

thespin

SPINAL CORD INJURY BC

SUMMER 2018



TAKING CHARGE

Five SCI BC Peers explain why they prefer to manage their own attendants—and provide their best tips for ensuring your own self-managed care success



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COVER PHOTO: Maya Pankalla



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Check out SCI BC's accessible travel resources and start planning your next adventure!

- New Accessible Travel Guide
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- Packing Tips for Travellers with SCI
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Photo: Murray Sage

High Top Tables: Exclusion by Design

Vancouver is arguably the most progressive city in Canada. The city has developed forward-thinking strategies relating to transportation, housing, communication, health, LGBTQ issues, seniors, women and children, indigenous people, and more.

It's also a relatively accessible city, which is why it's a little bit surprising that the City has never had an accessibility strategy. That is, until now.

Thanks to the work of the City of Vancouver's Persons with Disabilities Advisory Committee, Vancouver City Council recently voted to draft, implement, and enforce a city-wide access and inclusion strategy. Kudos to the committee and all who rallied behind them to support the strategy (SCI BC was among those who expressed support). And kudos to city staff and council for adopting the motion.

Despite being a leader in accessibility, Vancouver still has a long way to go to achieve full accessibility for all Vancouverites, and all those who visit our city. The access and inclusion strategy is a vital step towards ensuring Vancouver is a place where everyone can fully participate and contribute. It will also further Vancouver's reputation as a destination for travellers and tourists with disabilities. And in the process, it will set an example for other BC cities and towns to follow.

The strategy's success will require a collective effort, with businesses playing an important role. In many cases, improving access and inclusion will be relatively simple, requiring improvements to obvious shortfalls. For example, consider the recent design trend of high tables in restaurants, bars, and event venues. These high tops are trendy and designed to pack more people into small spaces. But there's a downside: when establishments replace all or almost all of their regular tables with high tables, their businesses exclude most users of mobility devices.

I believe this is largely unintentional—it's more a case of business owners simply not being aware that these tables create accessibility barriers, and prevent potential customers from frequenting their establishments. When they're made aware of the problem, many owners are keen to make changes—especially when there's an easy fix such as replacing a few high tables with regular height tables.

This was certainly the case for SCI BC's SCI Resource Centre Manager, Jocelyn Maffin, and one of her favourite local hangouts, Storm Crow Alehouse. Storm Crow has almost exclusively high top tables. Its one regular table is located near the back, and is intended for large groups—and thus not always available for people with disabilities. So Jocelyn had a conversation with the management about the problem—and she quickly received a positive response: Storm Crow added two lower tables at the front that are prioritized for people who use mobility aids.

We'll wait and see what's included in Vancouver's access and inclusion strategy, but in the meantime, there are many reasonable business owners throughout BC wanting to make their businesses available to as many people as possible. After all, what business would want to exclude a big percentage of their potential customer base? Sometimes, they just need a little bit of information to let them know they're missing out on a growing demographic.

Like the good folks at Storm Crow, business owners and managers who remove barriers will be champions when it comes to making our communities truly accessible and inclusive. When this happens, people will realize that accessible and inclusive cities are not just good for people with disabilities, they're more livable and enjoyable for everyone.

- Chris McBride, PhD, Executive Director, SCI BC



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KINOVA JACO

The JACO is a powerful, dexterous robotic arm that's designed to help people with disabilities become more independent. Developed by Montreal-based Kinova, the JACO mounts to the frame of your wheelchair, and features 16 different movements and three flexible fingers in order to perform everyday activities such as picking up glasses, holding a fork, or opening a door. It interfaces with the ECU of your power chair and works with most controllers, including standard joystick, sip-n-puff, and headrest arrays. Carbon fibre construction means it weighs in at just five kilograms. Visit www.kinovarobotics.com to learn more and see video of the JACO in action.



TOMMY ADAPTIVE

Tommy Hilfiger recently took the wraps off its new Tommy Adaptive line, which features modifications to accommodate those with limited mobility. For example, one of the women's dresses in the line has magnetic closures at the shoulders, which allow it to be easily pulled on over the head of the wearer. For men, a pair of slim-fit jeans offers Velcro and magnetic closures instead of the traditional zipper and button, as well as hidden button loops at the leg opening that allow the hem to be raised up to four inches to accommodate leg braces or orthotic devices. All of the line's offerings are designed to look similar to the Tommy Hilfiger main collections. See it all at tommy.com.



Innovations

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

PULSE III SOLO

Although not designed specifically for people with disabilities, the Pulse III Solo is a "guybrator" that boasts the ability to provide satisfaction without the need for health practitioner intervention for men who have sexual dysfunction due to physical or neurological impairments. The Pulse III uses "PulsePlate Technology"—an oscillating, piston-type mechanism that provides penile vibratory stimulation, or vibrations applied in a specific manner that can make a man ejaculate involuntarily, even without having an erection. Once the penis is placed within the "wings" of the device, it can be used hands-free. Five speeds offer different levels of stimulation, and a built-in rechargeable battery provides the power. More details and an animated video showing how it works can be found at www.hotoctopuss.com.



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August's third-generation Smart Lock offers a secure, keyless entry for your home. You can lock and unlock your door, control keyless access, and keep track of who comes and goes, all from your phone. It can automatically lock your door behind you as you leave, and automatically unlock it when you get home. When you're away from home, you can send guests temporary virtual keys instantly from the August app. It easily attaches to your existing deadbolt mechanism in minutes with just a screwdriver. With an optional bridge, the August Smartlock will also play nicely with Amazon Echo products and other home assistants. Visit august.com to read and see more.

Room for Debate



Would you use a robotic arm, exoskeleton or vehicle equipped with a robotic arm in your daily life?

That's the question we recently posed to members of our SCI BC Facebook community. We asked them to respond with an A (Absolutely—the benefits outweigh the costs), B (I would if I could afford it), C (No way! It's totally impractical), or D (No...I wouldn't want to stick out like a sore thumb). For and against responses were about equal. Here's a sampling of what they said. (*Note: entries have been edited for grammar, spelling, and clarity.*)



Wearable robotics are the future for all people and will provide assistance for all ranges of ability—from heavy lifting to full body mobility. —*Chloe Angus*



FIX the problem, don't put a bandaid on it! —*Janice Lynn*



Exoskeleton would make every day easier. —*Trevor Zachary*



I don't think I would because of the unpredictability of the device. If the batteries die suddenly or it malfunctions, what would the person do? —*Robyn Artemis*



C and D. It's mostly personal preference. I can load and unload my chair faster than a robotic arm. And that's going to take up a lot of space in any vehicle; I need that space. As for sticking out like a sore thumb, I like to blend in. I don't think we need anything else for people to stare at. I keep my chair and equipment stripped down to the bare minimum. No bells, stickers, streamers or flags. Lastly, as Scotty says, "the more you over-tech the plumbing, the easier it is to stop up the drain." Hell, if they still made them, my truck would have roll down windows. —*Chris Ahearn*



Definitely B. I would cut my legs off and have robotic ones attached if it would mean I could walk again and have my independence. Robotics are going to be a part of our life in the near future whether we want them or not. It already is helping people in so many ways that are amazing. In Japan, for example, they're looking at using robotics to help the elderly with their daily living activities. And I believe in the next 25 to 30 years, we will have robots that are helping quadriplegics and other people with disabilities live a normal lifestyle...We already depend on many types of machines every day; what's one more? —*Troy Sussums*



Absolutely, I would use all three. As a higher level quadriplegic, I need all the help I can get. —*Stewart Midwinter*



My problem is relying on a battery or electronics. I don't want something that's going to die on me unexpectedly. —*Ann Hope*



Definitely A. Initially only a privileged few may benefit, but I believe in time with more research, robotics will become more accessible, as in all technology. —*Gwen Norman*



I would use robotics where failure of the robotics wouldn't have a high potential for catastrophic harm to myself or another person. —*Allan M. McLeod*



Whenever I read about the exoskeleton I also read the comments section. Often there are comments by non-disabled people who think there is no way a person can be independent or have a job if they don't stand and walk. I am interested in health benefits of standing and walking, but an exoskeleton as they are now will not give me independence, as I already have that (and a job). In a way, it would decrease my independence if I have to use crutches...The exoskeleton would have to become easier and quicker to use for it to be practical for me...It seems faster and easier to do things in a chair, such as cook. Looks like it might be a pain when using the toilet. How about using it outdoors on hills, or uneven pavement? Would love to try one for exercise ...but the price! And I work full time; I can't take a lot of time getting into a device. —*Shannon Alwaise*



I'm a B for the exoskeleton legs. I really want to try some of those and have that walking feeling again, or just be able to stand for a while. —*Chris Anderson*



Exoskeletons are way too expensive... —*Omer Farooq*



I thought my chair was AI. What happens when my robot needs three weeks to fix? —*Doug Hlady*

Visit facebook.com/SpinalCordInjuryBC to join in on this and other conversations.



Walk 'n' Roll for SCI.

Join SCI BC for another record-breaking year at the annual Scotiabank Vancouver Half Marathon & 5k Charity Challenge. After hitting a new record last year (\$64,000), we're going all out and aiming to wheel, walk and run our way to \$70,000 for SCI BC programs and services around BC. Can't join Team Walk 'n' Rollers on race day? Support one of our awesome racers at bit.ly/5forSCI or visit sci-bc.ca/scotiabank-5k to learn more.



Learn a new sport.

Kids from 11 and up can try a variety of wheelchair sports this summer at the Junior Wheelchair Multi-Sport Camp hosted by BC Wheelchair Sports. From August 8 to 12, participants will have the chance to try wheelchair basketball, wheelchair rugby, wheelchair tennis and more at the Cloverdale Recreation Centre in Surrey. For more information or to register, email Ana Karanovic at ana@bcwheelchairsports.com.



