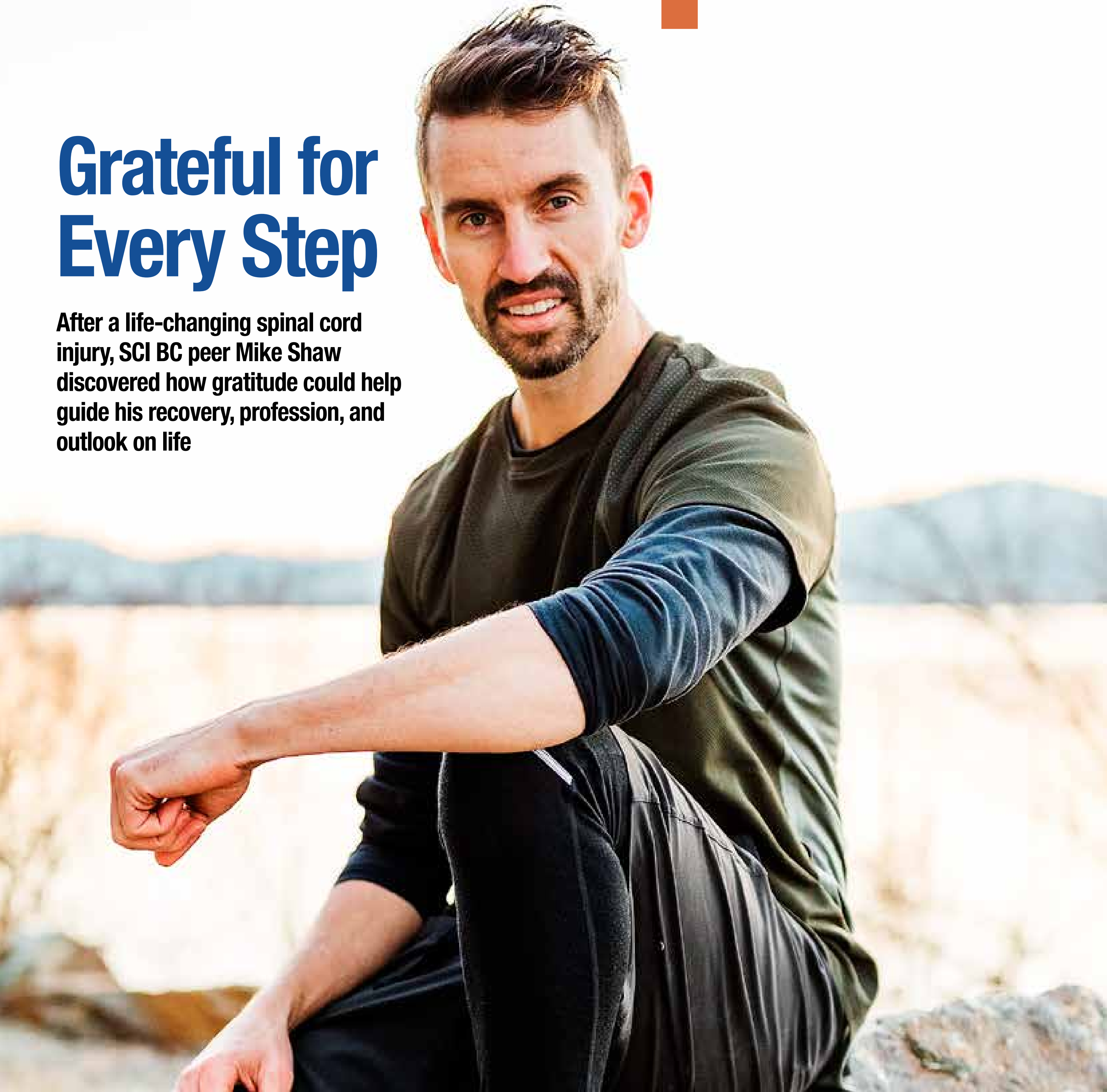
ACCESSIBLE GARDENING | CHRONIC FATIGUE | PEER SUPPORT TOOLKIT

thespin

SPINAL CORD INJURY BC

SUMMER 2025



Grateful for Every Step

After a life-changing spinal cord injury, SCI BC peer Mike Shaw discovered how gratitude could help guide his recovery, profession, and outlook on life

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Every Innovation
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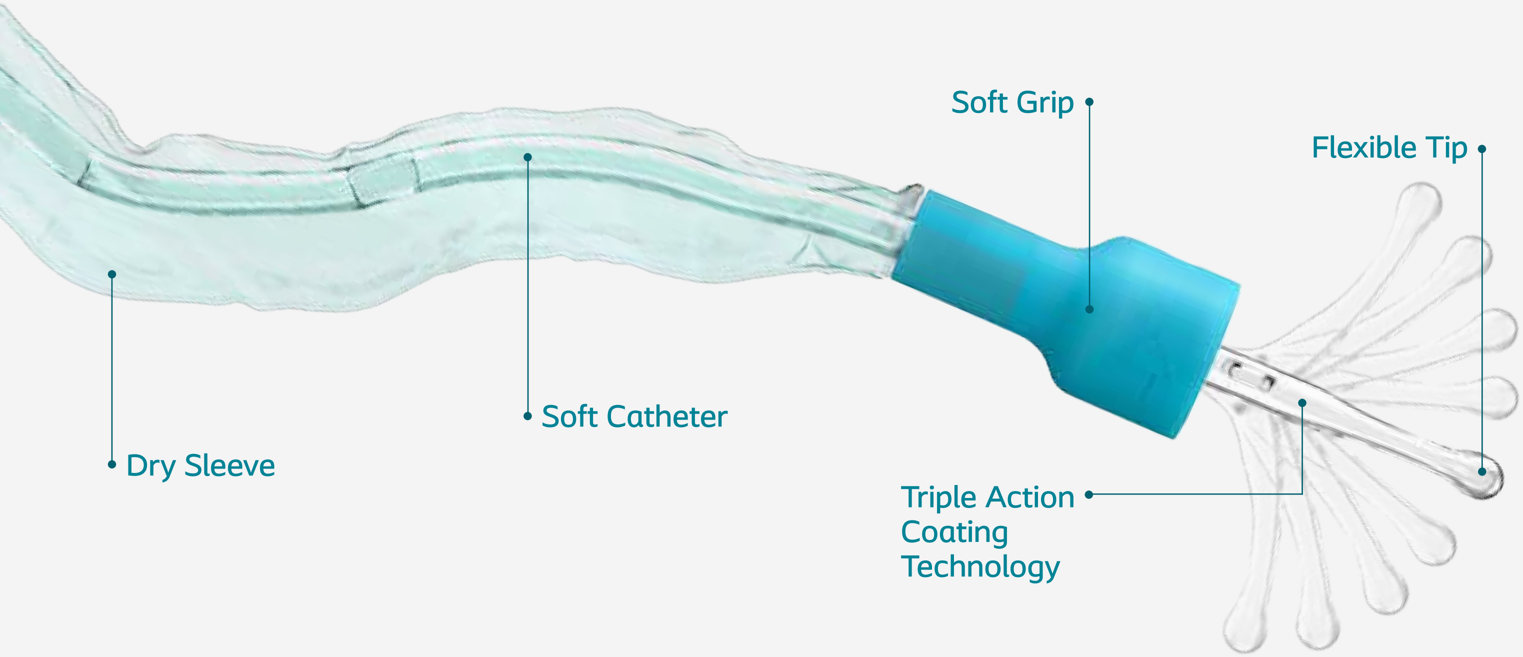

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COVER: SCI BC peer Mike Shaw poses for the camera. Photo Credit: Royce Sihlis.


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editor's message

Happy 80th SCI Canada!

This year, SCI Canada turns 80. In this moment of rising national pride, SCI Canada and the organizations that now run it have been and will continue to be invaluable contributors to what differentiates our country from our neighbours, and what makes our country so great.

The organization, originally called the Canadian Paraplegic Association, was founded by World War II veterans with SCI who returned to a Canada that was not accessible and lacked specialized rehab. Through peer support and advocacy, they quickly set to work changing all that. Over time, divisions were established in each of the provinces. These divisions eventually became independent organizations that were connected through what is now SCI Canada.

In 2016, SCI Canada underwent a significant organizational restructuring that saw the provincial SCI organizations take direct responsibility for its operations through what is called the SCI Canada Executive Directors Council (EDC). I have had the honor of being the chair of the EDC since its inception, with SCI BC's Board Chair, Ed Milligan serving as SCI Canada's Board Chair during this time.

The EDC has the option of hiring someone to run the organization's day to day operations and were fortunate to convince recently retired SCI Ontario CEO, Bill Adair, to hold off on his retirement plans to be the executive director of SCI Canada. Although the role was part-time, Bill, who has dedicated over three decades of passionate leadership for helping folks with SCI and their families adjust, adapt, and thrive, put in more hours than we were paying him for, most notably when he led a broad coalition of disability organizations that played a critical role in shaping and advancing the Accessible Canada Act.

Now, after nine years with SCI Canada, Bill is actually retiring. I have had the pleasure of working with Bill for over two decades and will miss his passion, optimism, and fierce but respectful advocacy. His are hard shoes to fill, so much so that SCI Canada will not even try.

As we enter a new chapter for SCI Canada, the EDC will take over all the operational duties of running the organization. We are dividing up the duties amongst our organizations and focusing our efforts on three key areas: collaborating to strengthen priority areas of service within each provincial organization, with a particular emphasis on peer support; federal government relations; and sustaining a strong, inter-provincial network of SCI organizations.

As continuing Chair of the SCI Canada Executive Directors Council, I am very proud of SCI Canada's history and the collective role our organizations have played throughout it. I am also excited about our vision for the future. The path forward can seem daunting at times, but as with the peer support our organizations are so well known for, working together as SCI organization peers, the work becomes lighter, more rewarding, and more impactful.

Happy 80th anniversary, SCI Canada! Cheers to a storied past and a bright future.

—Chris McBride, PhD, Executive Director, SCI BC

thespin

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SCI BC is grateful for the financial support of the BC Gaming Commission and the BC Paraplegic Foundation.

We acknowledge that *The Spin* is created on the traditional and ancestral territory of the Coast Salish peoples—Squamish, Musqueam, and Selilwitulh (Tsleil-Waututh) Nations. Our provincial work takes place on the territories of Indigenous peoples who have lived on and cared for the land for time immemorial. We are grateful to work, share stories, and connect in these spaces.

SCI BC InfoLine: 1.800.689.2477

ACCESSIBLE FURNITURE COLLECTION

Pottery Barn partnered with Michael Graves Design to bring you a collection of accessible furniture. The collection includes beds, chairs, dressers, and nightstands with practical features such as integrated armrests and storage space in beds, built-in power strips in nightstands, grab channels in dressers, and a nine-inch wheelchair clearance. Crafted from different types of richly grained wood, these products prioritize beauty, accessibility, and safety into the design. You can check out the Michael Graves Design collection at potterybarn.ca.

Innovations

New products, devices, and aids to daily living that might make a difference in your life...

THE ERA WHEELCHAIR

Bowhead, a company known for its adaptive mountain bike, launched the Era Wheelchair, a one-of-a-kind manual wheelchair that is highly customizable. The Fit-For-Life system allows users to adjust the width, height, and centre of gravity of the frame to accommodate the user's needs over time. The seat can be detached from the chassis with a quick release to provide more storage or travel flexibility. The Era is built using aerospace grade carbon-composite meant to last for a long time, with carbon-fibre, lightweight rear wheels and front caster wheels that feature a hubless design to avoid debris build-up. Roll into the Era Wheelchair at bowheadcorp.com/era.

