

the spin

SPINAL CORD INJURY BC

SPRING 2016

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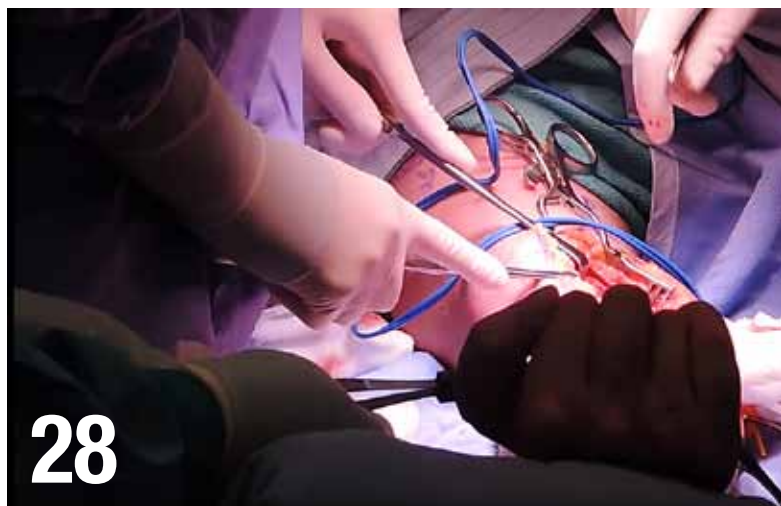
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Cover Photo: SCI BC Peer Jocelyn Maffin and her husband Tod. Photo credit: Sylvia McFadden.



Vitamins & a Flat Earth

Growing up, I hated taking vitamins. That is, until my mom started buying fun-shaped, chewable, sweet ones for kids (now marketed to adults) because it was kind of like having candy first thing in the morning.

I'd love to know how much my parents spent on vitamins over the years. I'm not sure I want to know how much my wife and I have spent on vitamins for the McBride household. Like many other Canadians, we believed that taking vitamin supplements was essential for maximizing our health.

The trouble is, there is no real science to support this. In fact, there's a growing body of evidence indicating that for most of us, vitamin supplements provide no health benefit. And they aren't cheap. To be clear, none of us McBrides has a medical condition that requires us to supplement our diets with vitamins, so all that money my family has spent on vitamins has literally gone down the toilet.

Many readers will be familiar with my criticism of unproven stem cell therapies and the unscrupulous clinics that are prying money out of people with SCI for what can only be considered false hope. To profit on the false hope of unproven "treatments" is wrong. So is profiting off "treatments" that provide false or unproven claims as to their benefit, or that don't work any better than a placebo.

The debate about such stem cell treatments receives well-deserved attention. But what about so many other health "interventions" such as vitamins that we spend our precious money on without enough contemplation?

Of course, not everything has to be definitively proven by science to be of benefit. SCI BC Peers have successfully tried a lot of things that science has yet to confirm—take medicinal marijuana for pain as an example. But have you really asked yourself whether you should continue to spend money on something as dogmatically promoted, and yet unproven, as vitamin supplements? And what about other alternative therapies for which marketing claims are not backed by evidence demonstrating they work beyond the magical trickery of the placebo effect? In a recent column in *Policy Options* magazine, Tim Caulfield, Canada Research Chair in Health Law and Policy at the University of Alberta, compares those who continue to believe the Earth is flat (yes, they are out there) to those who believe in un- and disproven therapies that are propped up by pseudoscientific rhetoric and popular belief. He uses Reiki, homeopathy, and store-bought cleansing and detoxification therapies as examples.

Proponents (likely to include some readers of *The Spin*) of such treatments will counter that those of us rooted in the western medical approach do not have an open enough mind to understand how they work, that they require one to believe that they work, and that, even if it is a placebo effect, it works. But is it ethical to charge money for something that hasn't been shown to work or, if it does anything at all, only does so because we want to believe it does so?

Can one be critical of unproven stem cell therapies but not unproven alternative therapies? We must apply the same critical thinking and analysis to all unproven and disproven therapies. The risks associated with taking vitamin supplements, a Reiki session, or suffering through a detoxifying cleanse may be different than travelling abroad for a stem cell "cure" treatment, but all offering these treatments are profiting off of hope and a willingness to believe in something that has no basis to support it. These are individual choices, but we must think about whether our money could be better spent.

In defence of the flat Earth believers, their belief may not be based on science, but at least their belief doesn't hit them in their pocketbook.

— Chris McBride, PhD, Executive Director, SCI BC



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handSteady is a cup designed for people with tremors, muscle weakness or limited dexterity, to help reduce spills when drinking. The secret is the cup's rotatable handle, which can rotate a full 360 degrees and uses gravity to keep the cup upright. This allows the user to hold it at whatever angle is most comfortable for them, and even if your hand shakes, the cup doesn't. Added stability and ease of use comes from its lightweight plastic construction, which makes it much lighter than a standard cup. It also has a hidden lid accessory so it can be used as a travel cup or with a straw. It can even be used one-handed with its oversize handle, and is dishwasher safe. Despite all this, it looks like an average cup made from bone china and nothing like a toddler's sippy cup. Check out www.handsteady.com for more information.



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Room for Debate

What kinds of words should we use to describe ourselves?

"Persons with disabilities" or "cripples" and "gimps"? We wouldn't expect society to use anything but the former, but the latter terms are frequently used by Peers with disabilities in reference to themselves and their friends. In this issue, we asked our Peers and online community to weigh in: Are you comfortable using words like this or do you think they should be permanently erased from our vocabulary? Should we stick to people-first language or reclaim such wording with pride?



Cripple? Sure am. One of my favourite shirts says "Spazz" on it. When I'm looking for disability parking, I often talk about "looking for a gimp spot." I go by "Queer" and "Snail", too.

We use words like these, often with humour, to help us to feel special and to celebrate our diversity. Individuals who have experienced stigma due to some kind of visible difference from the norm can find community and identity by using these words.

Reclaiming terms that we may have previously been hurt by, often with a sense of humour and as part of a special "in-language," can help us empower ourselves (and each other) when we've been hurt by those occurrences.

Many Peers on SCI BC's Facebook page appear to agree with me. Someone wrote of having a blog he called "Tales From the Crip." Another wrote, "I'm one speedy gimp that likes to chill with the crips."

I can relate. I grew up in a small community on Vancouver Island, often teased and bullied for being too sensitive and not like the other boys. My grade 2 teacher, quite the poet, made up a rhyme with my name which she shared with my school-mates—I was "Kenny Quayle, the slow old snail" from that day on. In addition to occasional violent incidents, the word "fag" was still being scratched into my school locker in grade 12.

Eventually I learned about reclaiming, and "Snail" is now a nickname that I sometimes choose and share (along with the story of its history) with people close to me. Better to laugh, I say. It feels stronger. Similarly, I choose to use the word "queer"—it's less of a mouthful than the changing (and growing) alphabet soup acronym, "LGBTQI".

Ultimately it all comes down to respect, and the ability to consider a given situation from the perspective of somebody else—somebody different. Even though I am comfortable with using words like "gimp" when talking about myself among friends, a recent visit to the dentist illustrated the importance of this for me. I was talking about how my marriage to my husband was the first locally publicized example of a couple of "fags" getting married after Canada changed its same sex marriage law. The dental assistant whirled her head around, telling me that, unlike me, she was raised in a family where words like that were never used, and therefore it was extremely "stomach churning" to her.

I apologised for having inadvertently upset her by flaunting my freedom a little too loudly in a public place.

— Kenn Quayle, Gibsons

Do you really think it's a good idea to call yourself a "gimp" or "cripple"? I don't. And you should think hard before you do.



Now is definitely not the right time to use such un-PC language or to start "reclaiming" words like gimp or cripple. We're simply not at a stage where we can start taking back and using words that countless people find hurtful and negative. There's not yet enough acceptance of disability to make reclamation work. When we (as people with disabilities) reclaim a word to regain control of it, we also run a huge risk of discouraging others from understanding who we are.

The general public is often afraid of disability. The hard truth is that, in the non-disabled populace, there is a huge lack of awareness about disability and what living with it is like. The biggest challenge I face is often not stairs or hills—it's attitudes.

We have to ask ourselves: would reclaiming words accidentally enforce stereotypes instead?

For an example, we can look at the reclamation of the "n word" and how that has turned out. The use of the "n word" has made some inside that community prouder of who they are, but it has also caused many outside of the community to shy away, rather than feeling more comfortable, aware and accepting. Similarly, if society already has a very limited understanding of disability, what kind of negative impact could reclaiming words like "gimp" or "cripple" have on how they perceive us?

Of course, some would argue that using these words can be a way to show pride. There is nothing wrong with being proud of being in a disability community, especially when it helps us accept ourselves and each other. But the general public still sees disability as a scary, daunting barrier to living life; being proud of that is odd to them. Before we use the pride argument to reclaim words, we have to change that opinion first.

— Arnold "Bucky" Cheng, Vancouver

Visit us at facebook.com/spinalcordinjurybc and weigh in on this and other topics. Plus, take our poll at sci-bc.ca/poll and see what others have said about language and disability.



Spicy conversation.

Realwheels' SexyVoices will challenge the myths surrounding the often taboo topic of sex and disability. The workshops will culminate in a staged burlesque production celebrating sexuality and relationships from a disability perspective. The workshops are underway, but mark your calendar for the stage productions on May 12, 13 and 14 at the Roundhouse Performance Space. For more information visit www.realwheels.ca.



Rugged competition.

The best wheelchair rugby teams in the world will be competing for the coveted Canada Cup from June 24 to 26 at the Richmond Olympic Oval. This is your chance to take in the thrilling action and cheer on Team Canada with national pride as our athletes look to hold on to their top world ranking heading into the Rio Paralympics. For more information and to purchase tickets, please visit www.canadacupwcrugby.com.



Body. Mind. Spirit.

SCI BC's annual SCI Forum aims to demystify misperceptions about mental health and explore strategies that help improve mental wellness. Healthy eating, fitness, mindfulness and building connections among peers and family members will all be on the agenda, as well as a free lunch. It all happens on April 16 at the Blusson Spinal Cord Centre—email Alfiya (abattalova@sci-bc.ca) or visit www.sci-bc.ca/events/ for details and to register.

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Stand By Me

Every relationship is unique. But being the spouse or partner of a person living with spinal cord injury often presents its own distinct set of rewards and challenges.



We often say that an SCI doesn't just happen to an individual—it happens to their family, friends, and community too. Throughout the province, there are support systems in place for men and women dealing with new injuries or facing the everyday challenges of living and aging with a physical disability. And yet the very people on the front lines, the spouses and partners, are often left out of the equation. For this issue of *The Spin*, we asked five partners of some of our Peers to weigh in on the experience of living with, and loving, someone with an SCI—caring about them and, often, caring for them. With marriages spanning just a couple of years to partnerships of more than five decades, disabilities ranging from complete to incomplete and traumatic to non-traumatic SCI, and partnerships kindled before and after injury, our couples have diverse experiences. But for many partners of men and women with physical disabilities, some themes are universal: learning not to sweat the small stuff, taking every day in stride, and crossing the line between partner and caregiver with courage, grace, and a daily dose of humour.

Tod Maffin, 45: “She has bad days, so do I. Sharing a life with someone who understands ‘I just don’t have it in me today’ is worth more than anything.”

I dread writing about my wife Jocelyn. It’s not that I don’t have wonderful things to say about her—hell, I could fill a book with the wonderful things. It’s just that, from a disability point of view, she’s not that interesting. Or maybe she is. I really don’t know. (Sorry, love.)

She knits, plays video games like a fiend, and wears the hell out of yellow.