Grab a handcycle.

Curious about the pros and cons of different handcycles? Join SCI BC on July 21 at the University of the Fraser Valley campus parking lot in Chilliwack for Handcycle Demo Day and Summer BBQ. Chat with vendors and other riders, and discover the recreational, social and cardiovascular benefits of handcycling. Plus, join us for a road ride! Contact Pete at pfroese@sci-bc.ca for more information and to RSVP.

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A Gripping Tale of Strength

More hand strength and dexterity is a dream shared by most people who live with quadriplegia. Over the years, many research efforts have arrived at solutions—but all have either involved invasive techniques with long wait times for results, or cumbersome devices such as exoskeleton gloves. Recently, researchers at UCLA unveiled a breakthrough approach.

The jury has been in for some time. In numerous surveys and consultations over the past couple of decades, people with quadriplegia have made it clear: priority one is regaining the ability to use their hands. Nothing, they've collectively said, would restore greater independence.

Many researchers have heard these pleas, and a number of solutions have been developed. But few have enjoyed widespread acceptance. Surgical techniques to transfer tendon and nerve function have been successful, but the cost and invasive nature, along with the length of time required for healing and results to appear, have tempered enthusiasm for these procedures. Meanwhile, many devices have been developed to allow people with quadriplegia to exercise hand function, but these offer only modest gains. Many bionic gloves have also been developed, but lack of practicality and high cost have limited their commercial success.

In April, researchers at the University of California (UCLA) unveiled a possible game-changer—a revolutionary new, non-invasive therapy that appears to restore hand function for people with quadriplegia. They described the therapy and how they tested it in the April issue of the journal *Neurotrauma*.



While more research is clearly needed, the experimental therapy must be considered a breakthrough—it appears to be inexpensive, easily administered over a short period of time (perhaps even at home) without surgery, and, above all, overwhelmingly successful—even for people who were injured years ago.

The UCLA lab behind the therapy is that of Dr. Reggie Edgerton, a leading expert in neuromodulation—interventions that involve the activation of the spinal networks after SCI using electrical stimulation applied epidurally (surgically implanted electrodes under the skin) or transcutaneously (electrodes placed on the surface of the skin).

You might recall that, in our Winter 2014 issue, we told you about the Edgerton lab's success with neuromodulation to improve bladder function. Parag Gad, a research assistant in Edgerton's lab, led that project, and he's also the lead author of this latest study on hand function.

"One of our earlier studies showed that the cervical spinal cord could be neuromodulated using epidural (invasive) spinal stimulation," says Gad. "Based on these ideas, our team wanted to test the efficacy of using the non-invasive spinal stimulation to enable hand function."

Gad explains that the therapy has two components. The first is transcutaneous enabling motor control, or tEmc, which involves the use of a small, portable pulse generator connected to electrodes. Once the electrodes are placed on the skin above the spinal cord at the C3-C4 and C6-C7 vertebral levels, electrical pulses are delivered at varying frequencies and intensities. This stimulates and awakens the dormant circuitry of the spinal cord that's responsible for delivering instructions from the brain to the hands. The second component is manual rehabilitation exercise during the delivery of the stimulation—in simple terms, repetitive squeezing of an exercise device.

"The spinal stimulation works on two principles," says Gad. "First, it increases the level of baseline excitation in the neural networks that control upper extremity (arm and hand) function. Second,



Pioneers of neurostimulation therapies: Dr. Reggie Edgerton (left) and Parag Gad

it acts as a 'hearing aid' to amplify descending commands that the brain sends down via the spinal cord to the various muscles of the upper extremity."

In other words, subjecting the nerve pathways to a series of electrical stimuli "awakens" them so that the brain's instructions to the hand are able to get through much more easily. In turn, repetitively exercising the target muscles during stimulation leads to gains that persist months (and perhaps even permanently) after the therapy sessions have ended.

The researchers began by recruiting eight participants with quadriplegia, of whom six would ultimately finish the training sessions. Their time since injury ranged from one to 21 years. Prior to the study, none of the participants could turn a doorknob with one hand or twist a cap off a plastic water bottle. All had great difficulty operating a mobile phone. And three of the participants had complete injuries and couldn't move their fingers at all.

Each participant took part in eight 90-minute training sessions—two per week over four weeks. During these sessions, participants were provided with electrical stimulation while simultaneously squeezing a small gripping device 18 times with each hand, with each squeeze lasting three seconds. The gripping device measured the amount of force they were able to generate.

The results were quite remarkable.

"Within two or three sessions, everyone started showing significant improvements, and kept improving from there," says Gad.

After four weeks of training, participants' hand grip force increased on average by 325 percent in the presence of stimulation and 225 percent without stimulation. These improvements were witnessed in both left and right hands, regardless of which hand was dominant.

"About midway through the sessions, I could open my bedroom door with my left hand for the first time since my injury, and could open new water bottles, when previously someone else had to do this for me," says Cecilia Villarruel, a participant from California who was injured in a car accident 13 years ago. "Most people with an SCI say they just want to go to the bathroom like a normal person again. Small accomplishments like opening jars, bottles and doors enable a level of independence and self-reliance that is quite satisfying, and have a profound effect on people's lives."

Surprisingly, some participants also experienced other benefits beyond improved grip strength and finger dexterity, including improvements in blood pressure, bladder function, cardiovascular function, and trunk control.

The results were so positive that even the researchers admit to being surprised.

"After just eight sessions, they could do things they haven't been able to do for years," says Edgerton, adding that



Cecilia Villarruel, a research participant from California, regained the ability to open bottles and doors.

this is the largest reported recovery of the use of hands that has been reported in patients with such severe SCI.

“We were initially not expecting the results to be as effective as they were, especially in the autonomic functions and trunk function,” says Gad. “The entire team was super-excited to see and hear what the patients reported back to us.”

As for permanence of the benefits, results are again promising, as two of the six returned to Edgerton’s laboratory 60 days after the training ended and clearly still had their grip strength intact—they could still turn a doorknob or use a fork with one hand, and twist off a bottle cap. But Gad concedes that the permanence won’t be known for some time.

“We’re still exploring this aspect,” he says, adding that there were no adverse events or side-effects experienced by any of the participants.

While exciting, the study can’t really be considered conclusive because of the small size and the lack of a control group to compare with those receiving the treatment. Gad says the immediate priority is confirming the benefits with more people, via controlled, blinded studies (studies in which participants are randomly selected to either receive the therapy, or a sham therapy, with no one, including the researchers knowing who is in which group).

“Studies are being planned by us and some of our collaborators around the world to test this in a larger cohort of subjects over a longer period of time,” he says. He wouldn’t put a timetable on this, but confirms that, because the technology is relatively inexpensive and the treatment so easily carried out, a larger trial could happen as early as next year.

Meanwhile, the prototype stimulation device used for the treatment, which was developed in Edgerton’s lab specifically for this purpose, has already been spun off into NeuroRecovery Technologies, a medical technology company Edgerton co-founded. Currently, the company is seeking FDA approval for the device so it can be used by rehabilitation clinics and others. Approval could happen quickly if the company can make its case that the stimulator is a Class II non-significant risk device.

Many readers will end up here wondering, “OK, great, but when can I get my four weeks of training, and can I get it locally, ideally in my own home?”

“Best case scenario, it could take two to four years,” says Gad. “We hope that this device can be used by as many people as possible, at home, in the doctor’s office, in the rehab centres. We see this as an effective and inexpensive solution that could help thousands of patients in the near future.”

The research was funded by the Christopher and Dana Reeve Foundation, the National Institutes of Health’s National Institute of Biomedical Imaging and Bioengineering, the Dana and Albert R. Broccoli Foundation, and the Walkabout Foundation. ■

Research Suggests Neuromodulation Can Restore Sexual Function

While Dr. Reggie Edgerton’s UCLA laboratory is ground zero for most research in neuromodulation in SCI, there are many other complementary projects taking place around the world.

In April, University of Minnesota researchers reported that neuromodulation, delivered through an implanted (epidural) device, appeared to restore some degree of voluntary movement, bladder and bowel control in two women with paraplegia. Not only that, one of them also regained orgasmic function.

The research was led by Dr. David Darrow, a fifth-year resident in neurosurgery. He believes that perhaps the most significant benefit of the therapy for the two women, both in their 40s, is the increased ability to support their bodies, leading to greater independence.

“These are big benefits to patients,” Darrow says.

The findings are first results of the Epidural Stimulation After

Neurologic Damage (E-STAND) study, which were recently presented at the American Association of Neurological Surgeons (AANS) 2018 Annual Meeting.

“It’s been about 10 years since the serendipitous discovery that if you apply spinal cord stimulation below their lesion, patients with thoracic paraplegia can regain some ability to control their legs, despite not having moved them in up to four years,” Darrow says. “This changed the paradigm of how we think about complete spinal cord injury...and opened up the opportunity to look at the narrative of spinal cord injury from the perspective of neuromodulation.”

As with the UCLA work to restore hand function, the stimulation is not directed to the actual site of the lesion, but instead delivered within a segment of the cord where there are intact neural connections that pass through the lesion.