ZIPPED BRANDS SHOES

If you have limited mobility that affects your ability to put on shoes and want to wear mainstream brands, Zipped Brands' shoes are the right fit for you. Well-known brands like Nike, Converse, and Dr. Martens are adapted to include a discreet zipper on the side and around the toe, allowing the upper section of the shoe to open and close with ease. The collection includes shoes for men, women, and kids. Get your new shoes at zippedbrands.com. Similarly, BILLY Footwear, owned by SCI peer Billy Price, also features the same innovative, inclusive shoe design for various types of footwear such as sneakers, sandals, and trail boots. Read our Spring 2017 issue of *The Spin* to learn more about Price's story.

NEIL SQUIRE'S MAKERS MAKING CHANGE

Neil Squire's Makers Making Change Program has an online library of over 200 assistive technology products that help people with all types of disabilities live a high quality of life with more independence. Create an account, assemble the product yourself with the provided instructions, or request a volunteer to build the device for you with a small fee to cover material and shipping costs. At little or no cost, these devices range from assistance for daily living to gaming and technology accessories. Examples include adapted scissors, grips for the Nintendo Joy-Con, braille keyboard overlay, and so much more! Scroll through the Makers Making Change library at makersmakingchange.com.

References: 1. Burns, J, Pollard, D, Ali, A, McCoy, CP, Carson, L & Wylie, MP 2024, 'Comparing an integrated amphiphilic surfactant to traditional hydrophilic coatings for the reduction of catheter-associated urethral microtrauma', ACS Omega. https://doi.org/10.1021/acsomega.4c02109. *Data from Burns et al.

Come join the fun at G.F. Strong.

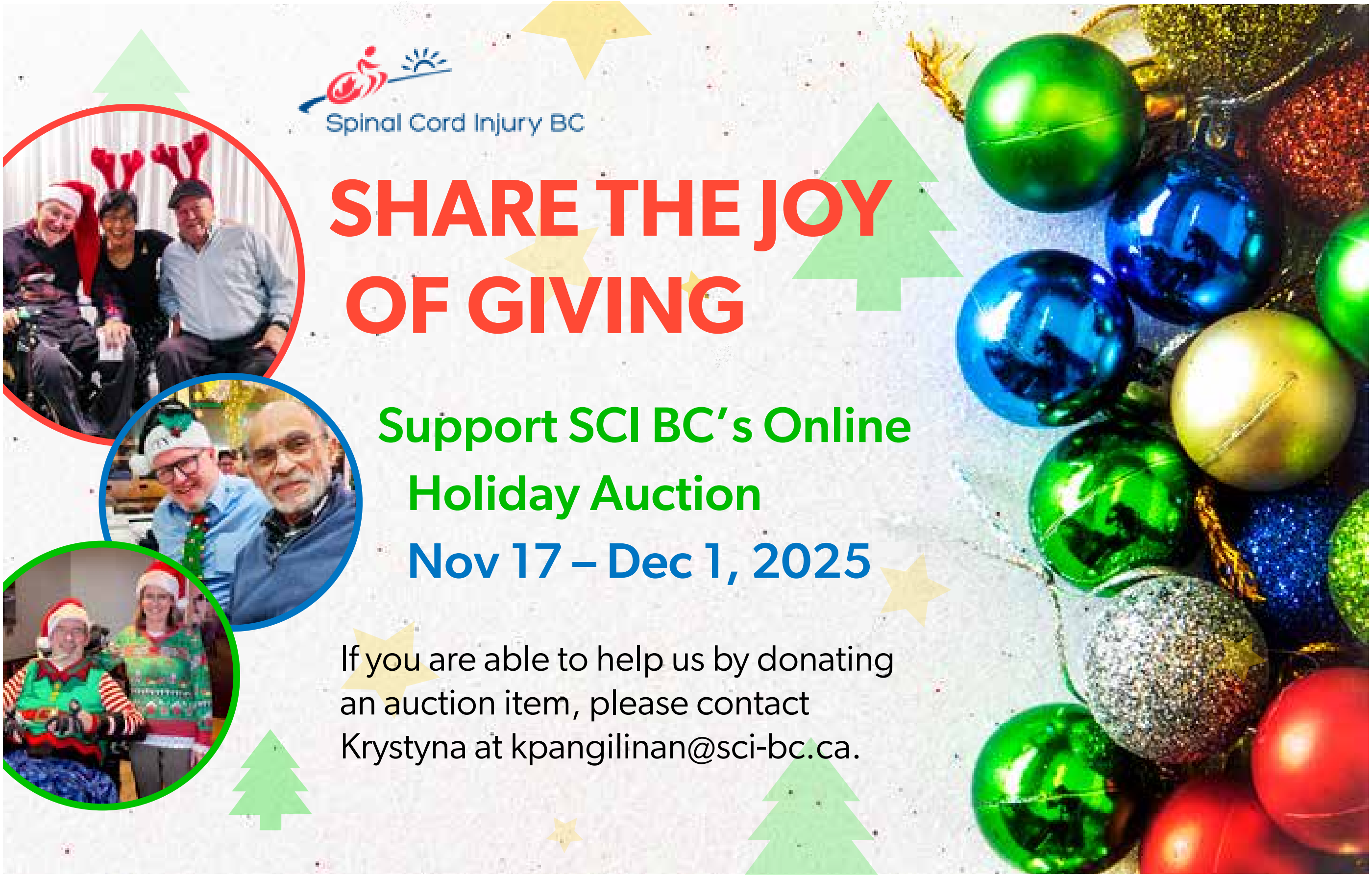
SCI BC, BC Rehab Foundation, Vancouver Adapted Music Society, and the Disability Foundation are proud to host a lively and inclusive BBQ celebration for the G.F. Strong community! Come enjoy an afternoon of great food, music performances, games, local artisans, and more on July 10 from 2 - 6 PM at G.F. Strong. Registration is required to attend this event. Save your spot by letting Ryan know you'd like to attend at rclarkson@sci-bc.ca.

Get crafty with woodworking!

Have fun learning new skills in Tetra Society's Woodworking Shop. Designed to help people with disabilities explore woodworking, all tools and machinery in the workshop are adapted for people with dexterity limitations. Workshops run Tuesdays and Thursdays from 10:30 AM – 2:30 PM at the Blusson Spinal Cord Centre and cost $10. Register at disabilityfoundation.checkfront.com/reserve. For more details, contact Kees at TetraWoodshop@gmail.com.

Your camping excitement awaits.

Do you love sleeping under the stars? Roasting marshmallows and telling stories around the campfire? SCI BC is excited to team up with Power To Be to offer an exciting weekend of camping at Prospect Lake in Victoria from July 25-27. All accessible camping equipment will be supplied by Power To Be, so relax, enjoy the great outdoors, and connect with other campers! Get in touch with Scott at sheron@sci-bc.ca to register and for more information.



Spinal Cord Injury BC

SHARE THE JOY OF GIVING

Support SCI BC's Online Holiday Auction

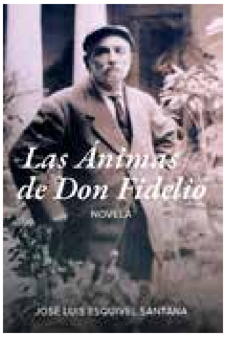
Nov 17 – Dec 1, 2025

If you are able to help us by donating an auction item, please contact Krystyna at kpangilinan@sci-bc.ca.

Peer Shoutouts

Victoria's **CODY FOURNIE** and White Rock's **DANIELLE ELLIS** are in a league of their own! The two were named BC's 2024 Male and Female Athletes with a Disability at Sport BC's 57th Annual Athlete of the Year Awards. On the track, Fournie made a golden Paralympic debut in wheelchair racing, winning two golds in the T51 100m and 200m sprints. His time of 19.63 in the 100m set a new Paralympic and Canadian record. Fournie switched to Para Athletics in 2022 after years on Canada's wheelchair rugby team. As team captain, Ellis led Canada's sitting volleyball team to a bronze medal at the 2024 Paralympics. Now retired from sport, she's studying to become a Pharmacy Technician. Legendary performances from two incredible peers!

MICHELLE STILWELL is always in the fast lane! A true trailblazer, she's receiving the Order of Sport (Canada's highest sporting honour) and being inducted into Canada's Sports Hall of Fame. Stilwell made history as the first Canadian Paralympian to win gold in two summer sports: wheelchair basketball and wheelchair racing. Across four Paralympic Games, she raced to six gold and one silver medal, smashing world records along the way. But Stilwell didn't stop at the finish line. As an MLA and cabinet minister in BC, she brought her athlete's drive to government, championing accessibility, inclusion, and disability rights, including support for the BC SCI Network. Today, she keeps driving changes through mentorship, public speaking, and advocacy. On the track or in the community, Stilwell is built for impact.



A storybook shoutout to **JOSÉ LUIS ESQUIVEL** on publishing his debut novel, *Las Ánimas de Don Fidelio*! Written in Spanish, this haunting tale is inspired by Esquivel's roots in small-town Mexico. After a globe-trotting career in business and hospitality, Esquivel now channels his experiences into storytelling. He writes to "transport readers to vibrant settings, where food, customs, and the voices of the people become the heart and soul of every story." He's already working on two new books: *So You Want to Start a Restaurant* and *Every Wheelchair Tells a Story*. Grab your copy at amazon.ca.

AINSLEY WOOD is a cut above the rest! She was named Young Citizen of the Year at the City of Kelowna's 50th Annual Civic & Community Awards. Since sustaining an SCI as a teen, Wood has been a dedicated SCI BC Volunteer Peer Mentor, supporting others with compassion and care. She logs serious impact with PRAXIS Spinal Cord Institute and as Vice Chair of the Rick Hansen Foundation's Youth Leadership Committee, amplifying the voices of youth with disabilities nationwide. Fresh from her first year at UBC Okanagan, Wood will receive funding from the award to support her post-secondary education.

TOP: Team BC #1 BOTTOM: Team BC #2

BC sure knows how to rock the rink! Two powerhouse teams repped the province at the 2025 Wheelchair Curling Championships in Montreal. Team BC #1 swept up another bronze, with a clutch win over Newfoundland and Labrador. This team of stone-cold legends included skip **RICK ROBINSON**, vice-skip **INA FORREST**, second **GERRY AUSTGARDEN**, lead **GLEN MCDONALD**, and coach **SHARON MORRISON**. Meanwhile, Team BC #2 made a stellar debut, winning their first three games, and sliding into the quarterfinals. The Delta Thistle Curling Club crew featured skip **MARNEY SMITHIES**, vice-skip **ROB SPENCER**, second **KIM EGGER**, lead **LELAINIA LLOYD**, and coach **MARTIN MATSUTANI**. Congrats to both teams on hitting the button!

