you hire is that they have SCI experience. Talk to several before you decide who to hire and wait until you are discharged before you sign one on. A good nurse case manager will know what calls to make, purchasing to do and appointments to accompany you to.

Is there an advantage to hiring from a firm?

The most important factor in this decision is that they have experience. Ask them what they know about SCI cases, how many they have worked on and some non-specific examples of patients. Hiring from a larger company means that they will work with a multidisciplinary team and will be able to have quick access to information from an OT or SLP (Speech-Language Pathologist). They will also have a second set of eyes to help with reports and applications.

What if I don’t have insurance? Can I be my own case manager?

You still could use the services of a case manager and would be able to access one through the LHIN (or Ontario Health Team). They will help you find services and funding in your local community for assistive devices, therapy and other needs. SCIO has Regional Services Co-ordinators that essentially do this job. They are problem solvers, know your community resources and are able to help navigate the system which is specific to SCI.

It is possible for you to be your own case manager, but you likely lack experience. Before you choose to go this route, consider your support system. Do you have friends and family who are willing to attend appointments with you and take notes? How well will you be able to advocate for yourself? There will be a lot of questions to ask about medications, therapy, legal issues and insurance. Are you comfortable doing research, making calls, sending emails and completing paperwork in a timely manner? Do you have a network of people willing and able to help you do this? When you are ill, will they be there for you?
Insights from the Case Manager: Kelly Gillis, RN

“Problem solving becomes very important in this new SCI world. Insurance treatment plans need to be written by someone qualified and claims can often be denied; a case manager can help make an alternate plan.”

ME, THE CASE MANAGER

About a month after I came home from Parkwood, we had a follow-up meeting with my nurse case managers. They had driven up to our house from London and we met for about an hour. By this point, I had worked out where I was doing physio, what kind of car we would buy and had submitted most of my extra expenses from my time in hospital to the insurance company. After they left, I turned and looked at my husband and said, “That was an expensive meeting!” We paid for their time to drive, for mileage and for the meeting time.

It was then that I decided to take on the role of the case manager. For over four years, I have been making appointments, taking notes, keeping and submitting receipts, paying bills and purchasing equipment. It made me feel productive and in control. Not that case managers don’t have a role to play; they do, but I wanted to take it on and “cut out the middleman,” so to speak. In talking with others who have been their own case managers, they would agree that it was initially helpful to have someone to guide you, answer questions and make decisions about equipment and therapists.
If you are injured as a result of an accident, you will benefit from legal help. If someone else was at fault or you are covered by insurance, you can use a lawyer to help you get as much support as you can — you are going to need it. Choose a lawyer sooner rather than later because the responsibility for the accident may not be obvious and, in those cases in particular, an early investigation, usually arranged by a lawyer, is absolutely necessary.

**How do I choose the right lawyer?**

Take the time to research, interview and ask other people from your community (friends and co-workers) about their experiences with any personal injury lawyers. A lawyer’s reputation in the community is usually a pretty good indication of his/her competence. Do not take the first lawyer who knocks on your door and make sure that they specialize in personal injury law. Remember, while in hospital and rehabilitation, medical expenses are being covered by OHIP for most people.

**What will a lawyer do for you?**

An experienced personal injury lawyer will assist the client and their family in obtaining funding and access to services and assistive devices that will assist in rehabilitation in the hope of minimizing accident-related impairments. It is their job to make sure you get as much of your insurance claim as is possible. If you have a spinal cord injury, most likely your injury will be deemed catastrophic by your insurance company. What this means is that you will be eligible to receive a higher level of support and a larger settlement than if you were not. A lawyer, however, may not be in a position to advise you what your claim may be worth until you have reached maximum medical recovery.

If you have chosen the right lawyer, you will be kept informed throughout the process so that there is no misunderstanding as to why it takes as long as it sometimes does. Always confirm the best way to make contact; phone or email through the paralegal or with the lawyer and ask what your family members can do to be involved (e.g., keep a diary of events/communication).

In the case of motor vehicle accidents, if you have a lawyer, do not contact the insurance company directly as often it leads to a lot of confusion. You, as a layperson, could misunderstand information on either side, due not only to the complexities of the issue, but also to the fact that you are suffering through a personal trauma.