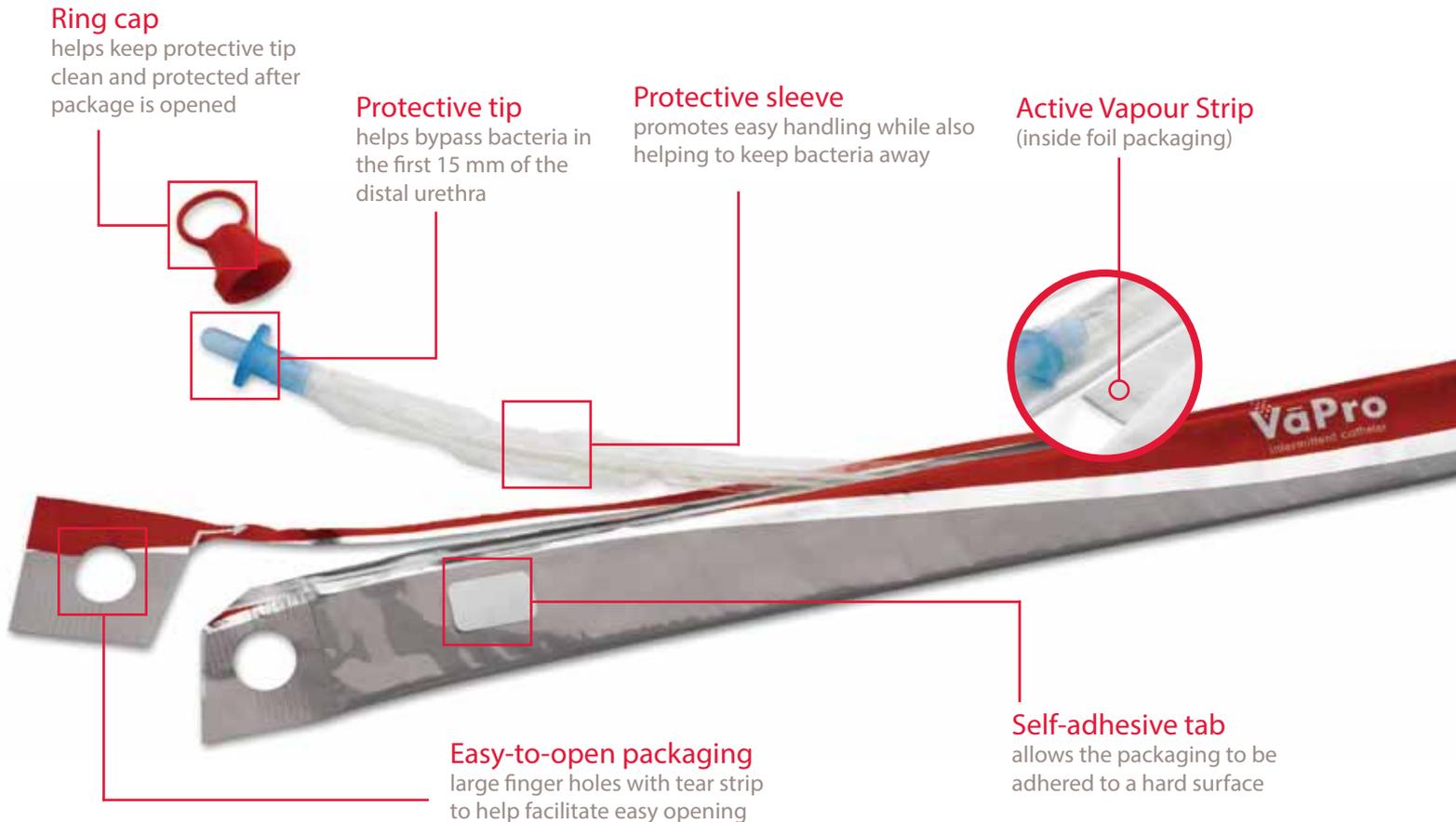
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Simply Smart

We believe that nobody could benefit more from a voice-activated smart home than readers of *The Spin*. Unfortunately, cost has prevented many of us from diving headlong into smart home technology. But that's changed in a hurry, thanks to the emergence of the Amazon Echo Dot and other smart home speakers or assistants, along with a number of devices that have been developed to work with them.

Imagine controlling your home's lights, appliances, temperature, and more...all with simple voice commands. It's intriguing, isn't it? But until recently, this type of home automation has been expensive—not to mention a little complicated. Enter the Amazon Echo Dot and other similar home assistants such as the Google Mini, along with a host of complementary devices that connect to them. Suddenly, a basic, easy-to-set-up, voice-controlled smart home could cost you less than \$500.

On the next two pages, we'll give you a quick look at how simple this is. Keep in mind, this is not a manual or guide. It's simply a glance at the possibilities; something to pique your interest and make you realize that the smart home of your dreams might now be within your reach.

You'll notice that we chose to focus on the Echo Dot and its onboard smart assistant, Alexa. The reason is simply a lack of space. While competitors such as the Google Mini are more than worthy, our research shows that the Echo Dot enjoys the highest sales, the best connectivity in terms of complementary devices, and the most favourable reviews from technology websites such as CNET.

What about setting it all up? In the past, many Alexa-compatible smart home accessories required a somewhat expensive separate hub. But that seems to be changing, as many products now offer Alexa connectivity without any extra hub. So our short answer is that we think if you're comfortable with all the nuances of your smartphone, you won't have a problem setting up the Echo Dot in combina-

tion with the above gadgets. There are plenty of online guides and accompanying instruction manuals.

What about privacy? It's true—the Echo Dot sends what you say to Amazon's servers. It sounds creepy at first, but remember it only starts listening when you speak its "wake word," which is Alexa. At that point, Alexa whisks your questions and commands away to the cloud, where your request is processed. Yes, your words will stay on the cloud, but you can delete them any time from the Alexa app.

If you want more privacy, the Echo Dot also has a mute button, but remember this basically renders the device useless.

We think people should watch what they say around the Echo Dot, and proactively delete their recordings regularly. But we'd also remind you that most people think there's nothing malicious about Amazon tracking you—the company is simply trying to learn how to make more money from you by understanding your needs and serving you up more relevant ads. Essentially, this is what every other information-based company is doing, every time you interact with them using any device—for example, when you Google something on your laptop.

A final caveat: this is addictive stuff. What we've described here is basic; it has the bare essentials you can easily and affordably get in order to create a voice-activated smart home. But in researching for this story, we discovered two things.

First, there are many directions you can expand a basic system like this. For example, you can add a powered Alexa-compatible deadbolt to your front door, and home security systems. You can integrate your home theatre. You can add outdoor smart plugs and irrigation system controls. You can even control iRobot's newest robot vacuum, the Roomba 690.

Second, people who write about this type of home automation are enthusiastic about the subject. And they seem to have one thing in common: when it comes to automating their own homes, most have started off small and modest... but have ended up going much, much bigger. You've been warned! ■

1 ECHO DOT: WHERE IT ALL BEGINS

Your smart home starts with the Echo Dot—the innocuous, puck-like bestseller from Amazon. The Echo Dot is a hands-free, voice-controlled, WiFi-connected device that uses Amazon's electronic assistant Alexa to play music, provide information, read the news, set alarms, and control smart home devices. Yes, there are other similar products on the market, including offerings from Google and Apple, as well as other versions of the Echo. But the Echo Dot is becoming the benchmark for this type of use—it's cheap, easy to use, reliable, and works flawlessly with a host of smart home products. Just plug it in anywhere in your house where there's a good WiFi signal, and where you spend a lot of time. Hearing range is probably the Echo Dot's biggest limitation, but that's why we think two or more make great sense—maybe one in your bedroom (where you can use Alexa's alarm feature), and one in your kitchen/living room. At \$60 or less, they're not going to break the bank. And remember, with two Echo Dots, you now have an intercom to communicate between rooms. At the time of writing, you could buy two Echo Dots for \$120.

2 SMART PLUGS: POWER UP YOUR APPLIANCES

The logical first gadgets you'll likely buy for your Echo Dot are smart plugs. The concept is simple: you plug these WiFi-connected plugs into an available wall socket, and in turn, connect anything that operates with a simple on/off switch—lamps, coffee makers, space heaters, music systems and more. Once connected, you wake up Alexa, and then tell her to turn on a specific plug or appliance (you can also group these so that many turn on with a single command). There are many different varieties and brands of these plugs on the market. Judging by customer reviews, the WAZA Smart Plug WiFi Mini Socket appears to be a winner. It requires no hub, and it's priced at \$13.99 with free shipping at amazon.ca. Start with six for a reasonable \$84 total.

3 SMART LIGHTS: EFFORTLESS ILLUMINATION

Next up are smart lights. Again, the concept is simple: you replace any standard bulb with a smart light, which is an LED bulb combined with WiFi connectivity. Smart lights are, for the most part, dimmable. This gives them an advantage over simply plugging in a lamp to a smart plug, which only gives you simple on/off functionality. Smart lights that communicate directly with Alexa without the need for a separate and often expensive hub are only now becoming more available. Currently, the offerings from TP-LINK appear to be quite popular. In particular, the TP-LINK LB100 is available in a kit of three for \$70 from Amazon. Yes, they seem expensive—but remember, they're LED and could possibly outlive you! For about \$30 a bulb, you could upgrade to a tunable version, which allows you to change the light appearance from soft white to daylight.

4 SMART SWITCHES: MULTIPLE LIGHT CONTROL

What about controlling a bank of lights, like what you commonly find in a kitchen? Obviously, replacing every bulb in kitchen lighting could be pretty costly. That's where a smart switch could be useful. A popular example is the Meross Smart Wi-Fi Wall Switch, which again requires no separate hub. It's \$28 at Amazon. We suggest two, for a total of \$56. But keep in mind, you'll have to shell out double this if you want to replace a dimmable switch used with dimmable bulbs in your fixtures.