Community Highlights

DISABILITY AND PUBLIC ENGAGEMENT IN PODCAST FORM

Kudos to Dr. Alfiya Battalova, a former SCI BC staff member and current Assistant Professor in Justice Studies at Royal Roads University, who continues to create space for open dialogue on accessibility. In her latest project, Battalova teamed up with Anu Pala, a disability advocate and podcaster, to produce *Our Voices: Disability Through a Lens of Public Engagement*. This four-episode podcast is based on Battalova's research that looks at how accessibility advisory committees have shaped municipal policy decisions and what the public can do to help make lasting, positive change in their communities. Key guest speakers include Karen Lai, City of Vancouver's Accessibility Planner, and Amy Amantea, Accessibility Consultant and Advocate. Listen to *Our Voices* at youtube.com/@Alfiya06/podcasts.

ADVOCACY EFFORTS ACKNOWLEDGED IN SURREY

Put your hands together for SCI BC's very own Board Member, Susan Bains, and Equal Access Collective (EAC) for winning one of the Surrey Women in Business Awards! Bains and EAC were awarded the Social Trailblazer category for being a leader in accessibility and advocating for accessible public spaces, including the installation of an accessibility mat at the White Rock Pier (Read the full story in *The Spin's* Fall 2024 issue!). "Being named Surrey Women in Business' 2025 Social Trailblazer from Surrey Board of Trade is an honour—one that comes from life happening and choosing to speak up. This recognition amplifies a message shared by so many in all the abilities, disability, and adaptive community: we are here, we matter, and we demand equal access," says Bains. With a background of 15+ years of experience in human resources and additional involvement in the Surrey Accessibility Leadership Team (SALT), we know Bains' strong leadership skills and the rest of EAC will continue to push for more inclusion initiatives in the future. We can't wait to see what Bains and the EAC team will do next!

SCI RESEARCH RECOGNIZED WITH UBC'S MOST REPUTABLE RESEARCH AWARD

A well-deserved congratulations to Dr. Brian Kwon for his outstanding advancements in SCI research that landed him the Jacob Biely Research Prize, UBC's most prestigious research award. You might recognize this familiar face as the new Director of ICORD, along with his roles as a spine surgeon at Vancouver General Hospital, Dvorak Chair in Spine Trauma, Director of Research for the Vancouver Spin Research Program, and a professor at UBC's Department of Orthopaedics. The Jacob Biely Research Prize includes a $3,000 honorarium which Dr. Kwon will donate to ICORD. He shares, "I am honoured and truly humbled to receive the Jacob Biely Faculty Research Prize… Here at ICORD, we are blessed to have the partnership and support of UBC, Vancouver Coastal Health Research Institute, Vancouver Coastal Health, the Rick Hansen Foundation, the Praxis Spinal Cord Institute, Spinal Cord Injury BC, and the VGH & UBC Hospital Foundation. Together, we will resolutely continue our shared mission of improving the lives of those with spinal cord injury through cutting-edge research innovation and state-of-the-art clinical care."

Ask InfoLine: Answering Your SCI FAQs

I haven't been to the dentist in years because I can never afford it, and now my teeth are starting to give me trouble. I also have no idea where I could go that's wheelchair accessible. Do you have any advice? —Tim, Pitt Meadows

To answer this question we turned to SCI BC's InfoLine Service Lead, Heather Lamb, MSW, RSW.

Dental care is very expensive, especially for those who do not have extended dental care coverage. While I believe strongly that dental should be part of our health care system for everyone, we have seen improvements in coverage with the introduction of the Canada Dental Care Plan.

Canadians who are over 65 or under 18, as well as adults who had the Disability Tax Credit in 2023 or later are currently eligible, as long as they don't have coverage through a private plan. Those with coverage through a provincial plan, such as through their PWD benefits, are still eligible for the federal plan; in this case, benefits will be coordinated to minimize gaps in coverage.

Note that if you do have coverage through a private plan (such as through an employer), you cannot gain access to the federal coverage by opting out of your current plan, even if you are paying out of pocket for your premiums.

Those with a family income below $90,000 are eligible for coverage, an amount that may be different for you if you have received other federal benefits like RDSP income.

Coverage for all other eligible adults was phased in starting May 2025. Those who are potentially eligible, based on the 2024 tax return, will receive a letter with instructions on the program and how to apply. You can also apply online at canada.ca/dental. Those who can't apply online can call 1-833-537-4342. For those already in the program, coverage needs to be renewed each year and letters will be sent with instructions.

Once you are accepted, you will receive information from Sun Life, who is administering this benefit on behalf of the Government of Canada. Once you receive your benefits card from Sun Life, you can make an appointment with any dentist who has enrolled into the program. I recommend asking your dental office before making an appointment to make sure they accept this coverage. Be aware that not all services are covered and people with higher incomes may have a co-payment.

You can search for a dental office on the BC Dental Association website bcdental.org/find-a-dentist where you can also filter results by the type of insurance coverage they accept and by wheelchair access. The search tool may not be very useful about wheelchair access, but it's a good place to start. Once you have a shortlist, it's smart to call the offices directly to ensure that the coverage information is correct and to ensure that their level of accessibility meets your needs. In a previous article in the Summer 2019 issue of *The Spin* we covered an accessible dental chair that power chair users can just roll onto without transferring. If you already have a dentist, you could ask if it's something they've considered. It's possible many practices aren't aware of it yet.

SCI BC's InfoLine team is here to help you find an accessible dental practice near you, apply for the new dental care plan, and any other questions you have about living with a physical disability in BC. Don't hesitate to call or email us at any time. 1-800-689-2477 or info@sci-bc.ca. ■

Accessible Questions to Ask Your Dental Office:

- Do you have accessible parking?
- Is there a level access route from the accessible parking (or closest transit stop) into your building?
- Do you have an accessible washroom?
- Is there sufficient space beside the dental chair for me to transfer into it from my wheelchair?
- Can your staff assist with my transfer?
- Do you have a pillow or props to assist me to sit comfortably or safely in your chair?
- Can I remain in my own wheelchair during the appointment?
- Are your staff trained to work with wheelchair users?

Dr. David Burdett's accessible dental chair at Diamond Dental Centre, featured in the Summer 2019 issue of The Spin.

From the Ground Up:

Accessible Gardening with DIGA

Get growing with beginner-friendly gardening tips and programs from the Disabled Independent Gardeners Association (DIGA).

When it comes to gardening with an SCI, there's a little bit more to it than just having a green thumb. Ground-level garden beds, limited hand function, uneven terrain, and unpredictable weather may all be challenging factors currently deterring you from planting roots in this new hobby—but don't worry, SCI BC and the Disabled Independent Gardeners Association (DIGA) have teamed up just in time (or should we say, thyme?) for the summer gardening season to help you get you started.

Established in 1987, DIGA is one of six societies supported by the Disability Foundation. Its mission is to help people with physical disabilities overcome barriers to gardening and provide them with the tools and support to flourish, both in their gardening plots and in their lives. Bryden Veinot, Senior Program Coordinator with the Disability Foundation explains the three main ways to get involved with DIGA: community gardening, home gardening, and workshops.

Community Gardening

"We operate out of eight community gardens right now," Veinot explains. "There's one at G.F. Strong, which a lot of people in our community are aware of, but we also run programming out of Still Creek, Pine Street, Brewery Creek, Pandora, Kerrisdale, G.F. Strong, Woodland, and Mount Pleasant." Each DIGA gardening space comes equipped with a raised plot or tabletop garden, an automated irrigation system for watering, access to a toolshed and supplies, and the option to work with a volunteer who can help with gardening tasks like planting seeds, weeding, harvesting, and regular maintenance.

"How participants manage their community garden space is totally up to them. If they have the ability to get in there and do it themselves, that's fine… having freedom and agency to do the things you love to do and being able to do them by yourself is important. But if you do find out there are barriers that are keeping you from doing certain things in the garden that you want to be able to do, then we do find volunteers to pair up [with people]." The community gardening season typically runs from May to September (depending on the

Community gardens from left to right: Pandora, Woodland, and Still Creek. Previous and top: G.F. Strong.

DIGA's Top 3 Things to Know Before You Grow

Use Adaptive Tools: Depending on your level of injury and grip strength, you may have difficulty using common gardening tools. Pushing and lifting a trowel or pulling a hand rake can require a lot of effort and off-the-shelf tools aren't also built with comfort in mind. DIGA suggests contacting your local Tetra chapter with your concerns and they can work with you to build a solution. DIGA has also had success using adaptive tools like trowels and cultivators using an Easi Grip Arm Support Cuff by Peta that has a 90 degree grip and an extended handle to brace against your arm.

Make a Plan: "A lot of the time, the success of the plant is based on when you plant it and the time of season and what kind of soil you have," explains Veinot. If you can, always refer to the seed packet or seedling container for instructions on when and how to plant. DIGA can connect you with extensive online resources like regional planting guides or maps, or they can help you keep things simple with one or two planting suggestions. There are no absolutes when it comes to gardening, but when in doubt, start with something that is known to grow well where you are gardening.

Enjoy the Moment: Gardening can teach us a lot about ourselves. It requires patience and commitment and a little bit of luck. Plants, like us, grow best with a good supply of water, nutritious food, a little bit of sunshine, and the support of others. "Being able to get outside and work with your hands or get a little dirty, is a lot of fun," Veinot says. "Once you're actually out doing whatever [DIGA] has set you up to do, you're not focusing on your barriers or anything to do with your disability. You're just there in the moment, hanging out with like-minded people and having a good time."

weather) and space fills up quickly. If you missed out on a spot this year, can't travel to your neighbourhood garden, or don't live in the Lower Mainland you can still start sowing with DIGA's home gardening program.

Home Gardening

Working in partnership with Tetra, another Disability Foundation affiliated society, DIGA is able to provide free home gardening planters upon request. For the unfamiliar, Tetra builds innovative solutions for people with physical disabilities through a national network of volunteers. Solutions can range from simple cup holders or hand grips all the way to voice controlled door openers or adapted wheelchairs. Each assistive device or creation is shared online via an open access database that includes designs, costs, and details that anyone can use.

The home gardening planters Tetra builds for DIGA have been adapted from commonly sourced outlets like Costco or Home Depot and are raised high enough so a wheelchair (or other type of mobility device or seating aid) can be used while gardening. "The planters are on wheels with locking casters, and there is also a hose attachment for self-irrigation," Veinot describes. "Anyone who's signed up as a participant with DIGA can request one and we will build it with Tetra and deliver it for free. Once it's all set up it's actually quite low maintenance." Because Tetra has a presence throughout Canada, there's no geographical limit to this type of home gardening support. "Even if you're on the other side of the country, you [should] be close to a local Tetra chapter and could put in the request for a home gardening planter and they should be able to build it."


Automatic watering system.