She’s quirky, has the periodic table memorized (hot!), and has this secret dimple that peeks out at you when she’s really happy.

I’ll admit, when we first were dating, I did wonder, “Am I going to have to take care of her?” Turns out, the answer was, “Yes.” But not for any mobility reasons. She forgets to charge her smartphone all the time. It’s a problem.

Here’s what I’ve learned about people with disabilities. For the most part, they’re kind of boring. They have hobbies, opinions, and lead mostly normal lives. If you’re hoping to become a

martyr for marrying someone with SCI, you’ll be sorely disappointed.

Sure, there are benefits. Of course, the parking. The occasional tax write-offs. Going into any hospital and being introduced to every single doctor and clinician who works there. And I’d be lying if I didn’t admit to being oddly thrilled when she jumps a curb in front of a streetful of shocked pedestrians. “Oh my God, is she going to be okay?!” Yes, Grannie, she’s got this.

By the way, have I mentioned that Jocelyn looked freakin’ adorable in her wedding dress?



Photo: Sylvia McFadden

As someone in recovery from addiction, I live with my own chronic medical condition. And while I have several years of clean time, my condition, like Jocelyn's, requires daily care and maintenance. She has leg spasms, I have brain spasms. She has bad days, so do I. Sharing a life with someone who under-

stands "I just don't have it in me today" is worth more than anything.

Did I mention how cute she looked in her wedding dress? She really did. You should check her Facebook.

We met on Facebook. I knew her sister, Buffy, from my church youth group days. Buffy and I got reconnected a few years ago and I stumbled across Jocelyn's photos on Buffy's profile. Cute blonde. Smart and sciency. Plays competitive basketball. Check.

Sadly, Jocelyn's primary disability prevented us from meeting earlier. No, not the whole "can't walk" thing. It was more the whole "can't tell when a boy is flirting with her" thing. Seriously, there should be a tax credit for that.

Our first date was over sushi. I knew she used a wheelchair, so I picked a place with a level grade. I probably should have asked more about her disability during the date, but we spent the time talking about politics and science instead. That seemed way more interesting at the time. It still is.

As for entertainment value, it's regular people who provide the most consistent laughs. The little old men who whisper, "Bless your heart!" as we pass by. The hipsters who tell her to watch the speed limit. The well-meaning but slightly creepy people who want to pray over her in the elevator. As for the guy who ran across the street to tell us about how his aunt got cured from paralysis using only cranberries and crystals, I probably should have told him off. But these people are hilarious. They really are.

So if you're considering getting married to someone with an SCI, all I can offer is my experience. Find someone with a good sense of humour, someone who treats you well, and someone with high XP in Dragon Age Inquisition.

While I dread writing about Jocelyn, I adore being married to her. It's an awesome and entirely normal life.

She's hot, and she's all mine. And seriously, check those wedding photos out... *You can check out those wedding photos at tinyurl.com/gimpywedding.*

Alex Saleh, 37: "I take our lives a matter of fact: this is the woman I choose every day, and so this is the life I choose every day."

My wife Nicole and I met in China in 2008. I was teaching English, she was studying Chinese, and we were both living in the same building. We spent countless hours in my apartment, keeping the conversation going long after our friends had turned in. We chatted about personal history and dysfunction in family, about culture shock, and about learning how to live in another place—one that's not exactly friendly to people in wheelchairs.

Nicole was injured in a car accident at age 10, sustaining damage at the L2 level. By the time I met her, she was 24 and had already travelled to several other countries in her wheelchair. I didn't know much about SCI, but Nicole's a practical person and makes everything easy. For her, being in a chair in China was just another adventure. For me, it was an education.

I learned what she needed to make her way around China, whether it was getting up and down stairs or moving around in a cramped sleeper train. I found myself proud to stand by her when Chinese people approached her on the street, impressed and inspired to see a person in a wheelchair out of the house ("I have a cousin/brother/uncle who uses a wheelchair, but he just stays at home learning a second language!"), and I

would advocate for her when accessibility and understanding became an issue. Once a shop attendant, talking to Nicole, used the word "little friend" which in China is usually used to refer to kids. Maybe there's some other use, but I thought, "You're calling my girlfriend a little kid?" Needless to say, I got pretty defensive.

Nicole taught me how to give hugs (an introvert, I'd always found a way to screw the process up) and how to ask someone on a date. And, eventually, I figured out that she was the only one I wanted to be hugging and asking out on dates after all.

We were married in 2010 and now have two boys: Noah, 2, and Simon, 4. Nicole's pregnancies were easy, but the first six months of parenthood were not. Simon was born the day before I was to begin orientation for my MA in theology. I missed the introductions, and rushed home from school every day after that to help Nicole, who was at home with the newborn baby, able to pick him up and put him down, but struggling to get him from place to place and to cook while watching him. We should have found somebody to lend a hand right away—we were grateful to friends who came for a few hours each week, but we needed more help than that. Eventually, we figured it out and got the help that we needed.

The challenges of parenthood didn't put a strain on our relationship, but they did put a strain on my studies. I was beginning to realize that I did want to go on to do a PhD, but I



wasn't getting as good of grades as I would have liked. At home, Nicole was struggling with postpartum depression. It was a hard time for each of us personally, and we could attempt to comfort each other, but neither of us from places of great strength.

We eventually got a nanny who stayed with us up until April of last year, an even greater help when our second son came along. We didn't want Nicole to have to chase the boys or coax them out of places she couldn't access if they went running off. By now, they've learned to listen quite well, and as they grow up they understand what the boundaries are because of mommy being in a wheelchair ("Mommy can't walk because she was in a car accident, right Daddy? And that's just the way it is.") On top of mommy's own situation, our younger son has a genetic disorder that affects his blood sugar, requiring us to feed him every three hours during the day and every four hours at night.

Nicole has her share of frustrations. There are some things that are hard because she's in a wheelchair and those don't necessarily get easier over time. I help her as much as I can,

trying to be sympathetic, comforting her, or just being present. But this isn't an occasional encounter with somebody in a wheelchair; it's day-to-day life and I'm still learning how to attend to my own needs as well as hers. Sometimes what each of us wants or needs comes into conflict. Nicole relaxes by getting out of her chair and into bed while I find more comfort in a chair. And since our bedroom has no space for a recliner or office chair, it makes it hard to spend the quiet time of the day together.

I take our lives a matter of fact: this is the woman I choose every day, and so this is the life I choose every day. Sometimes I try and catch myself to stop thinking in terms of ideals—of how things are supposed to be. Of course we're supposed to be able to take turns being alone with the kids. Well, that's not always easy, but mostly it goes well. I do feel guilty bringing things up, like when there are special lectures I want to go to. That would mean leaving her home alone with the kids. So I always ask, "What do you think, do you feel up for it?" It all comes down to voicing my own needs and concerns while still putting her first.

Generally we're pretty good support networks for each other. But our varying personality types don't always make things easy. Nicole is very social; I'm not very good at initiating social interactions and meeting new people. And here's where it gets tricky: even though Nicole's a very extroverted and outgoing person, like many people with SCI, she fatigues more easily. But being around other people revitalizes her and does well for her emotional state. So Nicole's fatigue requires me, a complete introvert, to bring people into the house or to take us out to interact with other people. I want to help her—and I do—but the very scenario that reenergizes her is taxing for me.

Our social lives will get easier when we move into our new house in Abbotsford. Nicole's dad is retiring, so her parents will move in with us. For Nicole, this means getting the constant social interaction she craves, and help around the house and with the kids as she finishes up her degree in counselling and takes on a practicum soon. For me, it's a chance to balance my family's needs with my own—a chance to crank out that Master's thesis and start teaching. Our lives are perfect in their own imperfect way. "Supposed to be" was never the goal anyway.

Helen White Brown, 54: "Everything has its moments, both good and bad. But then life before injury had its moments, both good and bad, too."

At the beginning, I was superwoman.

Ian was injured in April of 2010. He had been working felling trees, when one day a tree came at him from behind, shattering his shoulder blades and clavicle and leaving him a T5/6 paraplegic. It

took more than six hours to get him out of the bush. By the time he got to VGH, I was already waiting.

We celebrated our fourth wedding anniversary in hospital. (It was a second marriage for both of us, though in our earlier lives, before we'd lost track of each other and moved to our separate corners of the province, we'd been roommates and best friends.) I slept beside Ian's bed at VGH for two and half months, and lived outside GF Strong,

in our trailer in the street, for another three months. In the beginning, I took care of all of Ian's bathing and showering on my own. I just thought, "I'm his wife, that's just what you do."

Ian couldn't make a decision for the first four months of his injury, so I got more confident in not being afraid to ask stupid questions. I read voraciously—learning and trying to understand. Before, when I felt I was supposed to know something, I'd just nod and smile.

But now it's like, "Talk 'people talk' to me. Stop the medical stuff, I don't understand that jargon." I began talking to doctors the same way I did to the garbage man—if I wanted to know anything, I'd ask them the same way. As the de facto spokesman for the "Ian and Helen Swim Team", I don't shut up as much as I used to.

But eventually you realize that you can't do it alone—that you need the help. When you're in rehab, the only thing you can dream of is getting home. But my one piece of advice? Don't rush your way through the rehab—a safe place where you have help available to you—because it will be hard enough when you don't have it. The rug does come out from underneath your feet when you walk in your door the first time and realize there's no nurse at the end of a bell, and that your entire support team has disappeared.

When we first left Vancouver and made our way home, back to Madeira Park (a rural community near Pender Harbour), our house renovations weren't finished. So we had to live for six months and three days—not that we counted the hours (well, actually, we did)—in a hotel just up the road. It was "wheelchair friendly" but you had to jump over a sill to get to the shower, and the staff had to remove half the furniture so our room could accommodate the hospital bed.

When we finally got home, I worried about things that seem so trivial today. Simple things, like getting Ian ready for bed at night—hooking up all the right hoses, basically—terrified me. I didn't want to do anything wrong (I'm a good mother, but not to an adult!) These days, if the nurse aide counsellor can't make it, it's easy and natural. I never thought I'd adapt to a nursing role.

In the beginning, I was getting help with Ian's bowel routine from a trained nurse aide every second morning and a night aide helped ready him for bed. But I was still getting up every night at 3 AM to turn Ian over to avoid pressure sores, and with the daytime routine it got to be a bit too much.

Thank goodness we had insurance in one form or another! WorkSafe BC

immediately put more daytime care in place—and, two months ago, Ian was finally able to figure out a way to flip himself over at night. (One of his nurse aides brought him a small dual-triangle pillow that, when positioned between his knees, helps him to swing his body over and do a perfect roll.) That 3 AM roll was the last thing off my plate, as far as being the nurse or a caregiver rather than wife. (It's a very fine line to cross over, and you do cross it, back and forth.)

The hardest part, though, was Ian. He had such a wonderful attitude in Vancouver, in the hospital and during rehab. But once we got home he began to see how limited he was. He could no longer look out into the backyard—at our pretty half acre with a dog, chickens, ducks, and gardens—and get joy from it. All he could do was see things that he should be doing, or that I couldn't do. It got really hard that way for him, and that's still ongoing.

But we never considered moving. We're small town people, and we live where we live because we love it. Transit is difficult: we don't have a city bus, and Ian's temporary rental van is good for the city but not meant for the country. We can't even go to see a lot of our

friends, because we can't get to their houses, let alone into them. Our kids (we have a half dozen between us from our first marriages) and grandkids live everywhere from Vancouver, to Banff, to God knows where. But we can no longer just hop in the car and go away for the weekend—being spontaneous is no longer an option. Sure, I tire of planning (I'm the one who has to figure out all the details!) but it's just, "Suck it up princess." We don't really have a lot of options, and there's always a way to get around something—it just takes a bit of thinking.