5 SMART THERMOSTAT: VOICE-CONTROLLED COMFORT

Imagine lying in bed in the morning and really wishing your house was a few degrees warmer. Well, that's easily achieved with an Alexa-compatible thermostat that replaces your home's existing heating and cooling control. Originally, only the more expensive, learning-type thermostats were compatible with Alexa—for example, The Nest and the ecobee. But recently, a few new, more economical choices have reached the market. They don't have the same learning capabilities or bells and whistles, but they seamlessly integrate with Alexa so that you can control your environment by voice alone. The Sensi Wi-Fi Thermostat by Emerson appears to be a particularly smart choice. It's available for \$130 from Best Buy Canada or Amazon, and perhaps its single most important feature (beyond its Alexa-compatibility) is that it appears to be compatible with most existing heating, ventilation and cooling systems in Canada.



2 WAZA Smart Plug WiFi Mini x 6: \$84



3 TP-LINK LB100 Smart Light 3-Pack: \$70



1 Amazon Echo Dot x Two: \$120



\$460
Total Price
Plus Taxes



4 Meross Smart Wi-Fi Wall Switch x2: \$56



5 Sensi Wi-Fi Thermostat: \$130

Happy Trails

Great Accessible BC Trails to Wander this Summer

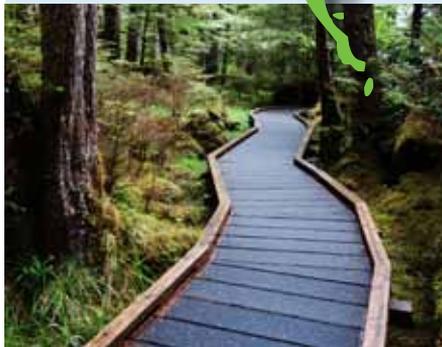
Maybe it's that low Canadian dollar, or maybe you just prefer to spend your spare time here in beautiful BC. Whatever your situation, if you're dreaming of a road trip this summer here in our province, keep in mind that there are a growing number of superb, accessible wilderness trails you could easily pencil into your itinerary.

We've highlighted what we think are some of the best on this page, attempting to cover all areas of the BC map. All feature wheelchair-friendly surfaces and grades, provide access to some of our province's most stunning scenery, and are completely free to use.

Keep in mind that the listings on these pages are only an introduction; we recommend you do your own research before you go to ensure the trails are a match for your abilities, interests, and needs in terms of other disability-specific features such as accessible bathrooms.

One final note: if you're planning a road trip to central or northern BC, check out our new Access BC website (accessibleBC.ca). To date, we have audited the accessibility of more than 450 outdoor spaces in North-Central BC, including municipal, provincial and federal parks, recreation sites, and visitors' centres. In-depth accessibility specifications, as well as virtual tours and videos, suggested driving routes and maps, and accessible tourism tips, are provided for each audited area. In the future, more accessibility audits will be completed (several are underway currently) and added to the site, with the overall goal of expanding the scope to the entire province.

Happy trails! ■



1 NAIKOON PROVINCIAL PARK

Haida Gwaii (formerly the Queen Charlotte Islands) is a string of islands located off BC's northern coast. On the northeast tip, you'll find Naikoon Provincial Park and its newly-extended wooden boardwalks that provide wheelchair adventurers with excellent access to some of the sacred territory of the Haida Nation, with its ancient forests and spectacular coastline. Magical, magnificent and mystical.



2 THE SHOREPINE BOG TRAIL

Tofino's Shorepine Bog Trail is a fully accessible, 800-metre boardwalk that will take you through a unique ecosystem in Pacific Rim National Park—a bog that only a few plant species are able to survive in due to the acidic soil found here. The only tree that can survive locally is the Shore Pine, which grows in fascinating, twisted, irregular shapes. After, you can hit the beach by borrowing an all-terrain wheelchair at Ucluelet's Kwisisit Visitor Centre, at the south end of Wickaninnish Beach.

3 THE GALLOPING GOOSE

The Galloping Goose is a converted railway line that's now part of the Trans Canada Trail. Beginning close to downtown Victoria, it extends some 55 kilometres to Sooke, and passes through the communities of Metchosin, Colwood, Langford, View Royal, and Saanich. The trail can be accessed at many points, allowing you to choose a journey of a length or duration that's perfect for you. And it features connections to many other trails and parks, including East Sooke Park.



4 SEYMOUR VALLEY TRAILWAY

It's hard to imagine getting bored of Vancouver's incredible Stanley Park Seawall trail. But if you really want a change, consider the Seymour Valley Trailway in North Vancouver. This paved, 10-kilometre path takes you through the incredible forests of the Lower Seymour Conservation Reserve. There are lots of picnic areas to stop at before you reach the end, where you'll find Seymour River Fish Hatchery & Education Centre.



5 THE VALLEY TRAIL

Located just outside of Whistler Village, the Valley Trail is actually a network with more than 40 kilometres of paved paths and boardwalks that connect all of Whistler's picturesque neighbourhoods, lakes and parks. There are many bite-sized loops you can try, including the Whistler Golf Club Loop and the Creekside to the Lakes Loop. A must-wheel if you're in the Whistler area this summer.



6 INLAND LAKE TRAIL

Located close to Powell River on the upper Sunshine Coast, this 13 kilometre trail circles Inland Lake and offers accessible routes throughout Inland Lake Provincial Park. The trail is composed of crushed limestone paths, boardwalks and bridges. It's well-marked with many different view points, and even has several pit toilets along the route. There are connections to other trails as well, including a loop trail around nearby Anthony Lake.



7 GRASSLANDS LOOP TRAIL

If you're travelling to or through Kamloops this summer, consider taking a spin on the Grasslands Loop Accessible Trail, located in Peterson Creek Nature Park. This one kilometre trail was re-opened last year after enjoying a barrier-free makeover. The trail is now wider, smoother and more stable, making it entirely accessible to wheelchair users. Along the way, you'll get to see the unique beauty of the interior's grasslands, along with great views of downtown Kamloops.



8

8 HEMLOCK GROVE INTERPRETIVE TRAIL

Just east of Revelstoke is Glacier National Park. Here, you can find the amazing Hemlock Grove Interpretive Trail, a 350 metre, fully wheelchair-accessible boardwalk trail that allows you to explore an ancient forest of breathtakingly immense giant cedars and hemlocks. Access is just off the Trans Canada, so if you're travelling the route, make time for this superb trail.



9 CARIBOO CHILCOTIN TRAILS NETWORK

The Cariboo Regional District, located in the BC Interior, is to be applauded for its extensive Low Mobility Trails Network. It features 19 wheelchair accessible wilderness trails throughout the region, which reward visitors with views of the area's stunning landscapes, wildlife and rich history. There's an incredible amount of diversity in these trails—we suggest starting at www.cariboord.bc.ca.



11 GREAT WEST LIFE MOBILITY TRAIL

Part of the Dougherty Creek recreational area 23 kilometres south of Prince George, this 450 metre trail meanders through mature spruce and Douglas fir along beautiful Dougherty Creek. It includes several bridges and resting areas.

12 KINUSEO FALLS

Kinuseo Falls are located south of Tumbler Ridge on the Murray River, in the Peace Country's Monkman Provincial Park. A 200-metre trail takes you to the lower viewing platform located at the lip of these spectacular, world-class falls, where you can witness them in all their glory.



10 ANCIENT FOREST BOARDWALK

The Ancient Forest, located 113 kilometres east of Prince George on Highway 16, received Provincial Park status in 2016. Constructed almost entirely through donations and volunteer efforts, it features more than 400 metres of boardwalk trail leading from the parking lot through a giant, old-growth cedar rain forest before ending at a tranquil stream.



Taking Charge

Managing your own personal care isn't without its challenges, but as five SCI BC peers explain, there are significant rewards.

BC's Choices and Supports for Independent Living program, or CSIL, provides a self-directed option for anyone eligible for home support. Since 1994, approved clients have received funds directly from their local health authority to purchase and manage all aspects of their own home support services.

Recently, in partnership with the BC Ministry of Health and with funding from the Law Foundation of BC, we developed a comprehensive workbook to give anyone with a disability the information they need to apply for and be successful with CSIL.

This workbook can be quickly and freely downloaded from www.sci-bc.ca. And it's amazing how often it is. In fact, our CSIL section is one of the most popular areas of our website. Clearly, many people have embraced the idea of self-management of their care, and it seems many more are considering it.

We wanted to explore the nuances of managing your own care in *The Spin*. But we didn't want to just summarize the workbook, or write any sort of guide to self-managing care—there's already plenty of excellent online resources out there. Instead, what we thought you might appreciate, as someone new to CSIL or self-care management via any funding source, was some expert advice and insight from a few of your Peers who have considerable experience managing their own staff of attendants.

With that in mind, we're pleased to give you a Peer's eye view of self-managed care in the next few pages. As you'll read, our five experts have all had some negative experiences—but these are completely overshadowed by their positive experiences and successes. They provide their best insider's tips to being a successful employer. You'll notice there are several repeating themes, but just as many unique approaches and tricks—all of which you can incorporate into your repertoire in your own quest for greater independence and autonomy.



Ken Legros | Prince George | C5-6

Ken Legros was injured in a car crash 32 years ago. He signed on with CSIL about 23 years ago, and was among the program's first clients. Now 53, Legros needs about eight hours of care per day.

"What prompted me to take the program on was a desire to have more flexibility in my daily activities and consistency with the same staff who know my routine, rather than being with an agency and having multiple staff coming in and needing to train all the time—which is rather frustrating and makes for longer shifts," he explains. "My success has been rather rewarding, in terms of being able to manage my own days and what I can plan for that day or coming days."

When it comes to recruiting staff, he's had success with both word of mouth and online advertising. He believes his best method of finding attendants is by placing an ad on Kijiji.ca

He screens applicants by discussing what the job entails. Then, if they're still interested, he schedules an in-home interview, where he gauges the applicant's interest, their willingness to help him live a comfortable life free of stress, and their overall outlook on life and work. He also ensures that applicants have a driver's license and vehicle.