Workshops

Still not convinced gardening is the right fit for you? We suggest attending a workshop. Held monthly, DIGA workshops are a low pressure way to learn more about a gardening topic that interests you. Workshops that are more hands-on run in-person at G.F. Strong

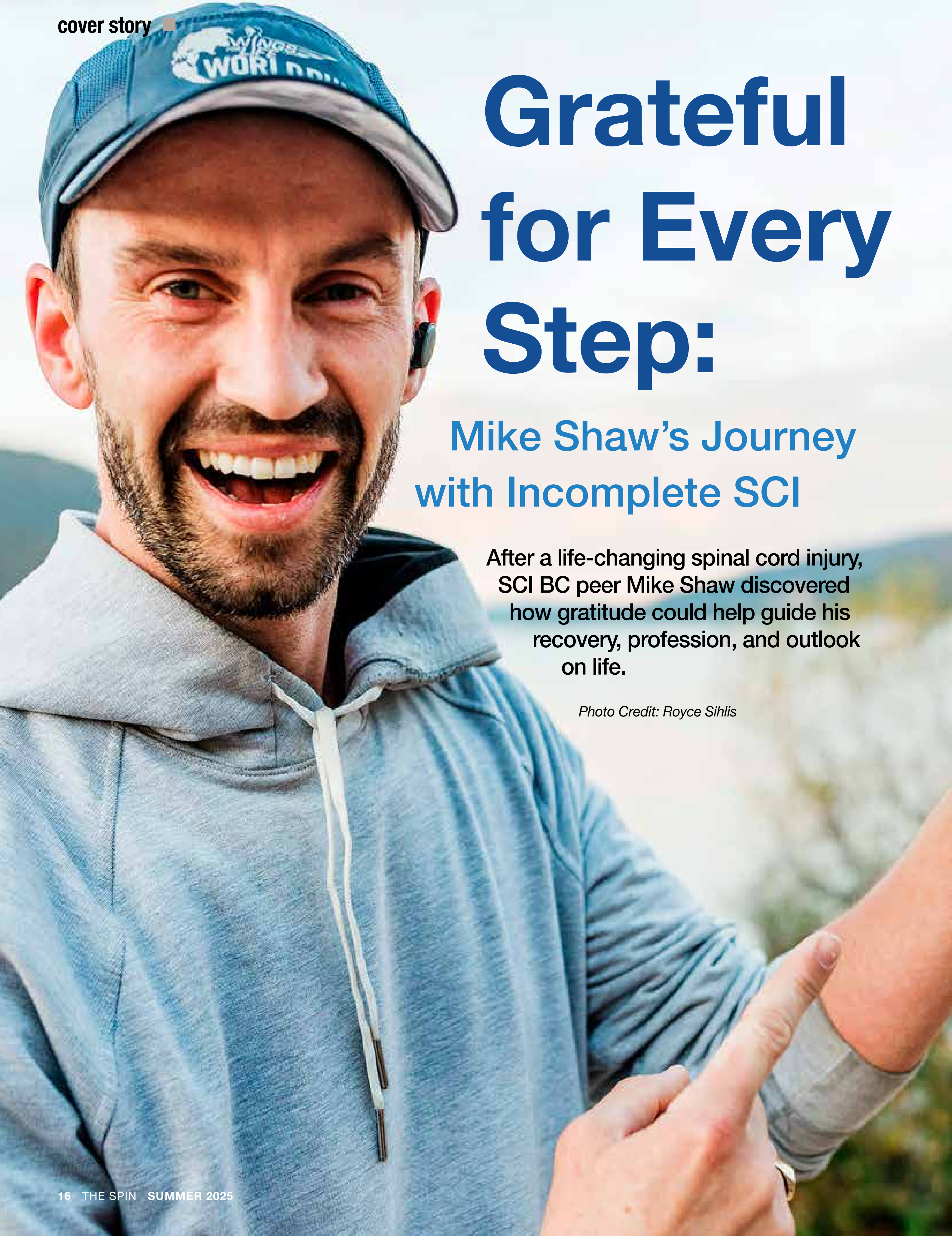
DIGA Pollinator Garden Workshop.

or the Creekside Community Center, while workshops that are framed as information or education sessions are delivered online.

"You don't need any experience," says Veinot. "You don't need to have a background in gardening or know anything. If it interests you, then reach out because through the workshops and with the support of volunteers or staff, we can fill in that knowledge and help you learn. Even if you don't think you have the skills to do it, there are people here to help you feel comfortable." One of the first DIGA workshops of the summer is scheduled for June 25 at VanDusen Botanical Garden and Veinot encourages new participants to attend. The workshop will include a guided tour of the facilities and all attendees will also receive a day pass to continue exploring the gardens after the event wraps up.

You can learn more about DIGA by visiting digabc.org, emailing info@digabc.org, or calling 604-688-6464.

The Disability Foundation is a member of the BC SCI Network, a collaborative network of five disability organizations including SCI BC, BC Wheelchair Sports Association, BC Wheelchair Basketball Society, and the Neil Squire Society. Learn more about the BC SCI Network here: sci-bc.ca/about-us/bc-spinal-cord-injury-network. ■



Grateful for Every Step:

Mike Shaw's Journey with Incomplete SCI

After a life-changing spinal cord injury, SCI BC peer Mike Shaw discovered how gratitude could help guide his recovery, profession, and outlook on life.

Photo Credit: Royce Sihlis

When *The Spin* first reached out to SCI BC peer Mike Shaw to learn more about his journey with SCI, he had already been on a run, given a CBC interview, and made breakfast—and it was only 9:30 am. As an ex-professional freestyle skier and coach, Shaw is used to busy, challenging days and his schedule on this particular day is reflective of the goal-oriented and value-based approach he now brings to his work as a certified counsellor and living life to the fullest with an SCI.

In December 2013, Shaw was coaching athletes on the Canadian Development Half Pipe ski team at a World Cup competition in Denver, Colorado when a routine jump resulted in an SCI. “It was a trick I’d done a thousand times,” Shaw describes. “I knew the snow wasn’t quite right but I ignored my gut instinct and performed the trick. When I landed, my body pitched forward and my feet came over top of me, like a scorpion tail.”

In the moments following Shaw’s accident, ski patrol and emergency personnel responded quickly. He underwent medical imaging and had a catheter placed even before leaving the ski hill. It was soon confirmed that he had dislocated his neck at the C4-5 vertebrae and sustained a fracture at C6. By midnight, he was in surgery. “The doctor described it to me like my spinal cord was in a barroom brawl, not a knife fight,” he says. “My spinal cord was displaced, but my bones had not splintered around it. Still, it wasn’t pretty.”

Shaw knew how fortunate he was to have been injured while under insurance coverage through his work and to have such immediate medical attention. At the same time, he also understood that luck would only get him so far. “When the spinal specialist in Denver said that I should prepare myself to never walk again, I left the door of opportunity open in my mind, even if it was just a small crack, that one day I might walk again. I didn’t eliminate that possibility.” Unknowingly, this early combination of luck and dogged determination within the first few hours of his injury would come to define his recovery in the years ahead.

After two weeks in intensive care in Colorado, Shaw was transported via air ambulance to Vancouver where he spent a week at VGH and then went to G.F. Strong. “This is where gratitude started to enter the picture,” he says. “The first thing I could feel in my body was emotions. I couldn’t feel my legs or arms. But emotions like gratitude felt warm, and things like despair and grief and guilt and loss felt cold or dark.”

Prior to his injury, Shaw wasn’t overly familiar with mental health practices or any therapeutic strategies, but he quickly recognized the impact of his feelings and leaned into a positive mindset. “I ended up purposely and intentionally focusing on the gifts in my situation. Fortunately, because I was experiencing some healing, I had reasons to feel thankful. But I think there’s a reason for anyone to feel thankful, even if you’re regaining a small form or part of your independence in whatever way that looks like to you.”

Whether it was being able to lift his hand high enough to touch his face or eventually transfer out of bed, Shaw looked for and celebrated every little achievement and credits the practice of gratitude as a critical part of his healing. Three weeks after his accident, he had enough strength to hold a toothbrush and, with the help of his mom and a nurse, was able to brush his teeth. “I used my tongue to move the toothbrush around to each tooth, because I didn’t have wrist dexterity and I ended up crying. I was so happy that I could do one part. It wasn’t even all on my own, but I had some of my independence and dignity back and I was so thankful.”

Another contributing factor in Shaw’s initial few weeks of recovery was peer connection. As a young skier, Shaw was coached by Josh Dueck, an accomplished freestyle skier, Paralympian, and former SCI BC Peer Program Coordinator. The two remained close throughout Shaw’s skiing career and Dueck was one of the first people Shaw called after his injury. “He didn’t sugar coat it. He told me, ‘Welcome to the spinal cord injury club’. No one wants an invitation to the SCI club and I wouldn’t wish it on my worst enemy.

Mike Shaw’s x-rays after surgery.

Mike Shaw and family.

It's devastating. There's no question about that. But he also said something like, 'Trust me—although it doesn't feel like a gift right now, there will be gifts that can come from this and they'll reveal themselves over time."

Over the next few months, Shaw kept Dueck's words in mind and began to look for silver linings during his painful recovery. He eventually regained the ability to walk and left G.F. Strong on his feet on the day of his discharge. Within a year, he was back on the mountains in a sit ski (following the exact same timeline Dueck had taken to return to the slopes) and looking for new challenges.

Shaw acknowledges he's been extremely lucky. "I was very fortunate in that I had a chance… I had a mechanism of injury that could recover and I know that's not the case for everyone." This recognition is something he grapples with everyday and it has proven to be one of the most challenging facets of his recovery, both in his personal and professional life. "Most of the time, people don't know [about my SCI]," he explains. "But my skin on the lower half of my body is still numb to soft touch. I feel pain and I can feel pressure, but there's been some pretty awkward games of footsie under the table. I don't have great proprioception. I lose my balance up to 50 times a day or more." As Shaw describes, oftentimes our identity is linked to our abilities or what we can and cannot do. For people in the ambulatory SCI community, this can be especially challenging because their disability doesn't fit neatly into a category of 'can' or 'cannot'.

"Most people associate SCI and paralysis with a wheelchair. So, if you're striving to live your life without a wheelchair, it can be hard because you don't look injured. If you use a cane or a walker, people may not understand that it's because you have an SCI and it's difficult not being recognized for that or feeling like you don't belong with the broader SCI community," he says. "Even though I look fully healed to the untrained eye, I know there's a zero percent chance I could go and play a good game of pickup soccer or go play basketball with my friends and keep up with them. So for me, it's a bit of a tug of war."

In 2023, Shaw earned his Master of Arts in Counselling Psychology and now works as a clinical counsellor with his own practice, Gratus Health ("Gratus" is a Latin word meaning grateful or thankful). His experience with SCI directly informs his therapeutic work, offering both valuable insight and unique challenges. "It's one of the most difficult things for me when working with the spinal cord community. I am very sensitive to people's experience and honour their view of the world," he explains. "You're the only person in the world who knows what you're physically, mentally, or emotionally capable of and I believe that you can do as much as you think you can do. Some people don't see themselves getting better. I have to honour where they're at while also moving them towards reflection and living a full life… those things don't always align at first." Through his counselling work, however, Shaw hopes to equip people with the tools to eventually bring those pieces together.

Shaw conducted a series of monthly workshops for SCI BC's ambulatory community in January to March of this year. In April, he delivered a workshop to SCI BC's Peer Program staff that discussed the feedback and findings from the workshop series, focusing on concepts of identity, goal setting, self-care, mental health, grief, and comparison through the lens of ambulatory peers. The main takeaways of the presentation included the importance of setting value-based goals tied to personal meaning rather than relying solely on your willpower to accomplish them.

Shaw explains that using a structured framework that moves from a long-term vision to daily behaviors, alongside narrative goal setting, can help create emotionally resonant goals and encourages progress aligned with one's values. Self-care is also an important part of accomplishing our goals and nurturing our well-being. When we're feeling "off", we can focus on the seven pillars of self-care: health literacy, mental well-being, physical activity, nutrition, risk avoidance, hy-

SCI peer and clinical counsellor Mike Shaw shares three pieces of advice for practicing daily gratitude.