There are perks to living in a small town, too. Everyone knows us and everyone wants to do as much as they can for us. After Ian's injury, the post office mysteriously had a new automatic door. And the IGA grocery store decided that it wasn't good enough that they only had one till where the PIN pad for Interac was movable. We have a Legion down the road. They don't talk about the war anymore—they talk about something else. But it's the same sort of thing and Ian likes to stop there and get his socializing in that way. I go to bingo once a week with all the other old crows. And on weekends, there's the meat draw.



We've totally changed what we do as a couple. Going into Sechelt for dinner is more of a production, with transit and timing for the care aide, and the spontaneity is pretty much gone. Our relationship is topsy turvy—nothing like it was before. Nobody's ever prepared for an SCI, right? I keep putting myself in Ian's place, thinking, "God, if I was stuck there, all of a sudden like that—how would I feel?" I don't feel sorry for him—

I just try to be empathetic and switch places so I can understand because I find myself getting impatient if he's constantly after me to do something. Since his injury, I find myself trying to be more patient than I ever would have been with him before, so I can help him figure out his frustrations and deal with them.

I just wish I had this "Yee-haw!" happy story. I wish I could say, "Thank God this happened, because..." That hasn't

happened yet. There have been learning curves thrown at us every day. But no matter how hard it gets day-to-day, I'm just so happy to have my husband with me. (The other option was just so horrific...)

Everything has its moments, both good and bad. But then life before injury had its moments, both good and bad, too. Now you just look at things from a different perspective.

Sherri Rich, 43: "How do you mourn for someone who is still here—someone who's just very different?"

I had a very challenging childhood and a rough start to life. So when David got injured, I felt that if it had to happen to anybody, it might as well be me—I'd built up the ability to deal with a lot of hardship and struggle. I thought at the time that I would have the strength to get through this one as well. But over the six years since my husband's accident, I've dealt with the biggest struggle in my life.

It started with a phone call. On Sunday morning, June 13, 2010, David had gone for his usual morning bike ride into the local North Shore mountains. He was due home around 11 AM, with the rest of the day planned as family time. But he was late and I was starting to get upset with him. When the phone rang and his number came up on the display, I started to chew him out. But a stranger's voice interrupted me. He told me he had found my husband—he was hurt and the ambulance was on its way. He told me to get to the hospital. And then, becoming quiet, he added, "Your husband can't move his arms." I knew then that my old life was over.

David broke his neck in three places and was diagnosed with an incomplete SCI at C3 to C5—central cord syndrome.

My previous life had been very ordinary: David worked in the film industry; I had a part-time job and was a full-time parent to our two wonderful girls, then aged five and eight.

But suddenly my life was a flurry of activity, with the weight of the world resting on my shoulders. I was raising two daughters alone, keeping with their regular routines and making sure they had stability in their lives. I was supporting David, making all of his meals and bringing them in, doing his laundry, and helping him through everyday routines that were new and unfamiliar. And, for the first time in my life, I was working a full-time job, trying desperately to keep a roof above our heads. (Thankfully, my friends came to the rescue, and we realized which friends were good enough to stick by us, and how lucky we were to have them.)

It's so easy to lose yourself when your spouse is hurt. You go from having the partner you chose and the life you built together, to having to be the sole caregiver to a man who is



also an infant. For months, I put all my energy into the hospital life. My children had lost their father but they also lost their mother, and my once-calm home became a ground for anxiety-fuelled anger, hostility, and stress. I went from having everything, to having to pull my life back together. I had to mourn my loss and grow strong again. But how do you mourn for someone who is still here—someone who's just very different? How do you mourn your dreams for the future?

With rehabilitation, David regained some movement and learned to manage the day-to-day complications of an incomplete SCI (fatigue, pain, spasms, hand function, and bowel issues) quite well on his own. But for me, as a wife, dealing with the SCI was never the biggest change. When David had his accident, he hit his head quite hard and sustained a brain injury as well.

Living with David's brain injury has been terribly frustrating. I have to constantly remind him of things. I need to organize everything—and then check each item over with him several

times to make sure he's on the same page and he knows what has to happen and where. I do all of the parenting. When David got hurt he kind of went back to being an infant learning to walk, talk, and take care of himself again. Through the years, he's matured, and right now he's sort of at that teenaged level himself. So I have three teenagers in the house.

Because of his injury, David gets easily frustrated and angry. His emotional response isn't always mature, especially when dealing with teenage daughters. Our younger daughter, Terra, has adapted well, but my eldest has not. Ayla is struggling at school and emotionally. Sometimes, when I try to discipline her, she freaks out, and then David freaks out too, and suddenly everybody's freaking out and nothing gets resolved, feeding my daughter's anxieties further. I've lost my supportive husband and now have to support an emotionally-challenged person, and that's been extremely hard. I have to navigate the rough hormonal rage years mostly on my own.

Sometimes I expect him to be the same person, because he looks like the same person. But then I don't get what I need, and I have to give myself a shake and say, "No, no, that's not going to be that way anymore." And then I have to grieve that and carry on. I go back and forth between being a caregiver and a partner (and that's more like a 75/25 partnership.) It's very different now, and I'm not sure I've figured out how to cross that line.

I've also had to deal with the loss of most of our family income (these days, David works part-time, and does some volunteering.) I'm a horticulturist, not quite a high-paying job, but we get by. We lost our house in the process, and now we're living in a rental house that nobody likes. It's still on the North Shore, in the kids' school district. But it's a dump and we don't like it here. Yet everything is so expensive, and there's nothing available. Our last place was neighboured by dealers and crack addicts. The loss of stability in my life has been a big struggle for me.

And yet there were some unexpected positives. About two years after David was hurt, not getting support from my own family here, I reached out to my paternal side of the family. I'm really glad I did. I found my father, whom I'd never known as a child, and I also found six welcoming siblings that I didn't know growing up. (A year later, my younger brother sustained a complete SCI in Calgary, and I flew to be with him. He found comfort in my support and experience. But he continues to struggle,

both physically and emotionally, and it weighs heavily on me to not be able to be there for him like I was for David. We've grown very close.)

Today, I feel I'm a much stronger person than I ever was before. At this point, I don't know if there's anything I can't do, and I feel very secure in that. My day-to-day takes a lot of self-awareness and patience. Honestly, I don't know of a lot of women that could pull through this. I understand why so many women leave. And what's the number of men that leave? Something like 99.3 percent? It's something every spouse has to decide for themselves.

This wasn't supposed to be my life. SCI takes so much from everyone in the family; it's every day and all day long. It comes with depression, anxiety, and poverty. It come with being constantly hurt and punished by a person who isn't really feeling ill feelings towards us—he's feeling it about himself. I have felt like I've wanted to give up. But I haven't yet. And I don't think I will, at this point. I do know that, regardless of our situation, our girls are better off having two parents together.

I stay very busy to deal with it all, busier than I was before. (I've aged about 15 years in the last five.) I'm part of an online support group called Wives & Girlfriends of Men with SCI. They're an amazing group of women—no BS there—so I talk with them all the time and they help get me through the rough patches and the small stuff too.

For his part, David still bikes and skis, though not quite with the same intensity as before. And I'm okay with that—it's good for his self-esteem. Last year, he biked from Dease Lake to Vancouver to raise money for Spinal Cord Injury BC—and, maybe for the first time since his injury, to successfully follow through on a big, meticulous plan. It was a double win.

I wonder about our future a lot—about when my girls grow up and leave home. I dream of leaving the city to disappear into some little homestead somewhere, to live a quiet, calm life and finally spend some time on myself.

For now I take things day-to-day (in the beginning it was hour-to-hour.) I tell myself that it's a long road but there's no turning back. We don't get to choose what happens to us, but we do get to choose how we feel about the situations we find ourselves in. When David got hurt I had to stand tall and strong for all four of us. And I will continue to do so.

Henry How, 79: "I want her to die first, because if I die first, there will be no one to look after her."

My wife Denise and I were married in 1966. More than five decades later, we're still travelling and filling our social calendars, and I'm still getting on the "the Boss's" nerves.

Today we have three sons and five

grandchildren, and we've come a long way together. We were both born and raised in Mauritius, a small island off the East Coast of Madagascar in Africa. Denise was one of 12 children; I was one of nine. When she was six years old, Denise and her brother both contracted polio. She got the worst of it, and has walked with a limp for most of her life. These days, she's more tired; she's been

using a wheelchair to get around outside of the house for just over a decade.

I first met my wife of 51 years at the office—we were both working as accountants at the same firm. At the time in Mauritius, and likely still today, the perception of people with disabilities was quite bad. In the workplace, people with disabilities had a hard time advancing despite their qualifications. At

home, even my own parents warned me against marrying Denise. “Think well before you marry her,” they said. “You’ll have to do all the chores around the house yourself.” (Eventually, realizing that Denise could not only do chores but that they were actually quite fond of her, my parents came around and even encouraged our marriage.)

By the 1960s, the independence movement was growing in Mauritius, a former Dutch, French and lastly British colony. Like many, we feared the growing unrest and the changes to come. And, because of Denise’s disability, accessibility to both places and opportunities was hard to come by. So Denise and I left for England, but we found much of the infrastructure there to be old and inaccessible. We moved to Canada in 1969 and most of our siblings joined us later, scattering across Montreal, Toronto, Ottawa, and Calgary.

We’ve done a lot of travelling together. We’ve cruised around Europe and South America, enjoyed the sights of Paris and Luxembourg, and driven across Canada at least 10 times. We’re still hoping to make it over to New Zealand and Australia, where I have a nephew, but are



worried about the long flight. As we age and Denise’s disability progresses, we find ourselves needing to upgrade to the “Comfort Class” seats more often.

Denise was recently diagnosed with post-polio syndrome, which causes new weakening in muscles that were previously affected by the infection and

Crossing the Line: Ten Tips for Partner Caregivers

When someone sustains an SCI, there are supports in our healthcare system for rehabilitation. But when a partner becomes a caregiver, there are fewer resources available. Spinal Cord Injury BC groups and activities can be a great way to find understanding and support—after all, an injury impacts family and friends too. And, where one-on-one support is not available for caregivers, there is an overwhelming amount of information online. These 10 tips can help you balance the roles of partner and caregiver successfully.

1. **Know who your trusted supports are and get them involved as soon as possible.** Even if you don’t tell them about your daily life, a quick update every now and then will suffice. This way, if you require their assistance at some crucial point, they are not clueless.
2. **Do not let others’ expectations guide you.** It’s common for people to ask questions like “Does (s)he take sugar with that?” or “Why aren’t you pushing him/her?” Over time, you will find a way to collectively respond to such remarks and be with each other

in the way you both want. And certainly make it clear to whoever is asking these questions that they should be addressing your partner, not you.

3. **Enjoy your sex life.** Contrary to popular belief, it doesn’t have to come to an end after SCI. There may be challenges, and it will be different. Yet intimacy post-injury is possible. Have a look at the sexual health resources on our database for ideas. Expect that people will ask you about your sex life but know that you do not have to answer.
4. **Have a life aside from your partner’s life.** This shouldn’t be any different than what you did before the SCI. It’s not selfish to indulge in self-care and put yourself first at times. You are more than your partner’s caregiver, and cannot be an effective caregiver unless you take care of yourself too.
5. **Be prepared to fight for your relationship.** At times, you’ll be up against those closest to you—remember that they don’t live your daily life and it may take time for them to understand why

in muscles that were thought to be unaffected. She tires easily and her muscles are weaker. Even with a walker she can go only a few steps, so accessibility is a big thing. Denise usually wheels unassisted, but on hills I do the pushing. On our most recent trip to Barcelona, I had to push her up a steep hill to get to the entrance of the Sagrada Familia Basilica. She keeps me fit and active...but I'm 79 and get tired pushing her up hills. (Luckily, her brother and sister were also there to help out.)