"Typically, you can tell in an interview if they're more interested in the pay than helping you," he says. "That's my way of disqualifying someone."

He prefers to interview in his own home, and if he doesn't feel comfortable doing it alone, he has another attendant or friend present. "It's best to be safe," he says.

During his interviews, Legros doesn't hesitate to get into the nitty-gritty of being an attendant. "I usually ask about my number one concern—if they've done bowel routines, and if they have no problems with doing it," he says. He also says that he judges applicants on their appearance, as well as their willingness to cover for other staff during holidays or emergencies.

"I also ask a lot about their past experience, as they must present a resume at my interviews so that, if they're chosen, I can contact references," he explains.

If he likes a candidate, and their references pan out, he'll usually have the person come back for a second interview.

"At this point, I'll take them on a tour through the house, explaining how I need things done and showing them where everything is. Also, I'll have them come in and train for a couple of days with another staff member, who shows them the daily routine and tells them not to be shy about asking questions. Then I'll get them to do the entire routine with another experienced staff member present, just in case they're unsure about any aspect of my care—this way they can be shown on the spot again,

and then take over. I also have a step-by-step care routine sheet I hand them."

When it comes to the employer/employee relationships, Legros says he initially keeps the arrangement on a strictly professional basis. Over time, with good employees, he allows the relationship to become more relaxed, but says that his personal care always comes first.

"As for boundaries, I try to tell them not to bring their personal problems from home to the job, and I try not to get involved," he says. "But I will listen if they really need someone to talk to. Most of the time, if they bring personal stuff to work, it affects their ability to concentrate on the job at hand. Basically, during the initial interviews, you must bring that up just so they know and are clear. If any of my staff do have issues, it's best for them to take a couple days off and clear them up—and then return to work fresh."

For Legros, the most important underlying principle is honesty. "I myself am honest and open, so I would expect that from my staff. I always say it's best to be honest and talk about things regarding the job, and not lying about things or holding issues in. I tell them, 'Let's talk about it and figure it out as adults.'"

As with all our experts, we invited Legros to give us his best tips.

When it comes to the administration side of CSIL, he suggests keeping a close eye on your hours, your monthly statements, and your surplus of funds. "A surplus sometimes means you can plan to do something extra, possibly an outing for the next month, knowing you have the funding to cover it and will not get into a deficit."

As for health care tips, he is extremely cautious about saving his skin. "Don't be afraid to sound like a broken record when it comes to asking how your skin is doing," he says. "Morning and night, ask for details on what things look like—for example, have them look for redness, open sores, or dry skin that can possibly split open. And if you want to see for yourself, get them to take pictures of anything concerning—that way you can show the other staff members."

Another tip he offers is having a keyless or smart lock installed. "Having the keyless entry is the answer," he says, "because if you have a staff member that you let go on bad terms, you can change the code and it prevents them coming in."

Although he's never felt the need to do so, he adds that some Peers might benefit from using a detailed report book, which each staff member makes entries in after each shift so that the next staff member can see at a glance if there are any issues or concerns.

Legros concedes that, over the years, he's had a few negative experiences self managing his care. "I have had to let people go, which means sitting down with them explaining why. If you don't feel safe doing this alone, have a friend or another staff member present. Also, some days are stressful when a staff member calls in sick just before their shift, which means you have to call other staff last minute and from bed. So I stress to my staff that, if they feel something coming on, it's best to take the next day off rather than calling in last minute."

Regardless, Legros would never consider doing it any other way.

"My advice to other Peers is that, if you're unhappy about being with an agency with different staff everyday, and you think you're comfortable doing this program, do it—it gives you so much more flexibility and control of your daily needs and plans. It's rewarding."



Want more insider tips and tricks to help you manage your own personal care? Check out sci-bc.ca/blog for further insights from our featured Peers.

Joe Coughlin | Victoria | C5-6 Incomplete

Joe Coughlin has had more than six decades to dial in his personal care. Injured at birth 64 years ago, he was originally diagnosed with cerebral palsy, but that was changed in his early 30s to C5-6 quadriplegia complicated by severe osteoarthritis and spinal stenosis.

For most of his life, Coughlin relied on others to manage his attendant requirements. But 13 years ago, he switched to CSIL.

"I wanted to control my own schedule, not have it controlled by a caregiving agency," he says. "I'm a performer, and going to bed at 10 PM every night wasn't conducive to keeping a nightlife." (By the way, if you're a jazz aficionado, this is the same Joe Coughlin who won Canada's 2008 and 2009 National Jazz Award for Male Vocalist of the Year.)

He's careful to point out that CSIL doesn't quite cover his funding needs. "I receive about five hours and 40 minutes a day from

CSIL funding, and I need approximately eight hours of care per day," he says. Here at SCI BC, we know of other Peers who also experience a shortfall—consider and explore this if you're thinking of signing up with CSIL.

Despite the shortfall, Coughlin has no regrets with CSIL. "I'm doing a much better job than anyone else could, and I'm saving the government a bundle as well," he says.

When it comes to recruiting staff, Coughlin believes that peer networking is invaluable. "I've established a decent network of locals on the CSIL program," he explains. "We're lucky to have a common bond of survival and help each other out. Friends referring to other friends is the most effective way of recruiting and retaining staff. I tried the advertising route, but didn't have much success."

While some Peers seem to prefer attendants who are newcomers to the profession,

Coughlin isn't one of them. "Experience with others in my situation is the only way for me. All my staff are experienced caregivers. The most important qualification for me is personal suitability and a sense of humour."

He interviews at home, or his local Starbucks, and always has a set of prepared questions and a detailed job description on hand. For those he hires, he strives to find a mix of friendship and professionalism.

"A balanced approach is always best," he says. "I've known most of my caregivers before they start working for me. We try to make routines as fun as possible—this makes the work seem light. Good communication is essential. I try to stay professional at all times, but encourage open dialogue."

He's a stickler for clearly laid-out routines and procedures, which, he says, "keeps things about the relationship clear." As for the CSIL program, he advises Peers to fol-

Brad Jacobsen | Vancouver | C4-5

"My focus from the get-go after my injury was that I was going to give it a shot on my own," says Brad Jacobsen, formerly SCI BC's Vancouver Peer Coordinator. "CSIL was in its infancy stages, and the moment I learned of it, it was a no-brainer. You can't get what you want or be where you want to be if you don't take control of your direction."

That was 24 years ago. Jacobsen, now 48, typically needs about six hours of assistance per day to maximize his independence.

"I've been doing it for a fair bit of time now, and I would say that, big picture, it's been a total success."

Jacobsen says recruiting employees has become a lot easier in recent years, thanks

to the Internet and sites like Craigslist and Indeed. But he adds that he's often relied on creativity when it comes to finding good attendants. For example, he's hired a server from a pub he frequents, several friends and neighbours, and even women he's dated.

"I've found most people can use some extra cash," he says. "Because I can always use a helping hand, it's often worth reaching out."

Jacobsen says being specific during screening can save a lot of time. "For instance, I always specify which days and which hours are available, so that applicants can decide if it fits their schedule before responding."

In addition to a resume, Jacobsen asks applicants to describe their personalities. "More often than not," he says, "the people who have given me the most interesting and creative versions of themselves in a few words have been the ones that I have hired."

He prefers to conduct interviews at his home, but he likes to be flexible, and has interviewed candidates on Skype and at places more convenient for them. He also stresses the importance of letting a relative, friend, or current staff member know when and where you're doing an interview.

He often looks for subtle clues about a person's character. "Arriving on time is always

a good start. My place is tough to find, so I'm always impressed when someone arrives without needing extra help with directions. Little things like taking off their shoes when they arrive, washing their hands if they've taken the bus, and even something so simple as asking if there is anything I need before they leave makes a big difference with me."

Good fitness and personal hygiene are qualities he looks for during an interview. While experience is important, it's not the most important qualification.

"Finding someone who is eager to learn and appreciative of the opportunity is what can stand out, regardless of their past experience. Some of my most successful and long-term employees had very little experience in healthcare before I met them. We just got along well and they were hard-working, open-minded and reliable."

He tries to treat each employee with respect and hopes for the same in return.

"From there, our relationship builds into what it needs to be to work for us both. A healthy balance of both friendly and professional is necessary." But he adds that, while he's reluctant to set boundaries, he never allows himself to be taken advantage of.

He used to rely on a written guide for new employees, but that's given way to a men-





Kory Heyland | Prince George | C5-6 Incomplete

Kory Heyland was injured when she was just four years old. Her mother was her first caregiver, but the family eventually hired a couple of private care attendants, one of whom ended up working for her for 30 years.

Now 41, Heyland typically needs assistance for two to four hours each morning—about 24 hours per week. Unlike the other Peers in this piece, Heyland has private funding.

“As the years went on, instead of hiring a second private care attendant, I started using a care service to fill in on the days when my long time care aide had days off,” she explains. “My long time private care attendant finally had to retire, and that’s when I transitioned to using a home care service full time.”

The service looks after the hiring of her attendants, but Heyland takes on all the training, and has ultimate control over who provides her care.

“If they’re good,” she explains, “they stay permanently on my schedule, and if they’re not, then I can fire them in a sense and not have them on my schedule. It’s very satisfying and rewarding having the control of training and, hopefully, having a long-time care attendant that actually cares about my well-being.”

In the past, when she did manage hiring, her preferred method of recruiting was placing an ad in the newspaper’s classified section. “I would ask them, over the phone, questions about themselves and about the hours they were available to work,” she says. “As for qualities and qualifications, I looked for people who were calm, caring, and articulate; who had at least a care aide diploma or certificate; and had worked in the field for at least two years. They would need to have references from prior employers.”