Use Gratitude Triggers: “A gratitude trigger is a specific moment, action, or object that’s part of your daily life that can prompt feelings of gratitude. It could be a cup of coffee in the morning or anything that you’re sincerely thankful for. The first time I noticed getting triggered with gratitude occurred when I started transferring in and out of bed independently. It didn’t matter which side of the bed I got out of—boom—gratitude triggered!”

End Your Day with Gratitude: “Finishing your day with thankfulness can turn bad days into good days. While I’m well aware some days are truly bad, most of these days are only bad because of one difficult interaction or situation. If you do a quick audit of your day, you might notice that things are most often weighted heavily in the positive but our negativity bias latches onto difficulties. If you take stock of the good things in your day and feel thankful for them, it can override stress and negativity.”

Feel It: “There is a vital component for making sure gratitude practices actually work. It’s not enough to think about all you have to be grateful for, you have to also feel grateful for it. When you feel thankful and connect with your body, it triggers neurochemistry that can foster a better mood and override stress hormones so your body is ready to heal.”

giene, and rational health service use. Having self-compassion for ourselves and practising healthy boundary setting are ways we can show up for ourselves while navigating challenges.

In regard to identity and the ambulatory SCI community, Shaw encourages peers to focus on enduring personal qualities like resilience, kindness, or humour rather than limiting yourself to labels or roles. “We unintentionally give our actions and labels, like job titles, the permission to take up a really strong foothold in our identity. But that’s not actually who we are. My definition for identity is, it’s who you are in all situations. The things that are with you no matter what’s going on; your core values, your moral fibre, your personality traits,” he says.

True to form, Shaw’s upcoming schedule is every bit as full as it was on the day he spoke with *The Spin*. He’s a new father, preparing to move from Lake Country to Vancouver Island, and busy building his clinical practice. Alongside his professional work, he continues to be a voice of support for the SCI peer community and offers speaking engagements and workshops to organizations.

Most recently, Shaw’s been involved as an SCI community partner in an upcoming clinical trial led by Dr. Chris West at UBC Okanagan, aimed at improving outcomes for people with cervical spine injuries. This research will explore whether using dobutamine—instead of the more commonly used epinephrine—to increase blood pressure after an SCI could help reduce secondary damage to the spinal cord.

Above all, Shaw remains thankful. “I just want to say thank you to everybody with SCI who shows up each day and keeps putting one, you know, figurative foot in front of the other and keeps moving because it’s hard. I appreciate that.”

You can contact Mike Shaw at mike.s@gratushealth.com or visit gratushealth.com to learn more. ■

TEDxStanleyPark: Grief Happens.

GRATUS
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CIty of Kelowna Rebound Conference.

Too Hot to Handle

Some like it hot—but your body might not! From cooling gear to hydration hacks, peers share their tried-and-true ways to help you stay cool this summer.

Feeling the heat more than usual? You're not alone. After SCI, your body may struggle to sweat or regulate temperature, putting you at risk for serious issues like heat stroke and autonomic dysreflexia. If you're joining one of SCI BC's summer events, don't worry—we'll have water, fans, and cooling supplies on hand. And to help you prepare, we've gathered peer-approved tips to help you stay comfortable and cool all summer long.

Olivia: Always carry some kind of liquid with you. Every morning, I fill my blender bottle and add a Nuun electrolyte tablet. I also like sole water, which is water that's saturated in Himalayan rock salts. You put the rock salt in a jar of water. The water is fully saturated when some salt remains and is not completely dissolved. I usually put about a teaspoon of that in my drink every morning. The salt content helps with my low blood pressure too.

Check out Olivia's video on How to Stay Cool & Hydrated This Summer at youtube.com/@QuadLife101.

Rob: When I play tennis in hot conditions, I put an ice pack between my thighs (having the ice pack near the femoral artery helps to cool the circulating blood). I always make sure to cool down immediately once I get indoors, whether that's with a cold shower or lying down in bed with ice packs.

Peter: A couple years ago, I participated in a research study and tried a cooling device called the RANVOO AICE 3. It's worn around the neck and blows cool air on the blood vessels leading to the brain. I was skeptical, but it is remarkably effective! It also has a heat mode and is nice to use in colder weather.

Jocelyn: (1) Ryobi bucket misting fans are really good, as long as you have an easy way to refill the buckets. But they can be hard to find mid-summer! For people with less hand function who don't sweat and need to spray themselves for evaporative cooling, pressure garden sprayer bottles can be easier to use!

Tyler recommends the (2) POWERFIST 1-1/2 Litre Multi-Purpose Handheld Sprayer (Princess Auto).

Olivia likes the (3) VIVOSUN 0.5Gal Handheld Garden Sprayer with Safety Valve and Adjustable Nozzle (Amazon).

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Peers HAM it Up!

Are you an Amateur Radio Operator and interested in connecting with others who share the same hobby? For the next issue of *The Spin*, we're putting together a list of peers lighting up the airwaves.

Email thespin@sci-bc.ca with your name, call sign, QRZ profile (if you have one), location (QTH), preferred frequencies or bands, and times you're usually active. We'll share the list in the next issue of *The Spin* so you can start making contacts on the air and in the community!

Measuring the Magic of Peer Support

A new tool is being used to plan and evaluate SCI peer support programs to enhance programming for people with SCI in BC and across the country.

Most people involved in the SCI BC Peer Program will tell you that it's special—that it creates a space for 'magic moments' to happen between people with shared experiences of SCI.

The challenge with 'magic moments' is that they're hard to measure. And capturing the magic of these programs in a quantifiable way is needed to show their impact to the funders who make them possible, or at least, affordable.

That's why the SCI Peer Support Community-University Partnership—a group of students, researchers, and community-based organizations, including SCI BC, that aim to better understand, promote, and optimize SCI peer support programs and services—recently developed a new tool to assess the outcomes of peer support programs in SCI organizations.

"The idea behind the tool is that the organizations want to show impact. There's a need for it. And from a research side we also wanted to highlight that impact quantitatively," says Dr. Shane Sweet, the partnership lead and an Associate Professor at McGill University. Sweet is also a Tier 2 Canada Research Chair in Participation, Wellbeing, and Physical Disability.

"In our first partner meeting, one of our partners was like, 'We really want to show the magic of peer support.' So, a running theme throughout our entire partnership was, 'How are we going to measure this magic?'" he says.

The Magic of Peer Support

Peer support programs foster interactions between individuals who share similar lived experiences, such as SCI, with the goal of helping them to adapt and thrive. They most often use a discussion-based approach featuring one-on-one or group gatherings.

While peer support programs are widely available in Canada and are believed to improve overall wellbeing and quality of life for people with SCI, there isn't a lot of high quality-evidence to show that they work—despite the magic we so often hear about through testimonials from peers.

At SCI BC, the Peer Program offers four broad types of services for members that go beyond the traditional one-on-one peer mentorship model.

"SCI BC is unique in that we have the peer meetups, which is your scheduled weekly or monthly meetups, often coffee groups or dinners. Then you have peer connection, which is that one-on-one peer mentorship. Then we have large-scale events, which can be outings like bigger barbeques or kayaking experiences or overnight fishing. And we also have peer coaching, which is more directed towards a specific outcome or goal that you're trying to achieve through peer support," says Dr. Rob Shaw, SCI BC's National Peer Support Program Lead.

"We offer over 300 different events each year. These range from larger scale overnight trips, education panels, and book clubs to smaller, intimate online sessions... So, it's a really big mix, which brings in a lot of people, and it kind of shows the utility of peer support, that it can be used in more than just one way," he adds.

Before coming to SCI BC, Shaw was a volunteer SCI peer mentor with SCI Ontario and completed a Postdoctoral Fellowship with Sweet and UBC Okanagan's Dr. Kathleen Martin Ginis, where he played a central role in developing the new SCI Peer Support Evaluation Tool. He is putting the tool to good use in his role with SCI BC, which involves leading SCI Canada's National Peer Support Working Group, a collective of provincial SCI organizations working together to improve

SCI Peer Support Community-University Partnership.

20 key outcomes for SCI peer support.

the consistency and quality of peer support programming across Canada.

The SCI Peer Support Evaluation Tool

The SCI Peer Support Evaluation Tool came from a need identified by partner organizations, including SCI BC, SCI Alberta, SCI Ontario, and Ability New Brunswick, in the SCI Peer Support Community-University Partnership. What they needed was a tool to help them demonstrate the impact of their peer support programs with the goal of promoting sustained funding and, in turn, improvements to programming.

The first step in developing the tool involved identifying outcomes associated with peer support. “We believed that understanding the outcomes associated with peer support could help take us one step closer to identifying its magic,” says Sweet.

To do this, the team reviewed existing research and interviewed peer support users, identifying 87 different outcomes. They then conducted two Delphi studies, a consensus-based process that allowed them to identify the most important outcomes for SCI peer support, through which they identified 20 key outcomes.

“We went through a Delphi procedure where we had peer mentors, mentees, and staff rate the 87 [outcomes] based on specific criteria… then we did another Delphi with the national directors and peer support managers,” explains Sweet. “So, it was all through consultation and consensus methodologies… peer mentees, mentors, and organizations are the ones that voted to identify which outcomes were most important for this context.”

The next step involved finding existing measurement tools to assess each of these outcomes. Similar to the process for identifying key outcomes, the team reviewed existing research and went through a consensus-based process with researchers and community partners to identify measurement items that best represented the 20 outcomes.

At the end of this process, the team had identified 20 items, one to assess each outcome—ensuring that the tool could be completed quickly and easily by program users. Each item began with a neutral statement, followed by a five-option rating scale. For example, to assess the ‘community engagement’ outcome, the item reads: Thinking about my experience with [the peer support program], I participate in programs, activities, or events in the community: (1) much less often, (2) less often, (3) as often, (4) more often, or (5) much more often.

TOP: Dr. Shane Sweet
BOTTOM: Dr. Rob Shaw, SCI BC’s National Peer Support Program Lead

The final step involved gathering feedback on the tool from leaders and peer support program coordinators at provincial community-based SCI organizations, then asking peer support users to complete the tool while providing live feedback to a researcher in what’s known as a ‘think aloud’ method.

“The think aloud process asked an individual to speak out loud and to have all the thoughts that are running through their head while they’re answering that question. And so, through that process, you’re able to gauge how clearly the question is being understood,” explains Shaw.

Then, 10 days later, the participants completed the tool again on their own. Overall, participants found the items easy to understand and relevant to their peer support experiences, and the two tests generally produced the same results for

National Peer Support Working Group in May 2024.

each participant, highlighting the overall rigour and consistency of the tool.

Measuring the Magic

The tool offers several benefits to both program providers and program users, like those of you involved in the SCI BC Peer Program. For example, organizations like SCI BC can use the tool to identify the strongest and weakest parts of SCI peer support programs, providing a guide for how to improve program delivery. It can also be used to show the impact of programming to funders, which could bring in more funding to support programming.

"This tool has the potential to provide a lot of really strong evidence of the benefits and impact of peer support, which then could strengthen grants, which then could bring in more money, which would allow for more programming or higher quality programming," Shaw says.

The tool is also customizable, meaning that individual outcomes and items can be selected to best match the goals of a specific program.

"It's an extremely practical tool in the sense that we can't state how organizations will use it because it'll be up to them," explains Shaw. "Some might choose to administer it online. Some might choose to do it over the phone. Some might choose to have all 20 items included in their outcome tool. Some might only choose to have three or four. So that's kind of the really neat thing about this tool is it can be customized to the exact needs of each organization."

