


ROADMAP TO RECOVERY

 Finding your way
forward after
spinal cord injury

By Julie Sawchuk
and Spinal Cord Injury Ontario



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Author: Julie Sawchuk | www.juliesawchuk.ca

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Back cover photo: At a 2019 SCI conference in Niagara Falls: (l-r) *Back row*: Ivan Rendulic, Bob Asham, Oda Al-anizi, Lubna Aslam, Crista Henry *Middle row*: John Chernesky, Randy Upper, Randy Kells, Anthony Viao *Front row*: Diane Morrell, Julie Sawchuk, Peter Athanasopoulos

Visit www.sciontario.org/roadmap for a digital version of this book and to share feedback.



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For Theo Sawchuk and all the other wonderful partners, parents, friends and family who have joined the SCI club.

- Julie Sawchuk

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

- Dr. Stuart Howe, CEO, SCIO

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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

PREFACE BY AUTHOR JULIE SAWCHUK

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.