Heyland says she would disqualify applicants who she perceived to be controlling, who avoided eye contact, and who didn’t appear to be calm and straightforward. Applicants were always interviewed from her home, with another family member present.

As for boundaries, she strives for having a friendly yet professional relationship with her attendants. The key, she says, is to make it clear from the outset that she’s in charge.

“They know I’m in control of my care, and I like it done a certain way,” she says. “And if they can’t get on board with that, then they don’t last long. Honesty, openness, trustworthiness, reliability and professionalism are key components.”

She concedes that she’s relaxed considerably over the years when it comes to caregiving procedures. “When I was first injured, we used a binder with a detailed list of my care routine and room for the care attendants to communicate any health issues I was having at the time. I don’t use any of that now, as I can tell them verbally what needs to be done and what issues I have.”

She also relies on a numeric, coded key pad lock for her front door so that the problem of keys is eliminated.

Her advice to anyone considering managing their own caregiving is to remember that you are the boss. “You are in total control of your own care and well-being, so be assertive and selective in the care attendants you hire,” she says.

Heyland no longer has to terminate caregivers officially; she simply informs her home care service that she doesn’t want a particular attendant. But that wasn’t always the case.

“Yes, I have had to fire people,” she says. “I have had care aides who were rude or who just never showed up for shifts. I usually just fired them over the phone; it was less confrontational and emotional. If they needed to drop keys off or something, I always had someone with me for moral support and safety.”



low the rules, and always be polite to your case manager.

“I’ve been very happy on CSIL,” he concludes. “I’m in charge of my life. If you can handle running a business and following rules, you’d be a good candidate for CSIL.”

toring process involving an experienced attendant. He doesn’t hold staff meetings, but ensures all staff are connected to each other.

As for CSIL tips, Jacobsen, like his peers, tries to keep a surplus in place for those times when you need extra hours. He also strives to create a comfortable work atmosphere, as it helps to avoid costly staff turnover. And he believes it’s important to be in touch with other CSIL employers. “Networking is important for not only learning from others, but also keeping you in the know in regards to good staff who might be looking for extra hours.”

Like everyone we spoke with, Jacobsen says that it’s not always a bed of roses. “Twice I’ve had to can someone for stealing. Fortunately, it hasn’t happened that often, and I have mostly had to let people go because of job performance issues or a lack of chemistry relating to our personalities. I can’t have someone working with me if I don’t enjoy their company or their care. And vice versa.”

If he has to fire a caregiver, he does so only at a time when his safety is assured.

His final advice for Peers?

“Having the opportunity to hire, train and direct my own care has been a blessing and allowed me many freedoms in my life,” he concludes. “I never take that for granted.”

Chris Marks | Victoria | C5 Incomplete

Chris Marks was injured in 2005, and he's been with CSIL pretty much since he came home from rehab. Like our other Peers, he wouldn't have it any other way.

"I wanted some control over who walked in my bedroom every day to get me up, and some choice with who I worked with, rather than being assigned random people," says Marks, who needs about six hours of assistance per day. "Being able to manage my own caregiving gives me the most incredible opportunities to find amazing helpers and develop a custom plan and schedule that works specifically for me. I couldn't live the life I live without it."

If he has to advertise, Marks prefers Craigslist. "But," he says, "more than 70 percent of my caregivers over the last six years have come from friends or other caregiver recommendations, rather than advertising."

As for screening, he starts with the response to the email—for example, whether or not applicants wrote an introduction or included a resume. Surprisingly, previous experience is not that important to him.

"I actually look for attitude more than experience, because I can teach the basics of the job. I'm looking for somebody that wants to be there, is punctual, and responds to text or emails in a reasonable time. It's a balance between having somebody with experience, and having somebody with way too much experience who is institutionalized—someone who walks into your house and starts to boss you around. That's not going to work."

Marks admits he's a little slack when it comes to criminal checks and references. "I just go on gut instinct during the first couple email exchanges, face-to-face interactions and training shifts," he says.

He interviews passing candidates almost exclusively in his home so that they see the real-life work situation firsthand.

"There's never a dull moment at my place, and so I need somebody who can thrive in that environment. Often the interview and the first couple of shifts are a way of feeling each other out, and I can see how they respond in different situations."

He adds that he prefers the relationships to develop into something more friendly than professional. "That said, you need to maintain

a level of professionalism; I took a lot of human resources courses in school to make sure I knew what I was doing. I expect professionalism and privacy because they walk into my house and are privy to my inner life."

He says a little consideration goes a long way, and characterizes his successful attendant relationships as being built on a mutual



foundation of respect, flexibility, compassion, and trust. "For example, when I'm getting them to help me make food, I try to feed them also. Not every caregiver can do every task, but they all have their strengths. I try to ensure that my caregivers are healthy and happy as much as possible, because if they get injured or can't work then we are both in trouble."

Priority one, however, is his own safety and health. "I have been almost 13 years with no skin issues or injuries because of my built-in safety systems that are based on injury prevention," he notes.

While he relies mainly on one-on-one training, Marks has developed a human resources-style information package for his

attendants that describes a general morning or evening, outlines his expectations, provides information on pressure sores and autonomic dysreflexia, and contains a daily checklist and payroll schedule.

He offers this tip for CSIL funding: "I pay between \$16 and \$18 per hour, and try to run as lean as possible to accumulate a small surplus over the winter so that, in the summer I can take two caregivers at a time camping or to festivals as a support team. I take two at a time wherever possible, so nobody gets overworked in theory."

Like his Peers, Marks strongly recommends using a keyless lock on entry doors. Unlike many Peers, however, he doesn't rely on notebooks and white boards for messaging, as he finds they're difficult to keep up-to-date.

As for attendants who haven't worked out, they are surprisingly few. "I send out between 17 and 23 T4s every year, so I have definitely had well over a hundred employees. Some have been with me off and on for almost 10 years, and some come back for a few months a year. Many are there two to six months, and a few for several years."

He concedes that, last summer, he had an unfortunate experience at a music festival.

"I had two caregivers walk off-site and hitchhike home, leaving me on the mainland in my camping trailer. It was respectful and I wasn't in much danger, but it was a serious wake-up call. After a lot of soul-searching and some phone calls, a couple friends came from Vancouver Island. I stayed for the rest of the event and threw myself upon the mercy of community. It was life-changing and one of the best experiences ever."

Marks offers some final advice to other would-be CSIL clients. "Develop an extensive list of names of people you can call if somebody doesn't show up, and keep it updated—you'll be surprised at how much it changes. And remember, during Christmas holidays and August long weekends, it's always hard to find people. Those that stick with you through those hard-to-fill shifts and hard times—like when your body decides to go to the bathroom and you aren't ready for it—well, reward those people. Become their favourite employer and maybe their friend, and it will pay dividends for years to come." ■



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Confusion in the Emergency Room

SCI BC Peer Barry Arana has had two scary experiences at his local hospital when he sought treatment for severe AD. You'd be forgiven for assuming Barry lives somewhere in rural BC, but that's not the case—he lives in Vancouver.

Barry Arana accepts that autonomic dysreflexia, or AD, is just part of the package of life with C-5/6 incomplete quadriplegia. Increased neuropathic pain and spasticity, along with extreme headaches, lightheadedness and vision impairment, are the hallmarks of his bouts with AD. And Arana, who is 35, has come to recognize in his seven years of post-injury life that severe UTIs are the most common trigger of his AD.

In 2014, Arana was in the midst of a particularly bad bout of AD. He couldn't identify any obvious triggers, such as a pressure sore or a bowel issue. His pain and discomfort were so intense that he decided to do something he'd never considered before: call 911 for an ambulance and a trip to his local emergency room (which is absolutely the correct thing to do when the cause of AD can't be quickly found, since it can be potentially lethal).

"I explained to the paramedics my condition by the level of injury and my symptoms," he says. "Once I was admitted in emergency, (staff) took my vitals and confirmed that my blood pressure was really high and above my baseline, and that I was experiencing AD. But they performed a lumbar puncture because they wanted to rule out meningitis. This

was my first time going to emergency for AD, and even though I was sure it was due to a UTI, I followed their advice."

Then, about four months later, Arana found himself in the midst of another brutal bout of AD, again with no obvious triggers and a UTI being the suspected cause. This time, he chose to bypass the ambulance and just checked himself into emergency at the same hospital. On this occasion, his reception was even more troubling.

"When it was finally my turn to check in, I told the admitting person that, 'I'm a tetraplegic experiencing AD.' I told her my level of injury, my symptoms of increased pain and really bad headache, and that I was getting really dizzy and lightheaded. She then told me to wait in the waiting room for my turn even though I felt like I could black out at any moment. I probably waited in the waiting room for 30 to 45 minutes before a nurse took my vitals. When I was finally admitted to emergency, I told the doctor, 'I'm pretty sure that I have a UTI which is causing my AD and increased pain.' I also told him that we could rule out (overfull) bladder and bowel issues."

But like the last time, the staff attending him insisted that a lumbar puncture was necessary to rule out meningitis.

"I reminded them that, not too long ago, I was in emergency for the same thing and that they had already performed a lumbar puncture on me just a few months ago," says Arana. "The doctors and nurses still insisted on doing the puncture."

He believes the two lumbar punctures performed within a short period of time led to an extended period of weakness.

"It took a long time to recover from those procedures," he says.

Looking back, Arana believes the underlying problem is that often, emergency room staff, even in such a large urban hospital, simply don't know much about AD.

