



CHAPTER ONE

# Julie's Journey



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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*



Physiotherapy has helped me recover as much core strength as possible. Here I am working with Marc Pitttock 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.

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**LIKE EVERYONE AFFECTED BY A SPINAL CORD INJURY, THE DAY MY LIFE CHANGED WILL NEVER BE FORGOTTEN.**

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, psychiatrist, 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.