**What should you expect for the length of time and amount of settlement?**

The surprise might be the time it takes to get matters resolved. Some cases take just over a year and others can take more than a decade. Some insurers take positions (regarding
reasonable and necessary expenses) that seem unreasonable. This is where your lawyer will step in. It is difficult to predict the amount of your potential settlement because the auto insurance system is always changing and not necessarily for the better. As of 2016, the limits are $1 million for medical/rehabilitation and attendant care combined. Housekeeping remains available, potentially for your lifetime. You can use all of the limits for med/rehab or all for attendant care, or split it any way you want once you settle.

**Can I sue?**

It depends. If someone else was at fault for your accident (another driver, your employer, etc.), you can sue and you should. This is called Tort Law; your lawyer will seek damages in accordance with your injuries, age, need of assistance and need for financial independence. For some people, the Tort settlement can happen as quickly as one year; for others it may take many, many years.

**How much will a lawyer cost?**

The prospective client has the right to negotiate fees with the lawyer before retaining the lawyer. The lawyer’s fees may be based on an hourly rate or on a contingency fee basis (a fixed percentage). In either case, the retainer agreement should be confirmed in writing. Before you sign any documents or contracts with your lawyer, be sure to understand what this fee would mean to your settlement. Most charge between 20 and 35%. You have to keep this in mind as talks of settlement begin because the amount of money you get will be 20 to 35% less, plus HST (13%) — another shocker if you are not prepared.

**Insights from the Lawyer:** Michael Lamont, LLB

“Trust and confidence are the cornerstones of the client/lawyer relationship. If you do not have trust and confidence in the lawyer, you are making the wrong choice.”
INSURANCE

If you were in an accident, there is a good chance that the first “non-medical” person you are going to talk to will be the insurance adjuster. They will want to know all the details you know about what happened, exact timing, all the people involved; they will dig into your memory until they can dig no more. You can stop them, if you need to — you can say *enough*. Don’t be afraid to say, “Please come back later.”

You are about to travel into a world that no one really knows about unless they have been there before. Insurance claims are complicated — and for a reason. They want serious proof that you really need the money you are asking for. If your claim is viable, don’t accept NO for an answer.

**How can I make a claim to my own insurance company?**

If you were an insured driver and a vehicle was involved (even if you were on your bike and were hit by a car), you can make a claim to your insurance company for both medical rehabilitation expenses (known as Med Rehab) and for attendant care expenses. If deemed catastrophic, the combined limit is $1 million. While you are in hospital, you can also make claims for travel and lodging expenses for family members and for personal items destroyed in the accident; however, insurance policies are tricky contracts to understand, as is the law around them. With such a significant injury, getting a lawyer is likely a very wise choice.

**When/how should I contact my insurance company?**

Because you have a contract of insurance with your insurer, you both have obligations. One of yours is to contact your insurer as soon as possible. Have a family member contact the broker on your behalf to report the accident. Don’t be afraid to speak to your insurance company, even if you think you may be at fault.

**What is Medical Rehabilitation?**

Med Rehab will cover such things as physiotherapy, equipment, housing renovations (or new construction), vehicle modifications and medical expenses not covered under OHIP or workplace benefits (e.g., medications, catheters, bowel care supplies).
What is Attendant Care?

This part of your claim will cover the costs of an attendant — someone to provide you with assistance with your everyday tasks. In order for a family member to be paid to assist you, your family member must not only show an economic loss, but must also be qualified to supply the assistance. This is the latest legislation which simply states in order to collect this benefit, the person supplying the care has to have experience and work in that field (so for example, a PSW, nurse or paramedic). If they are staying home from their job to supply care and therefore are suffering an economic loss, they would be considered eligible by insurance for some compensation, but likely not the full amount of lost wages. On the other hand, a store clerk, insurance adjuster, lawyer or fry cook would not qualify, for example. If the family member was not working at the time of your accident, they will not be paid to look after you. Hiring a qualified PSW will require proper documentation (such as a college certificate). (See Personal Support Worker for more details.)

Julie’s Journey

FUTURE COSTS

When someone says “insurance is paying for it,” YOU are paying for it. It is amazing how different you will feel about that money when you are writing the cheques. It may seem like a lot of money, but $1 million does not go very far when you have a major injury. Remember that it is in the best interests of the insurance company not to pay out the maximum on your policy, so you will have to fight. It will seem easy at the beginning; they will want to support you (as you have a “catastrophic” case) but, as time goes on, the insurance company will want to keep as much of that money as possible. After four and a half years, I have finally obtained a reasonable attendant care settlement from my insurance company.
How do I stretch my limits?