"I don't know how much more assertive I could be, which is the frustrating part. I told them exactly what was going on with me, my level of injury, my symptoms. But for some reason, they didn't consider it an emergency and still made me wait in the waiting room like an ordinary person. When I told them the terminology, autonomic dysreflexia, they looked at me with this strange expression, and I knew that they didn't know what that was. I do feel that they did put me in danger both times I went to emergency. They just weren't familiar with treating AD, and they didn't seem to consider it as a critical condition. Obviously, I also feel that it wasn't necessary for them to perform a lumbar puncture to treat my UTI."

Something that might have helped Arana is an AD wallet card—a handy card that anyone with an injury above T-6 should carry at all times. The idea is



Barry Arana

simple: present the card to paramedics or emergency staff so that they can, at a glance, learn about or be reminded of what exactly they're dealing with, along with the proper treatment steps to take. Variations of AD wallet cards have been created in many jurisdictions and western countries, including here in BC—you can even download and print yours direct from the SCI-BC database website (visit sci-bc-database.ca and search for "AD wallet card").

Arana concedes that, when these events took place, he didn't have an AD wallet card, as he was unaware at the time that they existed.

"Today," he says, "I have an AD card in my bag and with me at all times whenever I go out."

Obviously, it's not ideal that the very people charged with your critical emergency care often aren't aware of this potentially life-threatening SCI complication. Dr. Andrei Krassioukov, who is Arana's physiatrist, has long recognized this as a serious problem in our healthcare system. Arana is only one of his many patients who have experienced similar situations when seeking emergency treatment at a number of BC hospitals (which is why we're not providing the name of the hospital that Arana went to on both occasions—there's no sense singling out one facility when the problem appears to be widespread).

Working with other care providers, organizations and funders, Krassioukov has been working on ways to make emergency health personnel more aware of AD and how it should be treated. For example, he spearheaded the development of the ABC of Autonomic Dysreflexia website, which you can see for yourself at www.abcofad.ca. The site offers emergency health workers a comprehensive online course about diagnosing and treating AD. Krassioukov has been pleased with how the website has been received by BC's medical community. However, he believes more needs to be done to promote the site, and other ways of getting the AD message out must be developed.

Meanwhile, Arana offers some advice

for others prone to AD. "Know your symptoms regarding AD—for example, your baseline blood pressure, headache, blurred vision, etc. Have an AD card at all times. Tell the paramedics or emergency staff and doctors your level of injury, that AD is a serious problem

for people living with SCI, and that you need to get treated ASAP. And finally, don't let them make you wait in the waiting room as if you're just another patient—if you're in emergency with extreme AD symptoms, your situation is already critical." ■

Download your AD Wallet Card at www.sci-bc-database.ca

What is Autonomic Dysreflexia?

Autonomic Dysreflexia (AD) is a potentially life threatening complication of spinal cord injury at T6 or above. It is caused by various painful or irritating stimuli below the level of the Spinal Cord Injury. This in turn triggers blood pressure which may rise dangerously. The most typical cause of AD is a distended bladder. Other causes could be overfull bowel, constipation or impaction, pressure sore, sunburn, in-grown toenail, skin irritant such as rivet on jeans, infection, tight clothing, or fracture. Symptoms may include elevated blood pressure (from what your baseline is), headache, sweating, flushed face, anxiety, bradycardia (slow pulse rate). Treatment is to remove the cause. Once the cause is removed the BP will start returning to your baseline.



Spinal Cord Injury BC

MEDICAL ALERT

Autonomic Dysreflexia

Information on Symptoms and Treatment



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TREATMENT

Autonomic Dysreflexia

For caregivers and clinicians

1. Raise the head of the bed by 90° or sit person upright.
2. Take blood pressure every 5 minutes to until it begins to return to normal.
3. Check for sources of AD: drain bladder first, consider using topical anaesthetic jelly for lubrication of catheter if immediately available.
4. If signs and symptoms continue, check rectum for stool. If immediately available instill anaesthetic jelly to rectal wall before examination. Use digital stimulation to promote reflex bowel movement.
5. If signs and symptoms continue check for other sources of AD such as pressure sore or skin irritant, fracture, in-grown toenail, etc.
6. If blood pressure remains elevated at or above 150 mmHg systolic after above checks, give Nifedipine 5mg capsule via "bite and swallow" method, or sublingual Captopril or Nitroglycerin paste.
7. If not already present, seek medical help after step 6. In a hospital setting, repeat Nifedipine 5 mg bite and swallow if SBP still at or over 150 mmHg 30 min. after initial dose.

Attention ER physician:
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Reprinting of this card funded by Spinal Cord Injury BC

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Just the Facts

SCIRE Community makes SCI information previously intended for clinicians and researchers available to people with SCI by writing in everyday language, providing more background information, and explaining the science behind the research.

Fake news is everywhere, including the realm of SCI. False claims, unsupported “facts,” skewed and tainted results—unfortunately, these all exist on the fringes of the SCI research and treatment continuum. The sheer number of people who have bought into the unscrupulous claims of offshore stem cell therapy operators underscores this.

Fortunately, there are beacons of virtue on the SCI landscape. Among these is the SCIRE Project, which got its start

a decade ago in Vancouver when a group of researchers and clinicians, working in concert with a group from London, Ontario, received funding from ICORD and other sources to create a resource where professionals could find the most scientifically-credible practices in SCI research and care. SCIRE, by the way, is pronounced “sky-er” and is the acronym for Spinal Cord Injury Research Evidence.

SCIRE’s approach of systematically reviewing and rating SCI research and best treatment practices has been rec-

ognized worldwide. But if it’s had any downside, it’s that it was intended primarily for researchers and healthcare professionals—and not the end user.

“Many of the people involved in conceptualizing SCIRE found that they received lots of questions from people and families living with SCI and felt that they didn’t have a comprehensive resource where they could be referred to have their questions answered,” says Dr. Janice Eng, professor at UBC’s Department of Physical Therapy, ICORD researcher, and co-lead of the entire SCIRE Project. “It’s hard to find trustworthy health information online, and even more so if it’s a new or uncommon treatment or condition, like many of those we see after SCI. This lack of easily accessible information can lead people to make important health decisions based on misinformation or seek out treatments that may not work or are sometimes even harmful.”

The SCIRE Project’s response was to create SCIRE Community—a comprehensive yet easy-to-read online resource that strives to provide people with SCI with the most valid practices for care, and the science behind them (www.scireproject.com/community). SCIRE Community is a free online resource, available 24/7 wherever you live in BC, or the world for that matter.

“The website has several different components,” explains Eng. “We have written pages that provide information and summaries about research evidence related to SCI care, and we have also instructional and informational videos, and a collection of handouts and resources for people with SCI.”

Eng hopes readers of *The Spin* will come to see SCIRE Community as a place where they can get trustworthy answers to their questions about their health and treatment options.

“We hope it will also act as a bridge where users can learn more about the value of research evidence in healthcare in order to become even more informed about their own health and self-management. SCIRE Community is also flexible,

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which I think is important because it will continuously be updated as research evidence changes and will continue to evolve and expand over time. We hope to get continued feedback about further topics and things to expand on and improve upon as we move forward.”

From the beginning, SCIRE Community relied heavily on input from people with SCI and organizations that work for them, including SCI BC.

“In the last iteration of focus groups, we got feedback on what people thought of the resource at that point,” says Eng. We had positive feedback on a number of aspects, like the visual appearance, the mobile responsive design, and a lot of the web features like the hover-over definitions. We’ve also heard from people that they liked that the content is informed by research evidence and that they can easily go over to the original SCIRE Project site for more information about specific studies or technical information if that’s what they want.”

Eng is grateful to those who contrib-

uted. “We would like to extend a big thank you to everyone who took part! The group really helped us to connect more with the types of information and resources that people in the community are really looking for and will find most useful.”

Looking forward, Eng believes that the potential for SCIRE Community is enormous.

“We’ve had so many really insightful and interesting suggestions about where this project could go in the future, and there are so many possibilities,” she says. “For example, we’re hoping to expand on our videos section to reach people who prefer to learn in other ways, and looking forward to further collaboration with people in the community, clinicians and researchers.”

SCIRE Community is funded by a grant from the Blusson Integrated Cures Partnership, a collaboration between ICORD and the Rick Hansen Institute that is supported by the Rick Hansen Foundation.

In addition to visiting the website (scireproject.com/community), you can follow SCIRE on Twitter or Facebook.

“We would love to hear your feedback and thoughts,” says Eng. ■



Dr. Janice Eng

ask the SPIN DOCTOR

Barry in Nanaimo writes, “As I get older, I seem to get heartburn more and more. Is this something I should be concerned about? I think I’ve read that there is a link between SCI and acid reflux.” To answer Barry’s question, we turned to Dr. Viet Vu, physiatrist at GF Strong and Clinical Assistant Professor in UBC’s Division of Physical Medicine & Rehabilitation.



Feeling the burn might be welcome when you’re working out, but not so much after you’ve eaten.

Acid reflux is a common stomach condition in which stomach acid and juices flow from the stomach back up into the esophagus, causing heartburn. Occasional heartburn is common, but when it’s frequent and accompanied by symptoms of dry cough or long-lasting burning pain behind the breastbone (especially at night or after eating), it’s considered to be gastroesophageal reflux disease, or GERD.

HealthLink BC recommends seeking treatment when you experience regular GERD symptoms, as it can lead to ulcers, damage to your esophagus, and even esophageal cancer.