Because mobility is an issue, Denise doesn't much like to be on her own. She often gets frustrated and impatient when I leave and she has to wait for me. Sometimes I go to the washroom and "take forever" to come back. Sometimes I "leave her" for too long in the shade. Sometimes there are street performances or celebrations that she can't see from her vantage point, but she's too nervous to move in case I can't find her when I return. It gets frustrating for her, and for me. I can't leave her alone—we do everything together. I always say I want her to die first, because if I die first, there will be no one to look after her.

Travelling does take its toll. We go away less now, and find ourselves happier and happier to come home. We've both been retired for over a decade (though our son still ropes us into doing the accounting for his business) and we've grown into our routines, though in a lot of ways we're opposites. I wake up early; she rises later. I adore English football; she doesn't. I sweep the floors and clean the house; she takes care of the cooking.

If I'm busy and Denise wants something, she'll ask me to fetch her something and to brush off everything I'm doing. But sometimes I get frustrated with Denise: I wish she could do more household chores, and get off of her chair. Mostly at home she doesn't use her wheelchair, and it's good for her to exercise. (But, conveniently for her, the recommendation for post-polio is to not overdo things.)

Our home isn't adapted, though our bedroom is on the first floor. But there are three steps to the front door, and they're getting more and more difficult for Denise to climb. We want to move into a condo, but it's hard to find something that's not on a busy street and has

amenities nearby, such as a library and community centre, a convenience store, and a bank.

Every weekday, I go to Catholic Church and bring Denise back the Holy Communion. We go together on Saturdays, and then on Sunday we relax. Our faith helps us to accept Denise's situation, and to not get frustrated. When frustration sets in for Denise, she thinks of Christ dying on the cross, and it gives her patience—otherwise she would be desperate. My faith gives me patience in dealing with Denise.

We have support from our families too: Denise and her sister in Montreal talk on the phone all the time. And I get support from our three sons, who always back me up in dealing with "The Boss." We spend time on Skype every day, talking to our siblings and children.

We also come out to most of the SCI BC events. For us, it's a chance to get out and meet people. Other than that we don't get out much anymore, but we still keep occupied.

We laugh when people tell us, "You're retired? What do you do all day?" Time goes by so quickly now, and somehow we feel we're busier than ever. ■

you choose to be with your partner. You may also have to remind yourself at times that your fight isn't with your partner, but that you are fighting together against your barriers.

6. **Get comfortable sharing.** You'll need to adjust to your new life, new roles, and the presence of new people and professionals in your life. Care aides, physiotherapists, occupational therapists, doctors, nurses, and maybe even lawyers will become a part of your team in caring for your partner. They are there to help you so reach out to them when you feel the need to do so.
7. **Expect to field lots of questions.** People will ask you questions out of sheer ignorance, a genuine desire to help, curiosity, and other reasons. You don't have to answer them all—in fact, the perfect response to a rude question might just be silence, and not dignifying the question with an answer. Regardless, be prepared.
8. **Stand your ground.** It is quite common to feel guilty when you're a caregiver, especially initially. This could be amplified if you, the caregiver, are able-bodied and your partner isn't. Don't let your guilt taint your decision making process. Ask yourself: Would I act this way if my partner didn't have an SCI? Several online forums, like apparelyzed.com/forums/, can connect you with people in

the same boat. They've been through similar experiences and emotions, and can help support you during this process.

9. **Join a support group.** Peer networking can be immensely helpful. Connect with a Peer staff member at SCI BC—they're experienced in matters specific to SCI and can connect you with other staff and community members with whom you can relate. Plus, there are support groups for caregivers that are facilitated by the Family Caregivers of BC all over the province. If you can't quite find what you're looking for, do a quick search for forums online.
10. **Do not become your partner's caregiver first—be his or her partner first.** While it is recommended that the roles of caregiver and partner be fulfilled by two different people, the reality is that most spouses do become caregivers of their partners. This is especially true in rural communities. Be mindful of your roles and prioritize them.

Spinal Cord Injury BC provides support services for people with SCI and related disabilities, along with their families. Head to sci-bc.ca to contact our Peer Program to find out if there is a local caregiver you can connect with.

Quick Change

Artist



Since 2011, Luke Anderson and his StopGap Foundation have created instant access at hundreds of small Toronto storefronts—and generated a whole lot of awareness of a barrier free society in the process. Now his Community Ramp Project is catching on in other cities and provinces, and Anderson would like nothing more than to see greater expansion into BC.



Sometimes, all it takes to create wholesale change is one pissed off, determined person. Case in point: Luke Anderson, a 36-year-old engineer from Toronto who is creating access to small downtown businesses and facilities, one simple, brightly-coloured ramp at a time.

Anderson grew up in Stouffville, just outside of Toronto. After high school, he headed to nearby Waterloo University, where he enrolled in the civil engineering program. But when he graduated in 2002, the self-admitted adrenaline junkie put his engineering career on hold and moved to Rossland, BC—a Mecca for outdoor adventure enthusiasts—to pursue his passion for mountain biking.

Months later, his life changed forever when he attempted a huge eight meter jump and came up short on the landing.

The result was a high level, complete SCI. After a stint in acute care, it made sense for Anderson to rehab at Toronto's Lyndhurst Centre, where he had family and friends close by.

"I'm not going to downplay the fact that it was a long road to recovery—I'm still learning how to live in this world that's not well-suited for someone with a disability," he says. "The first four years after my injury, there were some dark times and some lessons learned. I'm glad they're behind me."

After he regained his health and made some sense of his life with SCI, he contemplated work. In 2005, he took his first career steps, and began working from home as an engineer-in-training for a small structural firm. Then, in 2006, he was hired at a larger firm, located in downtown Toronto.

A natural problem solver, Anderson enjoyed the work. But a constant source of aggravation greeted him every morning when he arrived at the downtown office building that housed the firm: three steps at the sidewalk entrance. Every morning and evening, Anderson relied on friend and co-worker Michael Hopkins to deploy a portable—yet heavy and awkward—folding ramp so that he could enter and exit.

He also enjoyed living in quirky and colourful downtown Toronto, with its variety of ethnic neighbourhoods and vibrant street scene. But just like he was frustrated with lack of access to his workplace, he became increasingly disenchanted with many of the area's smaller retail shops and restaurants, rendered off limits to him and other wheelchair users by virtue of just one or two stairs at the entrance.

"I became increasingly frustrated with not being able to access the spaces that I really wanted to," says Anderson. "I realized it wasn't just me that was being affected; it was also all of my friends that I wanted to go out with or check out a clothing store with, or other retail locations. All of sudden, we are *all* unable to participate in that experience. I coupled that with the stupid situation that I dealt with for almost five years at work—this ramp that had to be put in place every time I wanted to come and go. All of those issues boiled over."

As he contemplated some kind of action, he noticed that when the portable ramp to his own workplace was deployed on the sidewalk, many other people wanted to use it—for example, parents with strollers and delivery people.

"Everything sort of confirmed that something needed to be done," he says. "And I also realized that nothing was being done about the awareness of the problem. This is a problem that's world-wide. And this isn't an issue that happens just here in Toronto—it happens all around the world and prevents so many people from engaging and taking part in everything that's going on in their community and reaching their potential. Four years ago, all of that pent up frustration came to a boil, and I just wanted to get people thinking about the problem."

In the fall of 2011, Anderson created the StopGap Foundation—a non-profit organization that he believed would allow him to take a stab at removing some barriers in downtown Toronto.



SHOCKINGLY SIMPLE: Anderson and staff from Snakes & Lagers admire the new StopGap ramp that allows equal access to the popular board game bar on College Street in Toronto. **PREVIOUS PAGE:** Anderson is a popular speaker in Toronto-area schools.



Anderson checks out ramp construction on the busy shop floor.

The foundation's first order of business was establishing the Community Ramp Project—an initiative to address what Anderson believed was the most pressing and most easily-addressed accessibility problem in downtown Toronto: small businesses and facilities that were excluding him and his fellow wheelchair users because they had one or two small steps at their entrances.

First, he asked himself, "Why?" The obvious answer was that, unlike other countries including the United States with its Americans with Disabilities Act, Canada has a glaring lack of legislation to mandate accessibility—businesses and facilities are only obligated to create equal access if they build new, or renovate. Anderson came to the conclusion that, in the absence of this type of legislation, lack of finances for code-compliant and permanent ramp solutions, along with a general lack of awareness, was holding small businesses and restaurants back from opening their doors to wheelchair users.

With a handful of committed volunteers including Hopkins, his friend from work, Anderson canvassed his neighbourhood businesses and found several were willing to start using a portable ramp. Then, with donations of building supplies from community hardware

stores, the Community Ramp Project constructed 13 simple, colourful, and relatively inexpensive portable wood ramps, which were donated to the willing local businesses.

He admits that, at the time, his expectations were modest. "I thought it might be just a little one-off project that we would do to raise some awareness," he recalls. "I had no idea. It was so successful that we had to keep the project rolling."

The ramps were an instant sensation. Other businesses started calling, wanting to get onboard. The media started to take an interest, and soon Anderson had to raise his expectations. A major reason for the widespread interest, he believes, was the ramps' high visibility.

"When people think of barrier free access, they sometimes think, 'Institutional, sterile, stainless,'" says Anderson. "So the bright colours are strategic—they draw people's attention; it gets people talking about the issue. But it also creates this kind of playful vibrancy that is key to removing the stigma attached to the concept of barrier free. There's a real need to incorporate some fun when you're tackling a really serious issue like accessibility. It's a topic that comes with a lot of ignorance and fear, so crafting a positive tone has proven to give us better traction."

As Anderson predicted, business owners soon found out the benefits of having a StopGap ramp extend well beyond providing access to customers with disabilities—they are also friendly for delivery people, the elderly, and people with strollers.

He is quick to concede that the ramps were intended to be a quick fix, and certainly not a perfect solution. They're lightweight and temporary, and therefore not designed to the same standards as permanent ramps. They're also often slightly steeper. But Anderson points out that, because they're deployed when needed, they allow a business to avoid a lot of bureaucratic red tape. More importantly, they get owners to recognize the business benefits of inclusiveness, and generate a buzz about accessibility in general within the community. And because they don't cost small businesses a small fortune or require applications, permits and the like, they continued to pop up throughout the downtown core at more and more businesses.

Over the course of the next four years, StopGap's profile and output continued to surge. Anderson quit his job as an engineer in February of 2015, becoming the foundation's fulltime director. He and his foundation became media darlings, which in turn fuelled more growth. By the end of 2015, more than 800 StopGap ramps had been built and put into service. The majority of these were in Toronto, but increasingly, individuals and groups from across Canada began approaching the foundation and, using a partnership approach, began initiatives in other cities and provinces.

Last year, in Ontario alone, Community Ramp Projects took place in Guelph, Hamilton, Huron East, Kingston, Kitchener-Waterloo, London, Ottawa, Peterborough, Port Credit, Sarnia-Lambton, Streetsville, and Toronto. Meanwhile, in other provinces, Anderson and his foundation formed partnerships in Calgary, Charlottetown, Halifax, and Montréal. But so far, only a few small projects have been started in BC—a province where Anderson would love to create

some larger community partnerships to address lack of access in Vancouver and other cities.