“Insurance is paying for it” is a phrase you will no doubt hear quite often. Think twice when this happens because, even though the cheques are being written by the insurance company, that money is coming from your policy. That money is your money — and there is an end to that money. Be VERY aware of your limits, which treatments you participate in and what is being billed. If one form of treatment is not as beneficial as another form, don’t be afraid to stop what is not working. If you get through part of a treatment plan and do not want to continue, make sure that the unused portion is withdrawn so that it does not take up any available limits. The same can be said about plans with assistive devices. If a treatment plan is submitted for a specific cost for exercise equipment, for example, but when the equipment is purchased it is less expensive than what was submitted on the OCF-18, withdraw the unused portion.

What happens if I am denied by my insurer?

As much as the auto insurer may state that they are there to assist and they are on your side, ultimately, you will have to be your own advocate. They will review everything that comes in to determine whether they find it reasonable and necessary. Understand that, even with such a significant and life-altering injury, you may still face some resistance from your insurer. That is another reason why it is so important to have an experienced lawyer; they will have the knowledge to challenge the insurance company on their decisions. You will often face “denials” which will be very upsetting and discouraging. For you, it is an unknown system. Don’t give up — and use your lawyer and their staff to fight for you and take off some of the burden and stress. Throughout the process, never be afraid to ask questions. Stay informed. Stay involved.
There is a lot of paperwork — where do I start?

Forms must be filled out before payments are made. This includes weekly disability benefits or medical benefits. Here are some examples of the paperwork:

OCF-1 — The Application for Accident Benefits (OCF-1) is part of the package you receive after reporting a claim. It can be delivered by mail or by hand.

OCF-3 — If you were employed at the time, you will also need to have the Disability Certificate (OCF-3) completed. This is usually completed by the doctors while you are still in hospital and sent to your insurance company very shortly thereafter.

OCF-2 — If you were working, your Employer’s Form (OCF-2) should also be supplied to you. This should immediately go to your employer for completion. It will give the insurer your information on wages and any collateral benefits you may have an entitlement to through your employer. This is important for both sides so that payments are made in a timely fashion and in the appropriate amounts. It also assists in the calculation of any Income Replacement Benefit (IRB) that may be owed by advising the insurer exactly what amount, if any, is being paid by your employee benefits. This amount is entered into a calculation to determine if there is any shortfall owing by your Accident Benefits carrier.

**Insights about Insurance: Donna A. Marry-Warren, CIP**

“Insurance policies are tricky contracts to understand, as is the law around them. Getting a lawyer with experience is a wise choice; as well, keep your insurance company in the loop. Don’t be afraid to ask questions. Insurers have an obligation to be clear and answer all your questions. Ask when you can reasonably expect a response to your expenses and treatment plan (timelines are regulated). If you are not satisfied with your insurance adjuster’s answers, it is your right to speak to their manager. Beyond that, each company has an ombudsperson who is to liaise between the insured and the adjuster.”
WSIB: WORKPLACE SAFETY & INSURANCE BOARD

This is the path you will travel if your injury occurred while you were on the job. WSIB is an Ontario government agency, where injured workers (who are covered by their employer) are compensated on a “no-fault” basis. This means that compensation is paid no matter who is at fault: the employer, the employee or someone else. In return for the compensation you receive from WSIB, you cannot sue your employer.

The main focus of the WSIB system is to get you back to work as soon as possible. Through co-operation between all parties involved, it is the goal of the system for you to return to work as soon as possible/practical. If you can’t return to regular work, your employer may offer modified work. If the work is suitable, the injured worker must accept it.

From the WSIB website:

“The Workplace Safety and Insurance Board (WSIB) is an independent trust agency that administers compensation and no-fault insurance for Ontario workplaces. We are committed to delivering what matters to the workers and employers of Ontario: fast, accessible service and fair benefits at a fair price. The WSIB provides wage-loss benefits, medical coverage and help getting back to work — the best possible outcome following an injury or illness on the job.”

What do I need to know first?

It takes time to get everything set up; there are deadlines to meet and there will be delays. You are going to have to find your patience with the process and the people involved. Because you have an SCI, you will (most likely) be working with the “Critical Injury” program, which usually means you will have a smoother time working through the process. WSIB benefits are for life; unlike auto insurance, there is no limit for as long as you live, not just to retirement age.

Your employer must file the forms within 24 hours of the incident; the attending doctor must do so as well. You will start with Form 6 “Worker's Report of Injury or Disease.” If you are critically injured (which is what an SCI often is), the employer must also notify the Ministry of Labour. You have six months to make the claim from the date of the injury. Report even if your
employer tells you not to, or says you are not covered by WSIB. The number to call is 1-800-387-0750, Monday to Friday 7:30 am to 5:00 pm.