Taking the time to reflect on how the elements of a peer support program target specific outcomes is important for organizations to identify which outcomes they should measure. This process can provide organizations with more valuable information on whether their peer support program is impacting the outcomes they are trying to achieve.

Another key benefit is that the tool can be administered quickly and easily to program participants. According to Shaw, it takes about 15 to 25 minutes for a participant to complete the 20-item tool.

"We tried to keep it pretty brief with the 20 items… but it could be as short as three or four questions, which would obviously take much shorter," he says.

Putting the Tool into Practice

Shaw presented the tool to the National Peer Support Working Group in May 2024 and the response so far has been extremely positive, he says. While some organizations have been able to start using the tool to evaluate their programs right away, others are using the tool to support program planning and design.

"Some organizations don't have a peer program, but they're using the tool to then decide what might be core components of the peer program. So, it's used not only as an evaluation, but also as a planning tool," explains Sweet.

As a planning tool, organizations could figure out the outcomes that are important for their organization and then design the elements of the peer support program to target those outcomes.

"There's also a nice spot in the middle where you can use [the tool] to revamp your program. Learn what you did wrong. Learn why it didn't impact what you wanted it to. Revise what you're doing and try it again. And so, through that process, I think you'll have programming and services that are a little more highly tuned if you want it to be that way," adds Shaw.

According to Shaw, SCI BC is currently reviewing the tool to determine which outcomes are most applicable to its Peer Program, which involves identifying how the tool will be applied to each of the different types of programming.

As a next step, the working group has discussed how this tool can be used collectively to benefit all organizations. Through a series of consensus-based surveys and in-person meetings, the working group decided on three 'core' outcomes from the tool that every organization will evaluate (community engagement, quality of life, and reduced isolation). Having consistent, nation-wide data is intended to support joint efforts to secure funding for peer support programs across the country.

"It's harder to get grant money in the smaller provinces… so if we can get some more consistency with how we're evaluating these programs across the country, then maybe there is the opportunity to join together and apply for federal level funding that can then be dispersed out to some of those provinces that face more challenges than others," says Shaw. "So, it's not necessarily all about funding, but I think for the smaller organizations, there's a really big opportunity there to have that pooled data."

A Final Word for Our Peers

Of course, the success of the tool depends on how well participants of peer support programs are engaging with it. "The outcome tool is only going to be important and impactful if we have people using it and filling it out," says Shaw. "A fear of all of us in the working group is, 'How are we going to get people to fill out this survey?' If we want to sustain the programming and improve on it, then we need people to engage in the evaluation of it."

McGill

Spinal Cord Injury (SCI) Peer Support Evaluation Toolkit

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sci-can.ca

So, for our readers out there who are current or future members of the SCI BC Peer Program (maybe you're planning to join the program now that you've heard all about the magic it offers) please consider answering a few questions from us about your program experience if they ever come your way. We're asking because we value your feedback, we want to understand your experience, and ultimately, we want to make the program better for you.

To learn more about the SCI BC Peer Program, check out sci-bc.ca/peer-program. For more information on the SCI Peer Support Community-University Partnership and the SCI Peer Evaluation Tool, visit mcgill.ca/scipm. ■

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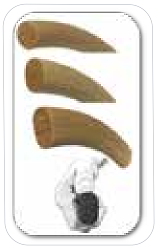

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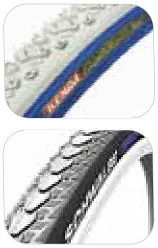

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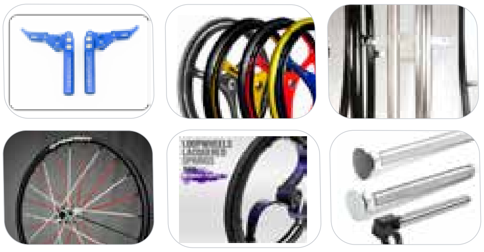

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Fighting Fatigue

Living with SCI can be exhausting—literally. Chronic fatigue affects up to half of people with SCI, and a new study reveals which treatments actually help, and why we still need better answers.

Most of us know what it feels like to be tired after a long day. But what if no amount of rest made a difference? For up to half of people with spinal cord injury (SCI), fatigue is a deep, persistent heaviness that rest doesn't fix.

Maybe you can only manage one or two activities before you need to lie down again. Maybe everyday things—cleaning, working, socializing—take twice as long and leave you completely depleted. You might feel low, but instead of bouncing back with connection or movement, fatigue keeps you isolated, and guilt creeps in. You might find yourself using your mobility aids or power chair more than you'd like because walking or wheeling becomes exhausting. And caffeine? It doesn't touch it.

This type of fatigue, referred to as central chronic fatigue, is more than just feeling sleepy. It's a full-body exhaustion that can isolate you and sap your quality of life.

While some research exists, strong evidence on effective fatigue treatments after SCI is limited. So Dr. Janice Eng, Professor and Canada Research Chair at the University of British Columbia, Co-Director of the Centre for Aging SMART at Vancouver Coastal Health, and Co-Principal Investigator of the SCIRE (Spinal Cord Injury Research Evidence) Project, plus Dr. Carlos Cano-Herrera, Postdoctoral Fellow, took a closer look.

With support from the Praxis Spinal Cord Institute, ICORD, and the Rick Hansen Foundation, they investigated the best available research on fatigue treatments in people with SCI. Their goal: find out what really works. Their paper "Treatments of fatigue after spinal cord injury: a systematic review and meta-analysis" was published in the journal *Spinal Cord* in March 2025.

Why Fatigue is So Tough to Treat

Eng and Cano-Herrera's approach to the study was to review research published on treatment for fatigue in people with SCI and analyze the methods and findings. To keep the evidence strong, they only included randomized controlled trials (RCTs), the gold standard in clinical research, in their review process. Fatigue after SCI involves both physical and psychological factors, and Eng explains that with so many variables, the placebo effect (where participants in control groups show improvement despite no active treatment) can be significant. Using only RCTs, where participants are randomly assigned to treatment or control groups, helps reduce this effect and strengthen the findings.

With these strict criteria, they found just six high-quality RCTs. "We were surprised," says Cano-Herrera. "Just six studies is low compared to other topics where we have many higher quality studies."

Measuring fatigue itself is another challenge. "Some papers measure fatigue in different ways," says Cano-Herrera. The most commonly used tool was the Fatigue Severity Scale, a set of nine questions that assess how severe fatigue is and how much it affects daily life. However, only half of the studies looked at fatigue as the main outcome; the other half looked at factors like pain or fitness and only measured fatigue as a side note. As Eng explains, "One of the problems if the primary purpose of the paper is not fatigue and they measure fatigue as one of their 10 or 20 measures, is that this study is not really powered to have enough people to detect fatigue. The reason fatigue is not shown to be significant is they simply didn't design it for fatigue."

Fatigue rarely shows up alone. It's tied to pain, sleep quality, medication side effects, depression, anxiety, and more. For example, one study found people with high pain were nine times more likely to experience elevated fatigue. Everyone who reported depressive mood also had fatigue, while none of the participants with low fatigue reported depressive symptoms. While many studies measured pain and mental health symptoms, none examined sleep or medication issues—two major contributors to fatigue. That's surprising given previous research shows sleep-disordered breathing is common in people with SCI, especially with higher-level injuries, and


Dr. Janice Eng


Dr. Carlos Cano-Herrera

20 Years of SCIRE Community

SPINAL CORD INJURY RESEARCH EVIDENCE

When the SCIRE (Spinal Cord Injury Research Evidence) Project launched 20 years ago, it started as a bold idea: What if we could bring SCI research together into one accessible, evidence-based resource?

"At the time, I was the Associate Director of Rehabilitation for the ICORD Research Center. John Steeves had asked each of the three Associate Directors to come up with a small project," recalls Dr. Janice Eng. And so, the SCIRE Project was born.

Some warned that sharing systematic reviews online would prevent journal publication. But the opposite happened: journal editors asked her to submit SCIRE's work. "One of my complaints was that we publish all this information in journals and it's not accessible to clinicians or people with lived experience. Having it public provides a sense of transparency of what research is actually doing and what it is actually telling us."

Dr. Andrea Townson once carried printed spiral-bound copies and CDs of the first SCIRE edition to conferences. "Seeing it grow into the go-to online reference for clinicians and health professionals with ongoing updates has been a wonderful evolution," she shared in SCIRE's Spring 2025 newsletter.

Over two decades, that idea has grown into a global standard and an international collaboration between scientists, clinicians, and consumers. Co-led by Eng and Dr. Robert Teasell, she shares, "We have a quarter million people who come to the website each year and that continues to grow. SCIRE provides a credible source of evidence to support clinicians in their practice and for people with lived experience to see the evidence behind, what we hope is, a comprehensive selection of treatments."

The SCIRE Professional site, created for health professionals, now includes 100+ publications. Its most-used content includes outcome measures and treatment options—practical resources that can be immediately applied in clinical practice. Eng notes they aim to offer clear, specific information, like recommended frequencies for electrical stimulation, which are often hard to find in journals.

In 2017, SCIRE expanded with the launch of SCIRE Community, a companion site for people with lived experience, their families, and caregivers. It now features 60+ articles on topics like Botox for spasticity, osteoporosis, stem cells, autonomic dysreflexia, and more. "Neuromodulation has been a topic we've recently addressed because there's so many new sensory or motor stimulation devices that people are wondering about," says Eng. "We try to be responsive to what people in the community tell us can help make the website more of a one stop shopping for them."

At SCI BC, we consider SCIRE one of our most trusted sources of up-to-date SCI research and encourage peers and professionals alike to explore what it offers.

Visit SCIRE Professional at scireproject.com and SCIRE Community at community.scireproject.com.

medications often prescribed after SCI, like baclofen, gabapentin, and amitriptyline, are known to cause fatigue.

Overall, Cano-Herrera says, "[We need] higher level of quality studies like RCTs, focusing on fatigue. For people with SCI who want to deal with fatigue, we need more recommendations and more guidance about the interventions that improve fatigue and the dosage required."

So, What Works?

The interventions studied fell into three categories: massage therapy, exercise-based interventions, and behavioural interventions. While massage therapy (including Swedish massage, broad compression massage, and reflexology massage) didn't improve fatigue, exercise-based and behavioural interventions showed promise.

Exercise treatments significantly improved fatigue for participants. This echoes evidence in multiple sclerosis and the able-bodied population, where exercise is a leading recommendation for managing chronic fatigue. The studies included in the review were an upper limb virtual reality exercise program (45 minutes, three times per week for six weeks) and a moderate-intensity arm-crank home exercise program (50 minutes, four times per week for six weeks). However, there isn't enough evidence yet to say which types or amounts of exercise are most effective in reducing fatigue in people with SCI.

"Sometimes if you have fatigue, you don't think that exercise is going to help you. You think that if I'm doing exercise, I will be more fatigued," says Cano-Herrera. But Eng emphasizes the long game: "You might feel a bit more tired at the front end, and that's normal and natural. It's about building up some endurance, so you can overcome that."

Behavioural interventions focused on promoting active lifestyles also led to meaningful improvements. One intervention involved self-management education through a book and 10 group and individual sessions over four months. Another used Motivational Interviewing over eight months with 13, one hour in person meetings.