Some research indicates that GERD may be considerably more common among people with SCI than in the general population, although this evidence is inconclusive. Regardless, the research suggests that common complications of SCI are known risk factors for GERD, and that GERD is poorly diagnosed and often found at an advanced stage among people with SCI. Impaired sensation may also prevent individuals with higher injury levels from detecting symptoms of GERD. Also, I’ve seen GERD cause AD when people with SCI are lying down. So it’s important to understand GERD, and especially its symptoms and risk factors specific to SCI, so you know how to respond to it. Individuals with SCI may have specific risk factors for heartburn, acid reflux, and GERD:

- **Slow digestion (motility):** The gastrointestinal system of people with SCI moves at roughly half the speed as that of someone without SCI, and sometimes even less than that for people with quadriplegia. This slow motility means delays in stomach emptying, which can in turn lead to reflux.
- **Positioning:** Spending more time lying down or reclined in your wheelchair can make GERD symptoms worse.
- **Abdominal Pressure:** Increased pressure in the abdominal space, due to abdominal muscle spasticity, chronic constipation, and bearing down for bowel care routines, can force stomach acids into the esophagus.
- **Medications:** Many common medications taken by individuals with SCI for chronic pain or spasticity may put them at higher risk for GERD. These include opioids, anti-inflammatories like naproxen or ibuprofen.

- **Inactivity:** Physical activity aids gastrointestinal motility, speeds up the emptying of the stomach and preventing reflux—but SCI often makes it difficult to get sufficient physical activity.

So what can you do if you believe you’re experiencing GERD? Here are some suggestions:

- Avoid eating before bed or before you need to be horizontal. Remain upright in your chair, bed or couch for two to three hours after eating.
- If you’ve been prescribed medications that need to be taken with food, eat small amounts over a period of time to avoid stimulating your stomach to produce a lot of acid.
- Work to reduce your body weight to help reduce pressure on your abdominal cavity. Losing weight can be particularly difficult for individuals with SCI, so seek support and advice from a rehabilitation specialist or exercise physiologist familiar with SCI.
- Consult with a rehab specialist to discuss options for managing spasticity in the abdominal area if this is an ongoing issue for you. A discussion may be helpful to help balance needs for function, use of anti-spasticity medications and therapies, and managing GERD.
- Discuss medication for GERD with a physician familiar with SCI complications. Doctors may prescribe a limited course of a class of medications called proton-pump inhibitors (PPIs) or H2 inhibitors that can help treat GERD. Make sure to discuss the risks and benefits of this class of medication, as chronic use can increase risk for osteoporosis and fractures. A short course of PPI medications can also be a less invasive and more manageable way to diagnose GERD in individuals with SCI than an endoscopy procedure.
- You might also be a candidate for medications that can help improve your gastrointestinal efficiency, which can in turn decrease the time it takes for your stomach to empty (more time leads to heartburn, acid reflux, and GERD).
- Talk to your physicians and SCI specialists. As GERD tends to be under-diagnosed in people with SCI, have a conversation with your family doctor if you experience symptoms of acid reflux or GERD, and with your rehab specialist if you are concerned about how to recognize the symptoms of GERD.

Generally speaking, the same advice for managing GERD in the general public applies to individuals with SCI, so have a look at the excellent general resources on dyspepsia and GERD from HealthLink BC (HealthLinkBC.ca).

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.

Bowel Care and Cardiovascular Function After SCI

Overview: Dr. Victoria Claydon and her team recently conducted a survey of bowel care practices and cardiovascular responses to bowel care in individuals with SCI, and learned that bowel care and blood pressure control were areas of frustration following injury. Now they are testing the effect of a medicated lubricant on blood pressure changes during bowel care routines conducted at home.

What to expect: The study involves two at-home visits (the length of time per visit will vary depending on bowel care duration). Participants will have complete privacy for the duration of their bowel routine, and will be asked to complete questionnaires before and after.

Who can participate: To take part in this study, you must be over 18 years old and have a high thoracic or cervical spinal cord injury that was sustained at least one year ago.

Why participate: Ultimately, this research may help provide clearer guidelines for bowel care practices, but in the meantime, you will have the opportunity to meet with the study's Nurse Continence Advisor and can receive up to \$200 for participating in the study.

Location: Your involvement in the study will take place at your home (if this is not convenient or desirable, other options are available).

For more information or to sign up to participate: You can watch a short video about the study at bit.ly/bowelstudy. To sign up or obtain more information, contact the study coordinator, Vera-Ellen Lucci, by email (vera-ellen_lucci@sfu.ca) or call 778.782.8560.

Evaluation of Cerebrovascular Health after SCI Using MRI

Overview: Chronic high blood pressure in non-SCI individuals results in changes in blood supply to the brain associated with increased risk of stroke, changes in brain structure, and loss of intellectual functioning. In this study, Dr. Andrei Krassioukov is seeking to determine if temporary high blood pressure resulting from autonomic dysreflexia (AD) has similar effects as chronic high blood pressure. Therefore, this trial aims to study the effect of AD on brain blood vessel function and cognition.

What to expect: Participants will be evaluated during two visits to the clinic. The first visit will take three hours, and you will be given multiple blood pressure and flow tests, questionnaires, and cognitive tests. The second visit will take about 1.5 hours for an MRI scan of your brain.

Who can participate: You can take part in this study if you are over 18, have a complete injury between C4 and T6, sustained at least one year ago, and have daily episodes of AD, and can be cleared to undergo an MRI.

Why participate: This research will help provide a better understanding of the influence of AD on cerebral blood vessels and the extent to which this affects cognition. At the end of the study, you will receive a \$25 honorarium per visit to cover your travel expenses.

Location: ICORD at Blusson Spinal Cord Centre (first visit) and UBC MRI Research Centre (second visit).

For more information or to sign up to participate: Please contact the study coordinator, Dr. Tom Nightingale, by email (tnightingale@icord.org) or call 778.798.2710.



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



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Deconstructing a Panic Attack

Sometimes you expect certain moments in life to trigger grief or anxiety. I like to think each individual knows themselves and their journeys well enough to foresee how some situations might bring up difficult feelings. But sometimes, it's unexpected and it doesn't matter how well you know yourself or your journey. Sometimes, you're simply blindsided.

Today I am blindsided. Today, I drive past a construction site on the way to my boys' school. They're common places to come across, but, since I sustained my SCI on a construction site, they're something I prefer to avoid (I've become very skilled at averting my eyes). For whatever reason, this one catches my attention. It's only for a few seconds; however, sometimes that's all it takes for anxiety to find its opening.

My breath gets caught in my chest while my heart feels like it might beat out of it. My mouth becomes dry and my palms are sweaty. The trigger becomes a flashback, and suddenly I'm lost inside the moments—the seconds—that brought me the most pain I've ever experienced. I inhale sharply and momentarily lose the ability to exhale. My heart beats faster while my mind relentlessly streams my worst memories on a repeating loop. My body suddenly remembers to exhale, but it provides little relief when I instinctively gasp for air soon after. I know I've almost reached the threshold where I will no longer have the power to overcome the panic on my own. And then I see my children's school in the distance.

I run through my repertoire of techniques and am flooded with relief as (this time) they start to work. My heart rate slows down and my breathing normalizes. But then the panic gives way to

grief—a grief I wasn't expecting to feel this afternoon when I left our house. It's the kind of backhanded grief that feels like a betrayal of your own spirit because today I thought I had this. My eyes blur with tears and I wish so badly that I hadn't left my sunglasses at home. I park my car, wipe my eyes, and wish the bell would ring so I could pack up my kids and get home. For once, I'm thankful nobody comes over to chat with me, because I know that whatever is holding me together in that moment is delicate and unstable. And then I wait.

The boys finally appear and for a few blissful moments, I am distracted. I let myself be consumed with jackets, backpacks, car doors slamming, and questions about snacks and dinner.

If I were smarter, I would go home a different way. Autopilot takes over and, of course, I go right back past the construction site. I know better than to look at it this time around, but driving past it again brings my focus back to the anxiety, the flashbacks and the grief. They're thoughts I will try to ignore until later, because for the next few hours, I have mom life to get back to.

Later, I'm deconstructing my panic attack and the aftermath. In the moment, a panic attack is terrifying and debilitating. But even once the worst is over, it lingers like a bad hangover. Emotions remain



CODI'S COPING SKILLS

BELLY BREATHING: Take slow and rhythmic deep breaths into your lungs.

DISTRACTION: Shift your focus. Find something else to think about or a task to busy yourself with. If nothing else, I focus on my wedding rings. I spin them around, continually lining up my engagement ring with my wedding band.

POSITIVE SELF-TALK: Tell yourself that you're OK; remind yourself to breathe; remember the feeling will end.

ONE EYE INTEGRATION (OEI) THERAPY: I learned this with my counsellor and wouldn't recommend trying without one (it can be quite intense). It's a technique used to deal with trauma. You alternate covering one eye, which is supposed to help integrate the way your left and right brain perceives an experience. For me, covering my right eye can be much more calming. In the midst of a panic attack, I find that covering my right eye can help defuse the anxiety coming to the surface.

close to the surface and the sporadic inability to catch my breath leaves me on edge. It seems as though my grief and anxiety have become so intertwined that I can't have one without the other.

There are many scenarios I can anticipate and prepare for. But being hit with the unexpected means I can't preemptively deploy my coping mechanisms, and those feelings of trauma and loss blast through my resolve. In the end though, it's just another panic attack to add to my catalogue; yet another thing to come back from. ■

***Codi Darnell** is a T-11 paraplegic who was injured in March 2016 in a fall on a construction site. She's the awesome blogger behind [Help Codi Heal \(helpcodiheal.com\)](http://HelpCodiHeal.com), where she writes about her life as a woman, wife and mother with SCI. She lives in Vancouver with her husband and three children.*

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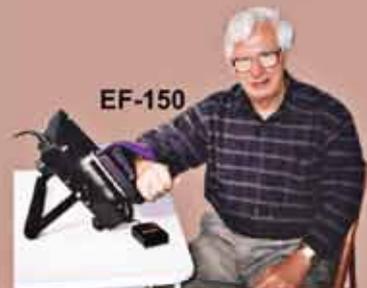
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