"We do have a little bit going on in BC, but I would love to see something happen in Vancouver and even Victoria," he says. "I encourage any group out there who would like to spearhead the project, with my support, to get in touch. I'm not going to lie; it doesn't happen overnight, and there's many moving parts—someone needs to engage business owners to participate, there needs to be a retail hardware store that's willing to help out with building materials, and there needs to be a community group or a team of volunteers to lead the project. But I can tell you that any person or group that's been part of the project has loved every minute of it. And a precedent has been set—there are many successes to emulate. Future projects will not be reinventing the wheel."

If you're inspired by the StopGap Ramp Project, Anderson has made it easy for you to get started with a number of helpful tools at his website at www.stopgap.ca (see sidebar below).

Not surprisingly, Anderson and the StopGap Foundation have gradually built a reputation as experts in the ramp business—so much so that they began getting requests to commercially build more permanent custom installations for retail, residential, and institutional locations. That, in turn, has created a new revenue stream, which helps offset the cost of the ramps that they continue to donate or provide for a modest price to streetfront businesses.

What's next? Not surprisingly, Anderson's expectations are no longer so modest.

"We'd like to see the number of ramps we have out there double in the next year or so. It would be great to see about 1,500 to 2,000 ramps by this time next year. I think it's totally doable, but it will take a lot of work. The big vision, however, is to take this thing around the world—and take what we've learned here to the USA, and into Central America and other places where it's really needed. It's totally possible." ■

StopGap: Tools for Change

Luke Anderson and his StopGap Foundation have put a great deal of effort into creating downloadable tools that individuals and groups across Canada (and even around the world) can use to start their own StopGap-branded community ramp project, including:

- *The Ramp Project Handbook* that provides a complete overview of how to proceed
- an educational brochure for prospective volunteers
- a survey and policy form to record businesses' details
- a building materials donation request letter template
- a ramp design spreadsheet to calculate all of the measurements for each ramp part
- an "access ramp available" sign which participating businesses are encouraged to display in their storefront window
- a stopgap.ca stencil used when painting ramps.

Accessible BC: The Royal BC Museum

The Royal BC Museum has to compete with many other attractions and landmarks at Victoria's Inner Harbour, including the BC Legislative Assembly, the iconic Fairmont Empress Hotel, and the harbour itself, with its incredible display of vintage yachts.

But BC's provincial museum is recognized as one of the most important museums in Canada—and shouldn't be overlooked.

Founded in 1886, the museum houses three permanent galleries: modern history, natural history, and local First Nations' history. The museum's collections include some seven million objects, artifacts, and specimens, almost exclusively from BC or its neighbouring states, provinces, or territories. Additionally, the museum has a rich history of presenting amazing temporary exhibits, and 2016 is no exception—beginning in June, it will offer the rare opportunity to see the larger-than-life exhibition *Mammoths: Giants of the Ice Age*, in partnership with The Field Museum in Chicago. Additionally, the museum's IMAX theatre shows educational films as well as commercial entertainment.

The museum offers visitors with disabilities good accessibility. There's a short-term disabled parking drop-off zone in front of the main entrance. Longer-term disabled parking is available at the rear of the museum in a pay-parking lot. Simply display your disability decal in both parking areas. As for getting into the museum, there are six ramps located outside the building.

All floors can be reached by elevator (located in the lobby, beside the information desk). Wheelchair-accessible washrooms are located on every floor. There are some areas on the third floor that aren't accessible—for example, the upstairs portion of the Grand Hotel in Old Town, the lumber mill in the industries area, and Captain George Vancouver's HMS Discovery.

If you're planning on visiting with an assistant, get your hands on a Leisure Assistant's Pass through Recreation Integration Victoria (www.rivonline.org). This pass provides complimentary admission to the museum and IMAX Theatre to an assistant accompanying a person with a disability.

The museum is located on Belleville Street at the border between downtown and historic James Bay, just steps from the Empress Hotel and the BC Legislative Assembly. Visitors to the museum consistently rate it among the top attractions in Victoria on Tripadvisor, Google, and other review sites.

More information can be found www.royalbcmuseum.bc.ca.



Cruising has long been

a popular vacation option for people with disabilities and accessible options, both offshore and on, are increasingly easier to come by—if you know where (and how) to look. We've asked some well-travelled Peers, and Accessible Travel Specialist Tarita Davenock, to give us a peek at their cruise packing lists.

- 1. Extra Personal Items.** Bring a few days' worth of personal items—such as catheter supplies, ostomy supplies, diapers, and anything else you need to get by—in your carry-on bag in case your luggage gets lost.
- 2. Chair Care.** Pack a spare inner tube, tire patching kit, and a small bicycle pump. Folding tires for emergencies, or a separate set of foam-filled “travel wheels,” can be handy too.
- 3. Photocopy of Your Passport.** Many ports of call will accept the photocopy, so you can leave your passport in your room safe. If you lose the photocopy, you'll still be able to get back on the ship (though if you're docked in Maui, you may not want to...)
- 4. Port Smarts.** An accessible ship doesn't necessarily mean the ports are. Itineraries that have ships “docking” at a pier provide easier access than ships that must “tender” guests ashore using small lifeboats which may have weight and wheelchair restrictions.
- 5. Tide Table.** Be aware of the changing tides. If the tide is out, the on/off ramp can be too steep and the ship may be forced to use a staircase instead.
- 6. Brakes.** Make sure you have (and apply) brakes or park correctly. Whether you're eating, taking in a show, or sitting pool-side, you're still technically in transit.
- 7. Excursion Etiquette.** When booking, opt for an accessibility-friendly itinerary. You can find excursion information aboard, but be sure to explain in advance that you'll be in a wheelchair and needing accessible accommodations.



Whether
items will



8. Accessible Amenities Brochure. Cruise lines typically publish online information spelling out what services are available and what staff will or will not do.

9. Accessible Room. “We’re accessible” isn’t always what it sounds like, so do your due diligence.

10. Workout Gear. Many cruise ship gyms don’t have the equipment you’re used to at home. Keep fit by doing laps around the boat deck or going for a swim in the pool.

11. Staying Mobile. Mega-ships can require covering long distances to get to the different dining and entertainment option onboard. Many travel companies can arrange for extra equipment, such as scooters or chairs, to meet you when you arrive in your stateroom so you can roam freely—just try not to get lost!

12. Assistance Dog. If you’re travelling with a service dog, book early and inform the cruise line. Have the proper documentation, such as service dog certification or vaccination papers, and ensure that foreign authorities will allow you ashore.

13. Equipment rental. Organize your rentals in advance. Some ships have a limited number of wheelchairs or other equipment available on loan; if you absolutely require a wheelchair, oxygen concentrator, scooter or other equipment during your cruise, book early. An agent can help!

You can read about the other cruise essentials in this photo and find more tips about accessible cruising at sci-bc.ca/stories/blog. Need help booking a cruise or getting your documents and rentals in order? Visit www.taritatravelconnections.com, where a portion of the proceeds from every cruise booked supports SCI BC programs and services. ■

Cruise Control

you’re a first time cruiser or a seasoned sailor, these must-pack help keep your accessibility concerns at bay on the high seas.

Outside In

Former model, dancer and Paralympic athlete Teri Thorson takes an inverted approach to confidence with her new consulting business for people with SCI.

It may not be what's on the outside that counts—but sometimes a polished exterior is the only way to the beauty within. At least that's how Teri Thorson sees it. The adaptive fashion designer, mom, and SCI BC Peer thinks of "opportunity" not as unattainable and random, but as something that you can attract and make happen for yourself.

"When you're presenting yourself well and showing off your best assets, you're building your confidence and self-esteem, and that presents more opportunities," says Thorson. "Not only do you become more approachable. When you're confident, you're approaching people and putting yourself out there."

Thorson remembers the way her sense of self imploded after her injury. "I lived in a really superficial world and image was really important to me," she says. "And I really felt like my whole sexuality got stripped away. I was no longer even a woman anymore. My wheelchair was my distinguishing feature."

She found the standard rehab fashion prescription of running shoes and pants with elastic waistbands hard to swallow. ("I've never owned a pair of track pants!") So she vowed to wear what she always wore, turning stylish fashion work-arounds into her own adaptive clothing line, Normal? Fashions.

Now, Thorson's philosophy and own life experience—as a designer, an extrovert and a person living with a disability—have spurred her to launch an image consulting business aimed at helping others put their best selves forward, regardless of ability, age, gender, or budget. Her custom one-on-one consultations can range from a single meeting to larger plans encompassing fashion advice (she will go through your closet), presentation tips (a little lip effort goes a long way), and referrals to nutritionists and personal trainers.

And she's always happy to hand out her go-to tip for free: "There's an old adage that says, 'Fake it 'til you make it. Just smile, even if you're feeling crappy. The times when we're feeling down are the times that we often don't see those opportunities—to make friends, to meet a partner, to find a job.'"

So when you can't really count on the inside, you just have to count on what's outside. "Eventually," Thorson promises, "if you keep on smiling, you'll kind of feel better, too."

I struggled for many years with body image—and it doesn't help when you can't find the right clothes. Either they're too baggy in the legs, too tight around the middle, show my butt crack, difficult to put on, or just all-around hideous.

Nineteen years ago I found myself in a unique position after an SCI. Previous to my injury, I was all about image. I was a model and dancer, and I rarely even spoke. I didn't need to—my power was my 5'11" height. I rarely had a problem getting positive attention when I needed it.

But that ended after my crash. Suddenly, it was like I lost my sexuality, my image, my femininity, and my power all at once. I saw myself as too skinny, yet also flabby and fat, short, and *GASP* having to rely on my brain. It's taken me a long time to learn to feel good about myself and to develop my custom clothing line Normal? Fashions, for women who are seated.

But not all of us can afford to custom-make our clothing. Along the journey, I've learned some tips and tricks to get you looking and feeling good, regardless of your budget.

1. Look in the mirror. What do you think is your best physical attribute? Do you love the colour of your eyes? Wear makeup to accentuate them, and make sure you use them in connecting with people—eye contact! Breasts? Invest in a good bra that fits you well, wear lower-cut tops and highlight your décolletage with a shimmery powder. Arms? Opt for T-shirts or form-fitting tops, put lotion on your arms, and build them up by doing a few weights, curling cans of food or using TheraBands.

2. Pick out an outfit or article of clothing that you own and love. Why do you love it? Is it the colour? The fit? The feel? Find other pieces that are similar and wear them more often. (Yes, even when you're not going out somewhere! It's important to feel good for yourself, not to impress or attract others.) And please rid your closet of clothes that are worn out,



out of date, or that don't fit anymore. Keep only the clothing that fits you in the body you're in now. If you can't bear to part with an ill-fitting item, take it to your local tailor.

3. Keep it clean. Grooming and hygiene are essential to feeling good. Make sure you are clean and showering daily (or every other day) if you can. Just a quick freshen-up with a soapy washcloth will work. (Even though some of us don't sweat, we still get stinky.) Trim, wax, shave as much as possible. For facial and pubic hair, trim up just using scissors or clippers—even if you like it long, make the hair a uniform length. And don't forget to keep your nails clean and trimmed.

As for those leg bags and tubing, keep them clean and fresh by rinsing with hot water daily, and occasionally with a little bleach. My personal opinion is to keep the bags tucked away. If you're wearing shorts or short skirts, shorten up the tubing and strap it to your thigh.

Cushion covers are another item that need regular cleaning.

Those of us who use wheelchairs seem to bash our feet up pretty good, so be aware of where they are and treat them with love. (You never know—we may need them one day!)

If you need assistance to do these things, you can hire an aesthetician, friend or family member.

4. Put effort into your image, even when you're not feeling up to it. A bit of lip gloss, blush and mascara are good staples. Just a spritz or two of perfume or cologne make a difference. And try to wear something other than sweat pants and slippers. We all want to be comfortable, but I guarantee that you can find *nice* clothing that is comfortable, easy to put on, and won't give any unwanted pressure.