"Having a coach, motivator, or yourself understanding the pacing and self-management aspects of physical activity are really important," says Eng. "You can figure out 'Okay, I'm going to schedule this in and see what parts of the day I'm really tired. Maybe I shouldn't be exercising at that part of the day. Maybe I should be exercising at this part of the day and how much and what quantity?' Those are aspects of self-management that I think are really helpful for a person to become attuned to."

And what about medication? Eng explains, "There are some medications that are used in other conditions with fatigue. For example, modafinil is used for post-stroke fatigue. However, in stroke there's a much larger population, so it's easier to do RCTs. There hasn't been any RCTs [in the SCI population], so the evidence isn't there yet."

One Size Doesn't Fit All

Both researchers agree that fatigue management calls for an early and individualized approach. Eng says, "It's important to look at the fatigue early before it becomes all-encompassing… Hopefully some of [the factors] could be preventative and reduce fatigue before it gets to such a level that someone can't cope with it."

Ideally, fatigue management would involve a multidisciplinary team. A physiatrist or general practitioner would start by reviewing your full health picture, ordering lab testing to rule out other conditions, and, "check[ing] for factors that we know are related," says Cano-Herrera. "Ask about the medication they are taking, ask about psychological symptoms like depression or anxiety, ask about sleep problems."

From there, treatment could involve education and practicing self-management skills like pacing (perhaps with help from a coach), adjusting medications that cause fatigue, managing pain, improving sleep hygiene, and starting a structured exercise program. "Physical therapists or other professionals prescribing exercise need to be aware of a person's fatigue status," notes the review. Exercise should be moderate, introduced slowly, and revisited regularly with follow-up.

And when it comes to mental health, the link with fatigue is clear. "That's one of the reasons to look at fatigue earlier than later," Eng says. "There can be really serious [mental health] symptoms that can develop if fatigue is not addressed." Treatments like cognitive-behavioural therapy (CBT) or selective serotonin reuptake inhibitors (SSRIs) may help ease fatigue associated with mental health symptoms. Interestingly, both CBT and self-management approaches focus on building self-efficacy. By helping you feel more capable and in control, they may empower you to regain energy and resilience and take back the reins from fatigue.

The bottom line is that fatigue after SCI is common and complicated. But it's not hopeless. Understanding fatigue and knowing there are steps you can take can help you take back some control.

Looking for the full research evidence on fatigue and SCI? Visit scireproject.com/evidence/fatigue-following-sci. ■

The Coach Approach

Peer support isn't new, but what if it could do more? Combining lived experience and research-backed training and tools, peer health coaching helps people with SCI live better. And this is your chance to get involved.

Peer support is powerful, but peer health coaching takes it to the next level. It's a practical, evidence-based program built around real conversations where lived experience meets professional training. Let us tell you how it began and where it's headed.

The Coaching Evolution

More than two decades ago, John Shepherd's life changed in an instant. He hit black ice while driving home to Montreal from business school. At the time, he was planning a post-graduate move to London for a career in investment banking. Instead, he found himself adjusting to life with an SCI.

Shepherd says, "This was the most challenging single time in my life. I was more undermined in my ability to use my own resources to deal with stuff. You need more capacity than you've ever needed before, and you have less than you've ever had. It's a really tough situation to be in and you're undergoing this intense transformation."

Eventually, Shepherd returned to business school and took a healthcare operations course that sparked his curiosity about SCI from an academic perspective. He began working with the Ontario Neurotrauma Foundation, focusing on the development of an online SCI education platform. He also served on several boards and committees but found himself wanting more than just volunteer opportunities.

John Shepherd

Determined to make a lasting impact, Shepherd pursued a PhD at the University of Toronto, blending personal experience with research. For him, studying SCI isn't just a career—it's a way to reframe and explore a life that is often misunderstood. "Living with SCI is typically conceived of as a frightening thing," Shepherd says. "Without negating the truth of any other perspectives, I am focused on how it's a fascinating experience to have and to look into. Perhaps all the more fascinating because it is so rarely looked into precisely because of the fears and anxiety around it."

The SCI&U Peer Health Coaching Program he now helps lead is the result of years of collaboration. Its earliest form came from Sarah Skeels at Tufts University in Massachusetts, who created a telephone-based peer coaching model called My Care, My Call. Skeels worked closely with the BC-based Center for Collaboration, Motivation, and Innovation (CCMI).

Around the same time, Shepherd and his supervisor, Dr. Susan Jaglal, were developing a similar project. They launched a Canadian pilot of SCI&U, adapting My Care, My Call into a video-based peer coaching model.

Barry Arana, now SCI&U Research Coordinator and Peer Health Coach with SCI BC, was there from the start: "I've been part of the SCI&U Peer Health Coaching study from the very beginning and [have] seen how it's evolved over the years. We started off with just 10 participants in the first stage of the study."

After the successful pilot, the team expanded SCI&U into a larger, 60 person randomized controlled trial, in partnership with SCI BC. A smaller, parallel trial also took place in the U.S. Over six months, participants showed improvements in health self-management. The gains were especially strong among those who had strong social support, were between one and six years post-injury, identified as white, were male, or had tetraplegia. The program also boosted life satisfaction, awareness of services, and overall service use.

Today, a new version of the SCI&U study is underway, this time focusing on people who are newly injured—within the first two years post-injury. The goal is to see how early support might make a bigger impact.

Teri Thorson, SCI BC's Manager of Peer Coaching and Outreach, was also part of the initial SCI&U study. "With research, when the funding ends, it ends," explains Thorson. "I felt passionate about this project, so

SCI BC's Peer Health Coaching team. LEFT: Teri Thorson, Manager of Peer Coaching and Outreach. ABOVE, LEFT TO RIGHT: Peer Health Coaches, Olivia Rey, Barry Arana, and Mary-Jo Fetterly.

thankfully, [SCI BC's Executive Director] Chris McBride saw the benefit of the coaching studies. Physios at G.F. Strong also felt that it was of value to peers." SCI BC's Peer Health Coaching Program was developed and is now open to anyone in BC with an SCI or related disability, regardless of your age, location, mobility, or time since injury.

You may have read about it in the Goal Getters article in the Spring 2024 issue of *The Spin*. Here's a closer look at how peer health coaching works and why peers find it so helpful.

Self-Management

The peer coaching model is simple, but powerful. Trained Coaches living with SCI meet with peers by video or phone regularly. Coaches help peers set meaningful goals, develop self-management skills, build confidence, and access resources needed to live well with SCI.

In healthcare, self-management refers to a person's ability and willingness to take on the daily management of their health care. That includes managing symptoms and treatment, maintaining routines and roles, coping with emotional challenges, and navigating the healthcare system.

For Shepherd, self-management is a useful term because it's a recognized concept in healthcare. Using familiar language helps researchers open doors and move new ideas forward. But he sees Peer Health Coaching as much more than self-management: "The full scope of what we're doing is helping people learn how to live with an SCI and that's important and underrecognized."

He points out that before World War II, people with SCI rarely survived long-term, let alone thrived. Since then, rehab systems have emerged, but they often fall short. He explains, "These experts, almost without exception, are people who don't actually live with SCI. They're teaching something that, in a certain sense, they not only do not, but cannot, know." And with rehab stays shorter than ever, often just several weeks, there's little time to absorb the kind of lived, practical knowledge that can't be found in books.

Programs like SCI&U formalize what peers have long done informally: sharing insights, tips, and encouragement that only someone who's been there can offer. It picks up where rehab leaves off and, in many ways, fills in what rehab can't provide.

Arana agrees, "As someone living with SCI, 14 years post-injury now, learning self-management skills is crucial and important to my livelihood and quality of life. Learning ways to better take care of yourself and building on your self-management skills can prevent hospitalizations, pressure sores, fractures, and UTIs. Honestly, the last thing I need as someone in a chair is other complications. I've learned so many things over the years, because I participated in research studies and attended events through SCI BC, ICORD, and the Blusson Clinic. That's how I learned that you could treat neurogenic bladder with Botox. That really improved my life. It was huge to have another tool to better self-manage."

More Than a Peer

"Lived experience is the raw material energy that powers the Coaching program," says Shepherd. "What makes it really distinctive is the way that it's refined through the training, the specificity of the role, and the way that the Coaches become experts in wearing different hats."

In an early My Care, My Call study, Skeel and her team analyzed transcripts from over 500 coaching calls. They identified three roles Coaches take on: Supporter (building trust and confidence), Role Model (sharing lived experiences), and Advisor (teaching, strategizing, and action planning).

While Supporter and Role Model roles are common in peer mentorship, the Advisor role is unique to Peer Health Coaching. And the way Coaches shift between roles is critical. Early on, Coaches lean into Role Model mode to build trust. As participants grow more confident and ready to take action, they move into the Advisor role. The Supporter role remains constant throughout, helping participants build self-efficacy.

Coaches are well prepared for this. As Shepherd explains, "They're extensively trained in a specific set of skills around Motivational Interviewing, Brief Action Planning, Mental Health First Aid, and the use of various tools in our coaching program."

In addition to these 90 hours of training, Coaches role-play coaching scenarios and meet weekly to debrief. Shepherd likens this process to the clinical supervision used by mental health professionals.

"We're intentional about making sure that the team is plugged into each other, well-resourced, and that we're continuing the journey together," says Shepherd. "We created an environment where [Coaches] feel their experience is not just valued but really forms the norm in terms of expectations and understandings."

The current SCI&U program includes an online platform covering various health topics. Coaches use it to help participants find reliable information and learn practical healthcare skills, like preparing for appointments and talking with providers. The team updates the platform regularly.

"[The coaching platform] supports the interaction between coach and participant in ways that nourish and enrich that interaction. But ultimately the interaction is what matters," says Shepherd. The goal is to eventually make the platform open source for use beyond SCI&U, including other peer programs.

The Right Ingredients

Peer coaching turns support into progress. It works because Coaches bring both understanding and structure, helping peers move from "stuck" to "started."

While many participants focus on weight management, physical activity, or nutrition, goals can be anything. Thorson says, "It doesn't have to be necessarily about health. Maybe it's booking an appointment, as simple as that. It doesn't have to be a big goal like losing 30 pounds. It can be a really small goal, and you can learn a lot about yourself by talking to someone who has expertise in Motivational Interviewing skills."

If you don't have a goal in mind, your Coach can help you figure out where to start. Arana says, "I consider it a win that they show up every single time to our coaching session. The fact I'm able to create a safe space for them to open up and share what they're struggling with or want to focus on. The first step is saying 'I want to work on this.'"

Coaching conversations are grounded in Motivational Interviewing, a communication style that helps people uncover their own reasons for change. Coaches use techniques like reflective listening, open-ended questions, and exploring personal values to guide the conversation.

Once someone's ready to act, Coaches use Brief Action Planning (BAP) to break things down into actionable, manageable steps. BAP draws on tools like SMART Goals and structured problem-solving, but its real value lies in helping people feel capable. Shepherd explains, "You frame a problem as something that you have a tool to address, rather than as something that could potentially destroy your day or your life. That shift is, psychologically, incredibly important and empowering." Coaches use the tools to offer structure, support, and accountability at the exact moment someone is ready to take a step forward.

Bryan's Coaching Experience

For Bryan Anderson, peer coaching came at a pivotal time. "Life for me has changed a lot in the last couple years," he says. A father of two teenagers and former heli-ski guide, Anderson sustained an SCI while body surfing on a remote island off the coast of Nicaragua. "I hit my head on the shallow sandbar and broke my neck. It was a bit of a show getting me home." After major spinal surgery in Nicaragua, he spent months in ICU and rehab before returning home to Golden that fall.