**What if I am not classified as Critically Injured?**
If you are *not* classified as Critically Injured (which is possible with an SCI that does not result in permanent paralysis), you will be working with a different set of WSIB regulations. It is possible to ask for a second evaluation from a doctor.

**I need a wheelchair and can’t live in my home; does WSIB help with that also?**
Yes, WSIB will help make modifications to your home; when you leave or sell that home, it is converted back to the way it was. WSIB will also help pay for home maintenance. You will have a team of OT/PT who does their own assessments and gets the home set up for your needs. If you are not able to live in your home, WSIB will pay for alternative accommodation until your home has been modified to meet your needs.

**Does WSIB pay for physiotherapy?**
You will have many assessments done by doctors and you will either receive a lump sum or a monthly benefit. This benefit will pay for physiotherapy treatment as well as transportation there and back.

**Why don’t I just sue my employer?**
Claiming WSIB is not the same as suing your employer. If you don’t want to go the route of WSIB, and think you should sue the employer instead, you can, but you are not guaranteed to win; plus you’ll have (out of pocket) legal costs to pay. WSIB will provide benefits that you will not receive if you sue your employer.

**I was in/driving a work vehicle — what do I do?**
If you were in a work-related vehicle, you have two options — WSIB or MVA — but you must choose one; the Province of Ontario will not allow you to receive the benefits of both.
How will WSIB help me get back to work?

WSIB has vocational rehabilitation teams who will support your return to work, up to 85% of your previous salary. You can have the help of your SCIO Regional Services Co-ordinator, who will help you start thinking about modifications for your workplace. WSIB will look at what the physician is recommending as a “return to work” plan and will note what your limitations are.

Construction companies that do the workplace modifications will provide blueprints and estimates to the employer/WSIB. If the employer is not able to do the modifications, then WSIB will do them with their own team. Depending on your age, WSIB may pay for retraining.

What if I can’t return to the job that I was doing at the time of the workplace accident?

WSIB has a complex return-to-work program. They may provide you with income replacement that stops at age 65. The closer you get to 65, WSIB may suggest that you put it into a pension type of investment.

What happens when I don’t agree with the initial assessment from WSIB?

If you don’t agree with the initial assessment ask (in fact, insist) for a second assessment. Be patient BUT persistent. If you don’t hear from them, call them again. This kind of situation is best described as “the squeaky wheel gets the grease.” Find someone (friend, family, case manager, SCIO Regional Services Co-ordinator) who can advocate for you if you don’t feel able to do it yourself.

Are there things that are considered “pushing the limits”?

Really, if you don’t ask about it, you won’t know; for example, if you are getting renovations done in your home and you have a second storey, ask for an elevator. If your approach is reasonable — assertive but not aggressive — you’ll have a better chance of getting the help you need. Be patient. It is possible for denied claims to be finalized 10 years after an appeal.
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
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.
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!
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!
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!
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).

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.


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.”


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.

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.

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.

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.
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.

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.


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!
Staying up-to-date with reliable information and accessing quality resources really contributes to confidence and independence. It’s a pleasure helping others with SCI find answers to their questions.

- Oda Al-anizi, SCIO Information and Resource Specialist
GLOSSARY OF ACRONYMS

ABI  Acquired Brain Injury
AD  Autonomic Dysreflexia
ADL  Activities of Daily Living
ADP  Assistive Devices Program
ASIA  American Spinal Injury Association
FES  Functional Electrical Stimulus
IC  Intermittent Catheterization
ILU  Independent Living Unit: a small apartment type of hospital room, located in the hospital, used to “try out” being away from the medical staff, but close enough to call for help if it is needed.
IRB  Income Replacement Benefits
LHIN  Local Health Integration Network (formerly known as CCAC)
LOA  Leave of Absence: used in the context of leaving rehab for a short period of time, usually to go home for a weekend.
MVA  Motor Vehicle Accident
ODSP  Ontario Disability Support Program
OT  Occupational Therapist
PSW  Personal Support Worker
PT  Physiotherapist
PTA  Physiotherapy Assistant
RN  Registered Nurse
RPN  Registered Practical Nurse
SABS  Statutory Accident Benefits Schedule: the document that describes the insurance regulations in Ontario.
SCI  Spinal Cord Injury
SLP  Speech-Language Pathologist
UTI  Urinary Tract Infection
WSIB  Workplace Safety and Insurance Board

GLOSSARY OF TERMINOLOGY

Activities of Daily Living (ADLs)
Basic tasks required for independent living, such as personal hygiene, dressing, eating, maintaining continence and mobility.