5. Smile. Even if you aren't feeling it, just smile. It makes you look open and approachable, and can help pick you up when you feel down. If you're having a hard time faking a grin, or feel goofy doing it, think of a time when you felt really happy. Sit with that feeling, building it up so you can relive that experience again. Not great at channelling old emotions? Fake it 'til you make it if you have to.

6. Alter it. Everything you buy from a store should be altered to fit you. No one except mannequins are meant to actually fit these clothes, and you can find a tailor almost everywhere. The tailor can measure you or, if it's difficult to try clothes on from your wheelchair, you can bring something that fits you and get your new item altered to those measurements. Make sure the clothes are fitted—loose and baggy clothing will make you look larger (or skinnier, for some). Your clothes should not fit tightly but skim your body by about a centimeter. When

you do buy a new item, fit the largest part of your body first, then get all the other areas taken in. And don't worry about the size! These are just numbers and every store is different.

7. Get active. Find something you're passionate about and just do it! There are endless opportunities to get engaged. Chances are that not everything will be a fit for you, so try a variety of hobbies or activities—anything from sports, to woodworking, gardening or the arts—until you find the right one. Can't find exactly what you're looking for? Create it! Not only will you get out doing things, but you'll also meet an amazing group of people that have the same interests as you.

8. Eat well, healthy and clean. Your body is a machine, so fuel it properly. Stay away from sugar and, unless you're really active, avoid carbs such as breads, pastas and chips. Try to eat small amounts more frequently (larger meals are harder to process) and opt for whole grains, vegetables and protein. Most importantly, steer clear of fast or processed foods—if you can still eat it after a week of it sitting on the counter, it's probably not good for you.

9. Stay positive. We all have issues to deal with, and venting can be good—but don't overdo it. Don't dwell on the negative—after you vent, let it go. Better yet, acknowledge it and make the conscious choice to not let it affect your mood. You are the only person responsible for how you feel, good or bad. We have all the power and control when it comes to our feelings. Don't give someone else the power to make you feel a certain way.

10. Get uncomfortable. Try a new activity, style, or way of dealing with things. Of course it's comfortable to do what you know, but why not try something different? (Especially if whatever you're doing isn't working for you!) Don't hold yourself back. If you find yourself making excuses to not do something, ask yourself, "What am I afraid of?" Chances are it's something you're scared of or uncomfortable admitting to, but I assure you that there's no greater feeling than getting out of your comfort zone and facing your fears.

Keep in mind that it's really not about doing these things in every moment. I fail at doing them many times myself—which is the great thing about being human. Failure creates options, choices and experiences. And remembering that we have options and choices can help us to get over the negative things that make us, and those around us, feel bad.

We all have our up and down days, and that's okay. Acknowledge your negatives—but don't stay in them. Find what makes you feel good and seek out new ways to add more of that goodness into your life! ■

For more information on *Normal? Fashions* or to book an image consultation, contact Teri at terithorson@yahoo.ca.

ask the SPIN DOCTOR

One of our readers from Vancouver Island writes, "I've got a friend who is paraplegic. He doesn't seem himself lately, and I'm wondering if he's going through some depression. Can you tell me what to look for?" To answer this question, we asked Kailey Toth, MSW, RSW, Social Worker at GF Strong Rehabilitation Centre.



Many people with an SCI suffer from depression, but that doesn't mean that depression has to be a part of life with an SCI.

Studies show that about 20 percent of people with SCI experience depression—a mood disorder that is much more serious than "feeling down in the dumps." We don't know the exact mechanism behind depression, but we do know that it can be triggered by trauma, stress, pain, psychosocial stressors and many other things, which in turn lead to a change in certain brain chemicals known as neurotransmitters.

There are many telltale signs. Major mood changes, lack of ambition, reduced ability to solve problems, lethargy, sleeping too little or too much, poor appetite, poor hygiene—these are all indicators that someone might be experiencing depression.

In turn, depression can lead to physical illness for people with SCI—they may not drink enough water for their bladder program, take care of their skin or relieve pressure properly, or manage their diet adequately. People with depression may isolate themselves from their friends and family. Substance misuse may become a concern as people attempt to self-medicate their feelings of low mood. It's important to note that serious depression can lead to suicidal thoughts or behaviours, often when people feel that they have nowhere to turn and no hope for feeling better.

If you're concerned about your friend, talk to him and encourage him to get the help he needs. He may be relieved that you have noticed that he is struggling and open to talking about it. You can encourage him to seek support and counselling, try antidepressant medications, or try a combination of treatments.

At times, living with an SCI can be overwhelming. Finding ways to connect with and give back to others can be a part of re-defining a new sense of self. Adopting a more active lifestyle can be a part of this and can also help to break through depression.

If you think the depression is worsening, and you can't convince your friend to seek help, you may have to connect with his family and extended support network to have his family doctor or other medical professionals intervene. One of the best things you can do is be open and honest with him about how concerned you are—let him know you are there to support him.

This year, SCI BC's annual SCI Forum aims to demystify common misperceptions about mental health and explore strategies that help improve mental wellness. It happens on April 16 at the Blusson Spinal Cord Centre—see page 8 for more details.



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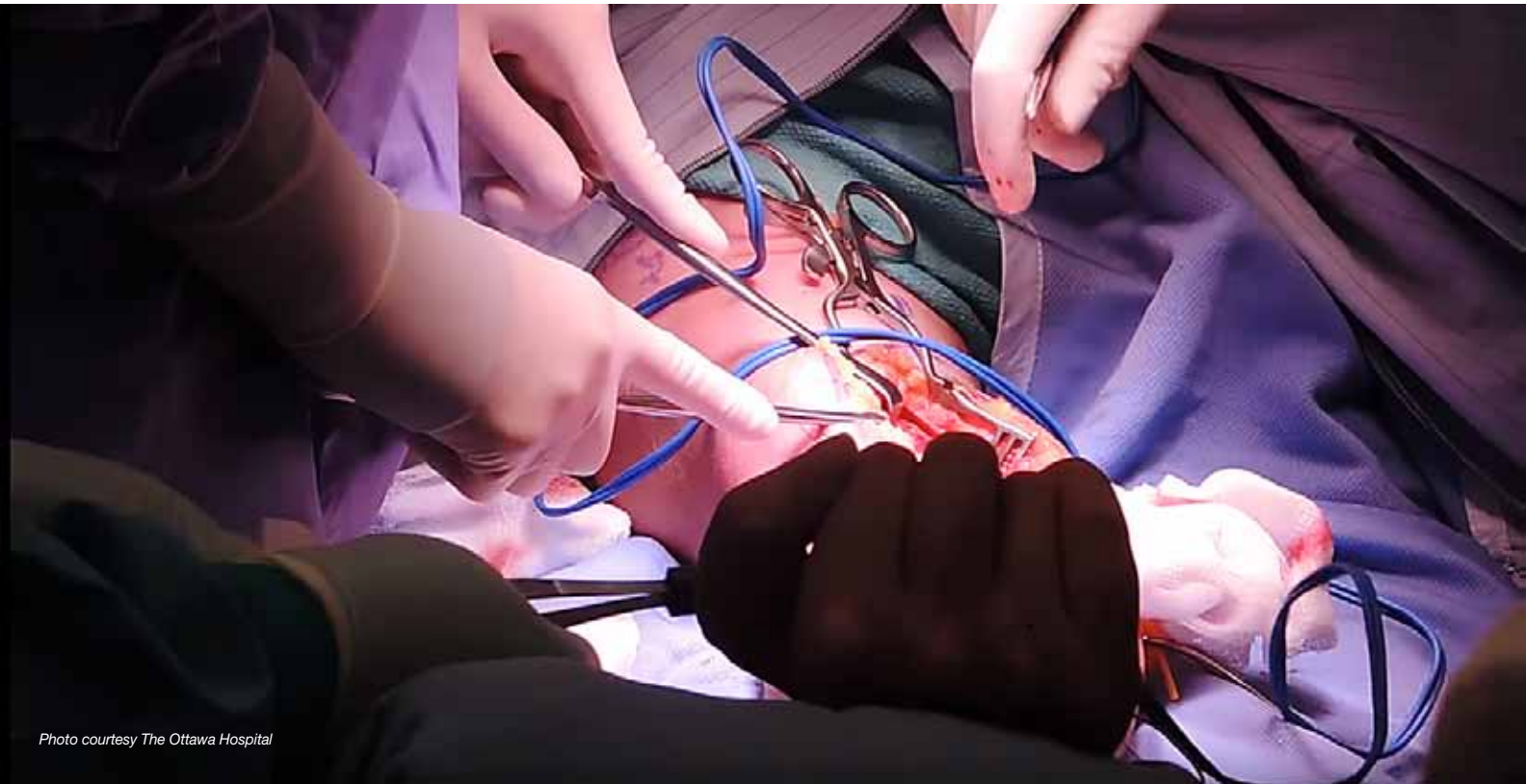


Photo courtesy The Ottawa Hospital

Getting Your Wires Crossed

A new study validates nerve transfer surgery as a way of improving hand function for some people with quadriplegia, just as the procedure debuts in Canada.

“Victory is won not in miles but in inches. Win a little now, hold your ground, and later, win a little more.”

— Louis L’Amour

Cowboy fiction writer Louis L’Amour probably wasn’t thinking about SCI when he wrote that iconic quote, but it’s certainly appropriate.

Case in point: nerve transfer surgery to restore modest amounts of function and strength for people with C6 - C7 quadriplegia. It’s far from being a cure for SCI, but that doesn’t make any of its recipients any less enthusiastic about it—while the handful of people who have had the procedure report incremental improvements

in function, they say those improvements have resulted in huge improvements in their quality of life.

Essentially, the surgery involves connecting a nerve in the arm that is healthy, but not functioning because it emerges from the spinal cord below the injury site, to another nerve in the arm that is fully functioning because it originates above the injury site in the spinal cord. The result in most cases is reestablishment of some communication between the brain and the paralyzed arm or hand

muscle being targeted. (Note that this description is greatly simplified—please see page 31 for a detailed explanation of how this surgery is performed and why it's successful for some patients.)

The surgeons who helped pioneer the procedure published the promising results from nine patients with quadriplegia in the October 2015 issue of the American Society of Plastic Surgeons' journal *Plastic and Reconstructive Surgery*. Meanwhile, the procedure has recently been adopted by a surgeon in Canada, with others considering offering it in the future. So with compelling evidence and emerging availability, nerve transfer surgery may be an attractive option for some readers of *The Spin*.

It's fitting that the procedure has found a home in Canada, as it was actually developed by a Canadian. Dr. Susan Mackinnon is a graduate of Queen's University in Kingston who moved in 1982 to the USA, where she has earned a reputation as one of the country's leading plastic and reconstructive surgeons.

Now the Chief of Plastic and Reconstructive Surgery at the Washington University School of Medicine in St. Louis, Mackinnon started exploring nerve transfer surgery in 1988. For years, she and her colleagues used the procedure to restore movement in the foot or an arm of patients with injured peripheral nerves. But about five years ago, she and

colleague Dr. Ida Fox began to employ the technique to restore some limited hand function in patients with SCI. Since then, a number of quadriplegics from across the USA have had the procedure.

One of those who have benefitted is a physician himself, and a colleague of Fox and Mackinnon at the Washington University School of Medicine. Dr. Michael Bavlsik was injured in a car crash in 2012. After the surgery, Bavlsik regained the ability to grip with his left hand—essential for his work as a doctor and assistant professor.

"Nerve-transfer surgery has been very successful in helping me because it restored triceps function and improvement in my grip," says Bavlsik. "I am extremely grateful for this surgery."