The first winter was especially hard. "I was struggling hard with all the secondary complications. Back-to-back pressure sores and bladder infections and in and out of the hospital." Living in a small town without much of an SCI community, Anderson felt isolated. "I'm one of two in a wheelchair, besides the elderly… trying to get outside in the snow, I struggled pretty hard."

That's when SCI BC's Peer Health Coaching Program came in. Anderson says, "It really helped me with my confidence and coping." His coach, Mary-Jo Fetterly brought lived experience and a background in yoga and massage therapy. "Mary-Jo was quite an incredible person to get connected with. We've been friends ever since."

For Anderson, the biggest shift was internal. "Pre-coaching I was feeling

Bryan Anderson and his children, Edward and Amaya.

useless, like a burden, and not feeling like I have anything to give back. I still get days where I feel like that for sure. Then I picture Mary-Jo in my mind, talking me through it, saying, 'Just breathe. You're loved. Take control of those feelings and use that.' She helped me more than anybody navigating through that crazy head space."

Anxiety became a regular challenge. "Since I broke my neck, I've had anxiety a lot and over the stupidest little things." Coaching gave Anderson the tools he needed. "If you asked me about yoga a couple years ago, there's no freaking way I would have sat down and made time. I come out of coaching more relaxed."

Fetterly's support helped both Anderson and his wife, Amie. "She was super helpful for my wife too. Really helped with both our headspaces and giving me tools and tricks to deal with the anxiety and my health."

One of the most valuable aspects of coaching, for Anderson, is how personalized and responsive it is. "My health bounced back and forth week to week. But Mary-Jo could see I was frustrated and then would focus on that. It seemed to me, she would start a session with something in mind, but she would maneuver the session according to how she picked up on how I was feeling and my current frustrations."

Coaching also helped Anderson rethink his habits. "Before my accident, I just ate whatever, whenever, I was very active. Now I eat food that I never would have eaten before." He adds with a laugh, "I was a little heavy when I broke my neck, not because of eating so much, [but more so] my love for beer. Mary-Jo helped me safely lose a bunch of weight, which has made everything easier." He also believes coaching has helped reduce the frequency of bladder infections.

Anderson adds, "You can tell when [your Coach] is talking, they have your interest 100%. They don't drift. You can tell they're not doing it for a job. They're doing it to help people and that comes through right away. You can't miss it." Although Anderson's coaching sessions have ended, he and Fetterly always catch up when he comes to Vancouver.

Why This Research Matters

Anderson's experience shows how powerful peer health coaching can be, especially in the early days of adjusting to life with an SCI. But proving that impact through research isn't easy.

Shepherd explains, "It's tricky. Getting a new intervention and getting it taken up in practice is very difficult. All the more so when there are aspects of what you're doing that cut against the culture of healthcare." Peer-led coaching challenges the traditional divide between patients and providers, something many healthcare systems are resistant to change. And, while healthcare professionals have established authority and funding within the system, peer Coaches face a steeper climb, requiring more research, evidence, and effort to get programs like SCI&U funded and scaled up.

It's also hard to measure. SCI has no single biomarker or universal metric for living well. Questionnaires like the Patient Activation Measure can help show improvements in self-management over time. But as we've seen, coaching is far more than self-management. It can prevent complications, reduce healthcare use, and build confidence, connection, mental well-being, and more! These benefits are harder to quantify and often overlooked by funders and policymakers.

That's exactly why research like SCI&U matters. There's no single number that captures the full impact. But by taking part in studies like SCI&U, participants help show the value of peer coaching and bring it closer to becoming standard practice.

Get Involved

We already know peer health coaching can be a lifeline. Research helps make it a reality for more people.

The SCI&U Peer Coaching Program is currently recruiting newly injured SCI peers (within two years post-injury) for a randomized controlled trial (RCT). If you're interested or have questions, contact Barry Arana at barana@sci-bc.ca. If you're not eligible for this trial, he will connect you with SCI BC's Peer Health Coaching Program, which is open to anyone with a disability (sci-bc.ca/coaching).

After screening, you'll review the consent form and take part in a brief (about 10 minutes) interview about your health and goals, followed by a set of questionnaires. These questionnaires will be repeated at six months and one year to track any changes.

Because this is an RCT, participants are randomly assigned either to the coaching group or the control group. After six months, those in the control group will also have the opportunity to receive coaching. All participants receive a gift card honourarium.

Once matched with a Coach, you'll meet via video or phone every one to two weeks for 8-14 sessions scheduled at times that suit you. Each session lasts approximately 45-50 minutes.

Ultimately, Anderson credits peer health coaching with providing the tools he needed to manage his SCI and rebuild his self-worth. "I keep reverting back to those coaching tips and techniques… Things I never thought about before, I'm now using and thinking about." Peer health coaching fills important gaps by combining evidence-based practice with peer connection, reminding us that healing is often a shared journey, and no one faces SCI alone. ■

SCI&U
FOR HEALTHY LIVING

Participate in Research

SCI research is about much more than test tubes, stem cells, and a far-off cure.

At ICORD (International Collaboration On Repair Discoveries), SCI research is also about improving bladder, bowel, and cardiovascular health; taming pain and autonomic dysreflexia; enhancing sexual health and fertility; new assistive technologies; wheelchair design and ergonomics; and much more. In other words, it's about maximizing recovery, independence, health, and quality of life. But it doesn't happen without you. That's why SCI BC and ICORD are partnering to help raise awareness and increase participation in world-leading research. Working together, we can make SCI research more meaningful and move it along at a faster pace, and we invite you to be a part of it.

Recreational Adaptive Devices (RAD) Study

Overview: ICORD researchers Dr. Ben Mortenson and Dr. William Miller have partnered with RAD Society to encourage outdoor recreational activity for individuals with mobility impairments. Together they have opened an adaptive device loan program in the City of Langford, BC and are interested in hearing people's experience using the program.

What to expect: Participation includes a pre-program interview, use of the adaptive device loan program, and a post-program interview. The two interviews will take 90 minutes in total, and an honorarium is available for your time.

Who can participate: You may be eligible to participate in this study if you are age 19 or older; have a mobility impairment; are available to attend in person the adaptive loan program located in Langford, BC; are able to transfer in and out of equipment with or without assistance (please note: the program cannot assist with transfers); communicate in English; have a device that can access the Internet for the pre-program and post-program interview.

Why participate: This is a unique and exciting opportunity to use and provide feedback on a new, innovative program that shares adaptive devices to encourage outdoor recreational activity for all. Participant feedback will help refine the program and support opening additional locations across BC. An honorarium is available. This can be through e-transfer or a gift card of the participants choice (Amazon, VISA, Tim Hortons).

Location: Langford, BC and remotely (online survey/phone/video call)

For more information or to sign up: Please contact study coordinator Aditya Dhariwal by email at (rehab.research@ubc.ca) or phone at (604) 734-1313 ext: 6292.

Vestibular Experience Study

Overview: When we move around our environments, our body uses special organs in our head/ears (the vestibular system) to monitor our movement and maintain balance. After an SCI, the vestibular system often has to adapt to new movement patterns and works hard to maintain balance in people who walk or wheel. Researchers Dr. Tania Lam and Dr. Jean-Sébastien Blouin want to understand more about how the vestibular system adapts to SCI and the new types of movement patterns that the vestibular system needs to interpret.

What to expect: This study involves two visits to our laboratory at ICORD. The first visit takes approximately 1 hour, and the second visit takes approximately 2 hours. Participants will be asked to wear small movement-detecting sensors while they complete various everyday movement tasks. The sensors will be placed your feet, hands, chest, and on a special mouthguard that is custom-fit to your upper teeth. Researchers will combine the data collected from these sensors with a 3D scan of your head to explore the different movement signals that the vestibular system has to interpret in people with SCI.

Who can participate: You may be eligible to participate in this study if you are 19 years of age or older, have a chronic SCI that has caused motor (movement) impairment, can speak and understand English.

Why participate: The vestibular system is important for balance and researchers have started to develop therapies to target the vestibular system to improve balance and other health outcomes in people with SCI. The results from this study will help us better understand the different movement signals the vestibular system has to interpret after SCI, so clinicians and researchers may design better therapies that target the vestibular system. Participants will receive an honorarium.

Location: Blusson Spinal Cord Centre in Vancouver

For more information or to sign up: please contact study coordinator Alison Williams by email (awilliams@icord.org) or at (604) 675-8815.

Learn more about what makes ICORD one of the biggest and best SCI research centres in the world, and the research they are doing, by visiting **icord.org/research/participate-in-a-study.**

last word

Red and White, But Not Blue?

What the Buy Canadian movement means for people with disabilities and made-in-Canada gems you might not know about.

You've seen the stickers and signs. A little red maple leaf on grocery store shelves. Shoppers scanning labels like detectives. Buy Canadian has become a kind of national call-to-action in response to American tariffs and comments about Canada being a "51st state."

But what does that mean if you live with a disability? For the SCI community, the conversation around buying Canadian hits differently, because so much of our everyday lives depends on equipment, supplies, and tech. And right now, some of us are thinking hard about where those things come from.

Let's be honest: buying Canadian isn't always easy. "Made in Canada" means at least 51% of the production cost is domestic. "Product of Canada"? That bumps up to 98%. Some companies are Canadian owned and operated but sell a mix of imported and local goods. Even knowing what you're supporting can be tricky.

Then there's the reality of cost. Many people with SCI and related disabilities are living on fixed incomes or stretching benefits to cover rent, groceries, caregiving, equipment, and medical supplies. The higher price of many Canadian-made goods may reflect quality or ethical production, but it's not always within reach.

Plus, many of the products we rely on just aren't made here. When you live with SCI, it can take months or years of trial and error to find what works for you. We love celebrating with peers when they finally find the right catheter to reduce UTIs or adaptive clothing that doesn't cause pressure sores! But the right product might be imported, expensive, or not covered by funding.

Access is another barrier. Inaccessible storefronts, limited transportation options, and long or unreliable shipping times, can make the feel-good push to buy Canadian start to feel pretty far away.

The point is: it's not all or nothing. You don't need to buy 100% Canadian to make a difference. You also don't owe anyone an explanation for choosing the cheaper catheter or the imported chair that actually works for your body, even if it ships from the U.S.

With that in mind, we've gathered a list of disability-related products made in Canada or sold by Canadian-owned companies (some are owned by SCI BC members). It's not a complete list, but it's a start.

Find the list with links and details at **sci-bc.ca/red-and-white**. We want to hear from you: Have a favourite Canadian-made disability product or business? Tell us! Email info@sci-bc.ca and we'll keep growing the list.

Supporting local shouldn't be about guilt, it should be about choice. And when you want to choose Canadian, it helps to know what's available. ■

The Buy Canadian movement at Save-On-Foods.

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> *I have been ordering my colostomy supplies, catheters, and leg bags through Chair Stuff since 2001.* ***My stuff is always on time and that's pretty great considering I live 900 kms away!***
>
> **— Crystle**

> *I switched over to Chair Stuff from one of the bigger companies, which was more expensive.* ***I like dealing with Steve because he's a dude in a chair who's got his own business. Anytime I need supplies, they're delivered to my door.***
>
> **— Kevin**

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