Acute care
Hospital-based care that provides the necessary treatment for a short period of time. The goal is to discharge patients (in the case of SCI, transfer to Rehab hospital) as soon as they are stable.
**Assistive Devices Program (ADP)**
ADP provides funding to Ontario residents who have long-term physical disabilities. It provides access to personalized assistive devices appropriate for the individual’s basic needs. Devices covered are intended to enable the person to increase their independence.

**Assistive Mirror**
A mirror with a long-extended (flexible) handle that can be used when checking your skin in hard-to-see places. It enables the user to do skin checks independently.

**Attendant Care or Attendant Services**
Usually provided by trained professionals, they can support physical needs and activities of daily living, such as bathing, personal grooming and hygiene, dressing, toileting, transferring and positioning. Sometimes a person can also be assisted with meal preparation, essential communications and even light housekeeping.

**Bowel Routine**
A schedule for bowel movements is necessary after an SCI because of neurogenic bowels. Usually, with controlled diet and the use of laxatives and/or suppositories, a routine that fits with one’s lifestyle can be established.

**Case Manager**
Case managers help patients connect with necessary healthcare providers, write and track treatment plans and work with other human service providers to keep a continuous plan for recovery.

**Catastrophic**
A term used by the legal/insurance industry to describe a severe injury to the spine, spinal cord or brain.

**Community Partners**
Health and social care agencies working together to pool expertise, resources and power. The goal of a partnership is to enhance the efficiency and quality of the service, working toward a common goal.

**Exoskeleton**
A wearable robotic device that provides SCI patients with powered hip and knee motion to assist with standing and walking.

**Injury level/line**
The term used by SCI patients to describe their level of spinal cord damage, e.g., T4.

**Inpatient**
A patient who stays in a hospital while receiving treatment (such as OT, PT and nursing).

**Insurance adjuster**
In personal injury cases, insurance adjusters work for the insurance company to assess the injured in order to determine what the claim is worth.

**Intermittent catheterization (IC)**
The insertion and removal of a catheter several times a day to empty the bladder;
necessary due to neurogenic bladder dysfunction.

**Lokomat**
A robotic treadmill physiotherapy training system.

**Medical Rehabilitation**
The term used in the insurance industry to describe the insurance claim funds used for physiotherapy, medication, devices (like catheters) and home modifications.

**Outpatient**
After a patient has been discharged from the hospital they can return (by appointment) as an outpatient for therapy, treatment and consultations.

**Peer Support**
It is recommended that both patients and family members seek out other individuals who have gone through recovery from SCI. SCIO runs a Peer Program where the newly injured and family can be matched with a mentor.

**Personal Injury Lawyer**
A lawyer who assists people who have been physically injured (or otherwise) as a result of the negligence of another person or agency.

**Physiatrist**
Doctors who specialize in physical medicine and rehabilitation from major injury or illness.

**Rehab**
The short form for “rehabilitation”. Rehab hospitals provide therapy and care to help SCI individuals adapt to their new body.

**Sliderboard/Sliding Board**
Usually made of shellacked wood, it is used to help people transfer their body from their wheelchair to bed, a chair, the car and other surfaces. (See also Transfer)

**Social Worker**
Social workers help identify the source of stress, mediate conflicts, offer counselling and help people develop coping skills to find effective solutions for their problems.

**Team meeting**
Team meetings are held during an inpatient stay to make plans for a patient’s recovery and eventual move home. Team members include the patient’s unit doctor, primary nurse, physiotherapist, occupational therapist, social worker, SCIO Regional Services Co-ordinator, psychologist, etc.

**Transfer**
Transferring is done by shifting one’s body from the wheelchair to other equipment or onto other surfaces, such as a commode, shower bench, bed or car.
### RESOURCES