Bavlsik's surgery, along with that of eight other recipients, was reviewed in the *Plastic and Reconstructive Surgery* journal article. The other eight also reported various levels of improvement in hand and arm function. The conclusions, as summarized in the article's abstract, leave little doubt that the technique can provide significant benefits. "Nerve transfers can provide an alternative and consistent means of re-establishing volitional control of upper extremity function in people with cervical level spinal cord injury," wrote the authors. "Early outcomes provide evidence of substantial improvements in self-reported function

despite relatively subtle objective gains in isolated muscle strength."

No doubt, the results of the study will create demand from more quadriplegics. Which brings us to you, the reader who is quadriplegic and might do just about anything to get enough grip or pinching strength to eat, self-cath, write, or button up clothes. No doubt you're wondering, "Well, when can I get this surgery?"

The answer is, perhaps you already can, providing you meet the criteria.

In February 2015, Dr. Kirsty Boyd, a plastic surgeon at The Ottawa Hospital, performed the surgery on two patients—44-year-old Tim Raglin, and 21-year-old Brett Nugent. Nugent and Raglin became the first Canadians to receive the operation, and it was also the first time the surgery had been performed in Canada.

Raglin, who became quadriplegic in a diving accident six years ago, can take credit for getting the ball rolling. When he learned about the procedure in 2013, he asked his physiatrist if he could get it done in Ottawa. In turn, his physiatrist referred him to Boyd. As it turned out, Boyd knew Mackinnon well—she had completed a year-long surgical fellowship with her in 2011, with the focus on nerve transfers. So she agreed to give it a try.

Boyd relied on Dr. Gerald Wolff, co-founder of Ottawa's Peripheral Nerve Trauma Clinic, to determine if Raglin was an ideal candidate. Wolff gave



NERVE TRANSFER PIONEERS: Brett Nugent (left) and Tim Raglin are Canada's first recipients of nerve transfer surgery to restore hand function in people with quadriplegia. After a year's wait, both are now beginning to experience some restoration of function.



the green light for Raglin, and also for Nugent, a quadriplegic as the result of a hockey accident who had been approached to see if he was also interested.

When the procedures were done last February, they were completed under the watchful eye of both Mackinnon and Fox, who travelled to Canada on their own dime to supervise Boyd's first two attempts at the procedure. By all accounts, both surgeries went flawlessly, and both Raglin and Nugent returned home to patiently wait for any signs of improvement—something that can take up to a year to show up.

Why so long? "The distance required for the nerve to regrow inside its new route and reach the new muscle is such that we would not have expected to see any changes within the first six months," says Boyd. "If the procedure is successful, then one may notice slow gains

between six months and three years post-operatively."

Fast forward to February 2016, when we reached Nugent and Raglin in Ottawa to talk about their surgery, and their progress to date.

"It took about three hours and went perfectly," says Nugent. "I healed quickly and had no complications. I was wheeling around on my own in about three weeks, and was back to playing (rugby) in about a month."

Raglin's surgery also went smoothly.

But what about results? As predicted, both are showing signs of success.

"The first little things that I noticed that kind of tipped me off about the transfer beginning to work was the fact that my fingers began to tighten up," says Nugent, a university student who leads an active lifestyle. "Before they remained fairly loose and my hand stayed

a little more open but now it tends to keep a more closed grip position. I'm not quite sure when this started since change is slow, but I would say around three months ago or so I noticed this. Now I notice I can tighten my grip in my hand a little more on my own, and it continues to get much stronger. Looking forward, I'm hoping to see more change in the opening of the hand as well."

For Raglin, the first sign happened during a therapy session just before Christmas when he noticed a slight twitch that he thought at first was simply a spasm. "It was only after sitting with the therapist that I realized it was actually me making my fingers move," he says. "From that point on, we've seen very small incremental movements that are controlled by me. Basically, I can open my fingers slightly more than I could before Christmas and I have

BC's Own Nerve Transfer Pioneer

If you're interested in having nerve transfer surgery, Dr. Sean Bristol and his team are likely your best (and only) option here in BC. Bristol is an Assistant Professor in UBC's Division of Plastic Surgery, and a clinical researcher conducting studies related to his plastic surgery clinical practice. Among his areas of interest and specialization is nerve and tendon surgery to restore hand function.

"I got into nerve transfer surgery generally because of the capabilities it provides over and above nerve grafts," says Bristol. "And we've never really had an option for tetraplegic patients before. The expansion of the nerve transfer into that field is exciting because it's about gaining more function where we never thought there could be any before."

Bristol and his colleagues have recently started a clinical trial to evaluate the impact of nerve transfer surgery for people with tetraplegia. But the specific surgery is somewhat different than the procedure that Dr. Boyd provided to Tim Raglin and Brett Nugent, as described in the main story. It involves transferring a nerve from the supinator muscle (the nerve is called a supinator motor branch) to the posterior interosseous nerve, or PIN, which is a nerve in the forearm that controls the muscles that allow us to extend or flex our fingers and thumb.

"The benefit is that (participants) will be able to extend their fingers and thumb, in order to grasp some larger objects," explains Bristol. "The great difficulty getting fingers and thumb out of the way without having to use the wrist as a fulcrum is challenging for the tetraplegic patient, and that's one that (surgeons) can't do well for using tendon-based operations. That's why we decided to focus on this procedure."

The first of five participants in Bristol's trial had the surgery just

after Christmas. As with all nerve transfer surgeries, it will be months before any benefits materialize. Bristol explains that the ultimate goal will be to determine the quality of life impact of the surgery, and adds that once a patient experiences some restoration of the finger and thumb extension, they could then be offered a tendon transplant to improve grip strength as well.

"I think we're approaching our study in a cautious and ethical way," he says. "We want to make sure we're going about it the right way, and not trying to just be the first one out of the gate."

While he's focused on the specific surgery employed in his study, Bristol has also performed several of the procedures that Dr. Boyd performed with Raglin and Nugent—but with patients who have a damaged brachial plexus nerve due to something other than SCI.

"I would offer those procedures now," he says. "Of course, we would like to enrol patients in our study. If they're interested in participating in the study, then we'll enrol them in the study. But if they're not, and they want to do other nerve transfers, then I'll talk to them about the risks and benefits of those other transfers. We can technically do those any time, and I'm happy to see patients in that regard."

Once again, there's the thorny issue of "who pays?" But just as Boyd has offered the procedure in Ottawa at no charge, Bristol is also adamant that there will be no cost here in BC.

"If they've got BC Health Care, it gets covered under BC HealthCare, as far as I'm concerned," he concludes.

If you think you're a candidate for either of the nerve transfer surgeries described above, speak with your own doctor or physiatrist about a referral.



slightly more control closing. Again, we're talking miniscule movement here—millimetres at the most."

Now that Raglin and Nugent are showing signs of improvement, they'll have to work hard to maximize any benefits.

"Patients are initially given some guidance on what they should be doing on their own for the first six months," explains Boyd. "After that, they start working with a hand therapist. The frequency of visits will depend on what gains the patient makes, how quickly the patient learns to perform new exercises, and

what supports the patient has at home to work on the rehabilitation program. Therapy will likely continue for up to two years."

This therapy is necessary to train the brain to recognize the new nerve signals. "In a nutshell, therapy involves loosening up my hand as the muscle is slightly tight, and then practicing triggering the muscles that move my fingers through various exercises," says Raglin. "As it stands now, therapy is scheduled to be pretty intense over the next couple of months and then slow down in spring and summer. I have plenty of exercises to

Nerve Transfer Surgery: The Fine Print

Who is it for?

This surgery is only appropriate for those with a specific level of injury—C6/C7. It typically does not help people who have lost all arm function due to higher injury levels. Although younger candidates may respond better, there is no age limit, nor are there any restrictions about time from injury. Candidates go through a rigorous evaluation to determine suitability. They must have movement in their upper extremities, which signals that there are nerves in their arms that still communicate with the brain. Arm and hand muscles must be well-preserved. Other factors include functional goals, neurological deficits, contractures and spasticity.

How does it work?

The technique restores some communication between the brain and the paralyzed muscles of the hand by rerouting healthy nerves that emerge from the spinal cord above the injury site and connecting them with the target nerves in the hand and arm that are damaged where they emerge from the spinal cord below the injury site. The benefits are not immediate—after the surgery, it takes six months or more for the nerves to merge and restore communication between brain and hand. Once a connection is established, patients undergo extensive physical therapy to train the brain to recognize the new nerve signals, a process that takes up to two years.

What does it entail?

Prior to the procedure, the surgeons determine which nerves they are targeting—both a donor nerve, and the recipient nerve.

Since the primary goal is to improve grip or pinch function, the recipient nerve is almost always the anterior interosseous, or AIN. Although it no longer carries signals, the AIN looks like any other healthy nerve, since it still receives blood and nutrients.

The donor nerve, meanwhile, must be redundant—in other words, it will be expendable because other nerves are present that perform the same task. In most cases, the donor nerve is the brachialis—a nerve that triggers flexing in the elbow. It's expendable because there are two other nerves that perform the same job.

Once the targets have been determined, the surgeons create a long incision on the inside of the arm and begin to unpack its muscles, arteries, tendons and nerves. They then search for the appropriate peripheral nerves, which look like cooked spaghetti.

The peripheral nerves are essentially nerve bundles—they consist of a bundle of smaller nerves that control specific functions. Once identified, the covering of the peripheral nerve is cut back to reveal the smaller nerves inside. Then, using a tiny electric current, each of the smaller nerves are activated to see which function they perform.

Once the donor and recipient nerve are isolated, they're cut and attached to each other. Again, however, there is no immediate connection—in fact, the interior of the recipient (the AIN) starts to die and disintegrate. However, the empty nerve tube remains intact, and the rerouted donor nerve slowly grows down to the muscles of the thumb and finger. That's a distance of about 20 centimetres, and the donor nerve only grows about one millimetre a day, which is why benefits of the surgery don't appear until months down the road.

With the new connections made, the surgeons return all the arm's components back to their original position and state, and the incision is carefully sutured.

What happens next?

The patient has to do intense physical therapy to relearn how to trigger hand movement. That process is more difficult than it sounds because the individual will be using a nerve that used to bend the elbow to move the thumb and index finger. It takes time for the brain to adapt to this new reality.

What are the limitations?

Right now, the surgery has a number of limitations. First, it is limited by the number of redundant nerves in the body that surgeons can "borrow" to put to use elsewhere. Second, it is limited by the rate of nerve growth following a peripheral nerve injury, which is essentially what the surgeons create when they cut the brachialis nerve and join it to the anterior interosseus nerve. The nerve must regrow to the target muscle within 12 to 18 months or else that muscle will become damaged. It means, for instance, that a nerve transfer in the leg is unworkable because of the required distance: by the time the nerve fibre reached its target, the muscle would no longer be responsive.

Researchers, however, are working to speed nerve growth and to preserve unconnected muscles so that they remain receptive to nerve growth for a longer period of time.

do at home—this will help move things along faster than just relying on the sessions with the therapist.”

Despite the long wait for results, both Nugent and Raglin have never second-guessed having the procedure. “Waiting was never difficult, since I had already learned how to manage everything using the amount of function I had, which was very little,” says Nugent. “I never really gave up hope as I was pretty optimistic and so were my doctors. Right now, the impact is pretty minimal in my life, since it’s still in the early stages. But I’m optimistic that it will make daily routines and functions a little easier. Right now it’s really still just a waiting game as things continue to progress.”

“I didn’t lose confidence at any time that something would happen,” adds Raglin. “Again the definition of what that is has yet to be determined, whether it be a small pinch or an actual grasp. I’m pretty confident something between those two extremes will happen.”

The surgeries for Raglin and Nugent were well-publicized, particularly in Ottawa-area media, and Boyd says that initially sparked interest from other quadriplegics in Ontario. But up to this point, no suitable candidates have been identified. Boyd says that’s likely to change, particularly since Raglin and Nugent are now experiencing some improvements. And she adds that at least three of her Canadian colleagues are interested in learning the procedure.

“Dr. Chris Doherty and Dr. Tom Miller have evaluated patients in London, Ontario, and are planning to perform these surgeries in the near future,” she says. “In Vancouver, Dr. Sean Bristol and his team have expressed an interest in doing this procedure (see sidebar on page 30). And there are a handful of surgeons across the country who are performing nerve transfers in the peripheral nerve injury population, and it’s possible that these surgeons will apply the technique to patients with SCI in the future.”

So it seems likely that the surgery may be an option for readers who meet the criteria. That, of course, leads to the million dollar question: who pays?

Here’s how Boyd describes that particular issue: “In the Canadian health care system, these surgeries are performed with no cost to the patient. There is no expensive equipment or implantable device that need to be covered. The only costs are the operating room time, the surgical materials, and post-operative rehabilitation. Unfortunately, given the unique nature of the procedure, there are no billing codes in the Ontario Ministry of Health Schedule of Benefits for Physicians that accurately reflect the complexity of the surgery and the time involved. Therefore, the procedure requires a surgeon who is willing to make a fraction of what they might otherwise make during a normal operative day.”

If you have the stomach to view it, The Ottawa Hospital has posted an excellent (but somewhat graphic) video of the surgery on YouTube—search for “first nerve transfer surgery in Canada” at www.youtube.com. ■

Botulinum Toxin & SCI Neuropathic Pain

Botulinum toxin type A, or BTX-A, is quickly becoming a common tool for treating several secondary complications of SCI. Today, BTX-A (also commonly known as Botox, which is Allergan’s trade name for its form of BTX-A) is being safely and successfully used to treat neurogenic or overactive bladder, as well as spasticity, for many people with SCI. Neuropathic pain could soon be added to the list.

In a study published in the February issue of *Annals of Neurology*, Dr. Zee-A Han and other researchers at the National Rehabilitation Center in Seoul, South Korea, outlined their apparent success in using BTX-A as a treatment for SCI neuropathic pain. The study, titled *Botox May Reduce Neuropathic Pain in Spinal Cord Injury*, enrolled 40 participants with SCI-associated neuropathic pain. The participants were randomly chosen to receive either a one-time subcutaneous BTX-A (200 units) injection or a placebo injection at the painful area. The study was double blind, meaning that neither the participants nor the researchers knew whether the participant was receiving BTX-A or the placebo.

Each participant was evaluated for pain before the injections, and then at four and eight weeks after the injections. Widely accepted methods of evaluating pain were used, including the short-form McGill Pain Questionnaire, developed by Dr. Melzack at McGill University in Montreal.

The researchers determined that those who received the BTX-A injection reported significantly more pain relief than those who were given the placebo. At four weeks after injection, 55 percent reported pain relief of 20 percent or greater, compared with 15 percent of those given the placebo. The result was similar at the eight week mark—45 percent versus 10 percent.

“These results indicate that BTX-A may reduce intractable chronic neuropathic pain in patients with spinal cord injury,” the authors wrote. They also made it clear that the treatment did not reduce motor or sensory function below the injury.

BTX-A is Botulinum toxin, one of the most poisonous biological substances known, is a neurotoxin produced by the bacterium *Clostridium botulinum*. It works by interfering with transmission of nerve signals by blocking the release of acetylcholine, the principal neurotransmitter at the neuromuscular junction, leading to muscle paralysis.

Please note that this was an industry-supported study—Medytox, a maker of botulinum toxin products, supported the researchers’ work.



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.

Increasing Knowledge and Physical Activity Participation Levels in People with SCI

Overview: Dr. Tania Lam and her team are recruiting SCI participants for a study investigating the effects of knowledge translation on exercise self-efficacy and physical activity levels in people with SCI. This research study is proposing that, by increasing one's knowledge on why, where, how much and how to exercise, we can address the common barriers to physical activity and increase one's self-efficacy and exercise participation levels.

What to expect: Eligible participants will meet at the Physical Activity Research Centre (PARC) at ICORD for a one hour meeting with either an SCI peer or UBC student non-peer to discuss SCI-specific physical activity guidelines, common barriers to exercise, and exercise goal setting. It will then be up to participants if they would like to meet again within the duration of the 12 week study. Additionally, participants will be asked to complete three questionnaires at four time points throughout the 12 weeks; some of these questionnaires will be completed at home.

Who can participate: This study is open to men and women, 18 to 65 years of age, who have had a chronic traumatic SCI for at least nine months, and currently engage in exercise less than 50 minutes per week. You must have reliable transportation to the Blusson Spinal Cord Centre and be in a stable medical condition. A physician completed PARmed-X form will also be required. This form can be found online at www.icord.org/wp-content/uploads/2015/08/PARmed-X.pdf.

Why participate: While it's not known if participants will derive any direct benefit from participating in this study, evidence indicates that participation in physical activity has the potential to improve and/or maintain functional ability, aerobic fitness, strength, fatigue and quality of life, and decrease the risk of chronic disease and depression for those with SCI. There are no costs for this study. Participants will have free access to this state-of-the-art accessible exercise facility. Free parking at the Blusson Spinal Cord Centre is available for research participants with a valid SPARC pass.

Location: Blusson Spinal Cord Centre, Physical Activity Research Centre (PARC), and by phone or email.

For more information or to sign up: Please contact the study coordinator, Megan Brousseau, by email (parc@icord.org) or call 604.875.8814.

Treating Episodes of High Blood Pressure Following SCI

Overview: Dr. Andrei Krassioukov and his research team are currently recruiting SCI participants for a clinical research study investigating the effects of fesoterodine (TOVIAZ®) on episodes of high blood pressure triggered by bladder contractions. This research study is proposing that by treating urinary bladder dysfunction with fesoterodine and preventing the bladder muscle from contracting, we will decrease the triggers responsible for these episodes of high blood pressure that are known as autonomic dysreflexia (AD).

What to expect: Eligible participants will undergo a series of invasive and non-invasive tests before and after 12 weeks of treatment. Additionally, participants will be asked to complete a series of questionnaires; some of these questionnaires will be completed at home.

Who can participate: This study is open to men and women 18 to 55 years of age who have had a chronic traumatic SCI at or above T6 for more than one year, have a documented presence of autonomic dysreflexia and neurogenic detrusor overactivity during urodynamic studies, and have hand function to perform clean intermittent catheterization. A full list of eligibility requirements and exclusion criteria are provided online (see website address below).

Why participate: While it's not known if participants will derive any direct benefit from participating in this study, there are no costs for tests, examinations, and medical care required as a part of this study. Some of these costs, such as 24-hour ambulatory blood pressure monitoring, may be part of a participant's routine care that may normally be paid out of pocket, in which case it will be provided at no cost to participants. Enrolled participants will receive \$50 per visit for participation in this study to offset the cost of travel for study visits. Participants will also be reimbursed up to \$12 for parking at UBC hospital; free parking at the Blusson Spinal Cord Centre is available for research participants with a valid SPARC pass.

Location: Blusson Spinal Cord Centre, UBC Hospital Bladder Care Centre, and by phone.

For more information or to sign up: Please contact the study coordinator, Andrea Ramirez, by email or call 604.675.8856. More detail is also available online at www.icord.org/studies/2016/02/treating-high-bp/.



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 www.icord.org/research/participate-in-a-study

Pain & Placebo

Science tells us that the placebo effect is very real. But does it get in the way of finding more effective treatment strategies?

The placebo effect is a complex and powerful mechanism in the human animal. Basically, it works like this: you're given a sham treatment for an ailment such as chronic pain, but because you're convinced you've received a real treatment, you begin to feel better.

Years ago, the scientific community was somewhat sceptical of this phenomenon. But the power of placebo is now accepted as very real, thanks to some excellent research in the last few decades.

Relief is relief, no matter how you spell it, right? But sometimes, the placebo effect can cause more harm than good.

"The placebo response is a fascinating concept, and sometimes a positive outcome for those experiencing discomfort," says Freda Warner, a research assistant at ICORD and a PhD student at UBC who focuses on SCI-related chronic pain. "However, when attempting to identify treatments for ailments such as neuropathic pain, the placebo response can sometimes be a detriment. Studies often want to demonstrate that a group who is receiving a treatment has improved outcomes over a group that is receiving a placebo. If the placebo group is demonstrating a strong placebo response—for example, decreased pain—this makes it less likely for the statistics to show that the treatment is more effective in decreasing pain than the placebo. So, for many studies, one goal is to limit the placebo response in order to show the true effects of the treatment."

"The problem is that clinical trials in the field of pain are extremely difficult to conduct and very often fail," adds Dr. John Kramer, a UBC and ICORD neuropathic pain specialist who is also Warner's research supervisor. "One commonly cited issue is unexpectedly large placebo effects. Effectively, these large

changes in pain rating without an actual treatment are thought to wash out the potential 'real effect' of the medication being evaluated."

For this reason, Warner and Kramer, along with several colleagues, recently finished a comprehensive systematic review and meta-analysis of the scientific literature in an attempt to identify factors that increase or decrease the placebo response in studies involving people with central neuropathic pain.

"Basically, our meta-analysis is trying to better understand placebo, so that we can predict what's likely to happen, and thus better design a trial," says Kramer.

FYI, the overall goal of a meta-analysis is to condense existing data from a large number of studies in a single document. In this case, the researchers reviewed the findings of all appropriate placebo-controlled trials examining drug and brain stimulation treatments for central neuropathic pain—in SCI, but also in stroke and MS. A total of 39 published trials met the criteria.

Overall, there was a significant effect for placebo to reduce central pain, regardless of what caused it. But again, the main goal of the review was to determine factors that lower the placebo effect. And some trends did appear as the meta-analysis proceeded.

"For example, we found that people with long durations of chronic pain experience less placebo, so one strategy to limit placebo would be to include only subjects with very long durations of pain symptoms," says Kramer.

He adds that smaller placebo responses were also associated with crossover-design studies, which have the participants randomly chosen to receive a *sequence* of treatments (which may include actual drug

and placebo), instead of just an either/or scenario. As well, including participants with a wide range of reported pain levels, as opposed to just individuals who report the same pain level, also tends to lessen the likelihood of having the results skewed by placebo effect.

In that sense, the review succeeded—it did determine that there are some effective methods of reducing undesired placebo effects. But perhaps more intriguing to some readers is the finding that, "Overall, there was a significant effect for placebo to reduce central pain."

Which leads us to ask: what about the possibility of better harnessing the power of placebo as an actual therapy?

"People have, understandably, quite controversial opinions about this," says Warner. "The placebo response is critically dependent on patient expectation of analgesia, which means that a level of deception is required in order to effectively 'prescribe' a placebo. This type of deception goes against what much of the population believes physicians should adhere to as a moral code, whereas others believe that any level of relief, no matter the reason, should be investigated."

"Placebo as a 'treatment' is indeed very controversial," adds Kramer. "On one hand, if we can reduce pain by any amount, with little more than a sugar pill, this could be viewed as a success. On the other hand, we're interested in developing medications that target the physiology and anatomy of chronic pain. So harnessing placebo to me means that we endeavour to better understand it, in order to determine how we might develop real treatments that tap into this complex network."

The study's findings, titled *Meta-Analysis of Placebo Responses in Central Neuropathic Pain: Impact of Subject, Study, and Pain Characteristics*, was recently published in the journal *Pain*. ■



Freda Warner and Dr. John Kramer

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