#### Spinal Cord Injury Specific Websites
- **American Association of Neurological Surgeons**
  Spinal Cord Injury
- **American Occupational Therapy Association**
  Occupational Therapy and the Care of Individuals With Spinal Cord Injury
- **Christopher and Dana Reeve Foundation**
  [https://www.christopherreeve.org/](https://www.christopherreeve.org/)
- **G.F. Strong Rehab Centre**
  Understanding Spinal Cord Injury
  [https://livingwithsci.ca/understandingsci/](https://livingwithsci.ca/understandingsci/)
- **Paralyzed Veterans of America**
  Publications & Consumer Guides
  [https://www.pva.org/research-resources/publications/consumer-guides/](https://www.pva.org/research-resources/publications/consumer-guides/)
- **Praxis Spinal Cord Institute**
- **SCI Action Canada**
  [http://sciactioncanada.ca/](http://sciactioncanada.ca/)
- **SCI-University**
  [http://sci-u.ca/](http://sci-u.ca/)
- **Spinal Cord Injury BC**
  [https://sci-bc.ca/](https://sci-bc.ca/)
- **Spinal Cord Injury Ontario**
  [https://sciontario.org/](https://sciontario.org/)
- **University Health Network - Toronto Rehabilitation Institute**
  Spinal Cord Injury Patient and Family Education and Information Handouts
  [http://www.spinalcordessentials.ca/](http://www.spinalcordessentials.ca/)

#### Legal and Government Websites
- **Employment Ontario**
  [http://www.tcu.gov.on.ca/eng/eopg](http://www.tcu.gov.on.ca/eng/eopg)
- **Government of Ontario: People with disabilities**
  [https://www.ontario.ca/page/people-disabilities](https://www.ontario.ca/page/people-disabilities)
- **Injured Worker’s Advocate**
  [http://www.injuredworkersadvocate.ca/home.html](http://www.injuredworkersadvocate.ca/home.html)
- **Neil Squire Society**
  [https://www.neilsquire.ca/](https://www.neilsquire.ca/)
- **Office of the Worker Advisor**
  [http://www.owa.gov.on.ca/en/Pages/default.aspx](http://www.owa.gov.on.ca/en/Pages/default.aspx)

#### Health & Sex SCI Related Websites
- **Fruitful Elements**
  Specializing in Nutrition for People with Disabilities
  [https://www.fruitfulelements.com/](https://www.fruitfulelements.com/)
Phoenix Attitude
Medical and Motivational Tracking
https://www.phoenixattitude.com/how_does_it_work

pleasureABLE Sexual Device Manual for Persons with Disabilities

Sexology, Sex and Disability
https://www.drmitchelltepper.com/

Sexual Health Rehabilitation Service
https://scisexualhealth.ca/

Accessibility and Disability support related websites

Access 2 Entertainment Card
https://access2card.ca/

Cortree Disability Education Centre
www.sciontario.org/cortree

Easter Seals Disability Travel Card
http://easterseals.org

Job Accommodation Network
https://askjan.org/

Julie Sawchuk: Living With Paralysis
www.juliesawchuk.ca

Ontario Disability Support Network
http://odenetwork.com/

Ontario Wheelchair Sports Association
https://onpara.ca/

Parasports Ontario
https://www.parasportontario.ca/

Tetra Society of North America
https://www.tetrasociety.org/

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# Roadmap to Recovery

### SCI
- Catastrophic Injury (e.g., MVA)
- Accident at home
- Sporting accident
- Virus/Disease
- Medical complication

### ACUTE
- Physicians
- Nurses
- Respiratory Therapists
- Physiotherapists
- Peer Support
- Social Worker

### REHAB
- **Medical**
  - Physicians
  - Physiatrists
  - Psychologists
  - RNs, RPNs
  - PSW
  - Social Worker
  - Dietician
  - OT & PT
- **Equipment**
- **Pain management**

### Insurance (if applicable)
- Claims adjuster
- Insurance company
- WSIB (if work related)

### Legal (if applicable)
- Tort

### SCIO
- Regional Services Co-ordinator
- Peer Support Program Mentor

### HOME
- **Home**
  - Home accessibility or alternative accommodations
  - Equipment, e.g., wheelchair, slider/lift, shower chair/bench
  - Supplies, e.g., catheters, bowel care, medications
  - Family Health Team and Physiatrist
- **Therapy**
  - PT at local rehab clinic or pool
  - OT equipment home/workplace/car
  - RMT and Kinesiologist
  - PSW
  - Psychologist/Social Worker
  - Recreation Therapist
- **Life**
  - Transportation and/or driving
  - Legal and financial issues, benefits, settlements
  - ODSP, RDSP, CPPD
  - Family, work, travel, sport, health
  - SCI community, SCIO Regional Services, Peer support, resources, events
Roadmap to Recovery is published by SCIO and funded by Ontario Trillium Foundation. Author Julie Sawchuk shares her compelling story and detailed information from health care professionals, family members and people with SCI about every stage on the SCI journey. We welcome your feedback at sciontario.org/roadmap.

Photo: Members of the SCIO community gather for an SCI conference in Niagara Falls, Ontario, 2019