

the spin

SPINAL CORD INJURY BC

SUMMER 2017

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COVER PHOTO: SCI BC Peer Coordinator Ryan Clarkson camping in Utah's Goblin Valley State Park. (Ryan Clarkson photo)

When Opportunity Knocks

One thing I've learned over the years is that when government asks for input, seize the opportunity. So when the Government of Canada invited proposals from disability organizations to lead consultations aimed at informing the historic development of critically-needed Canadian accessibility legislation, SCI BC didn't hesitate to join Spinal Cord Injury Canada's bid.

Working together, we quickly mobilized 32 well-known organizations of and for people with disabilities (and older adults) to form the Canadian Access and Inclusion Project or CAIP. In the fall of 2016, CAIP was chosen as one of eight projects to be awarded federal funding to conduct a community-based consultation. Our goal was to provide the Hon. Carla Qualtrough, Minister of Sport and Persons with Disabilities, with an accurate snapshot of the barriers preventing full participation of our respective memberships, recommendations for new federal accessibility legislation, and ideas for new programs that foster inclusion and positive attitudinal changes towards Canadians with disabilities.

In the first phase, we set out to identify the barriers that prevent Canada from being a fully accessible and inclusive society and what needs to change to make our country more accessible and inclusive to all. In January, CAIP project partners hosted 52 consultations in communities across the country, including one consultation dedicated to youth with disabilities. In addition, 10 workshops were held within First Nations Communities. An online survey version of the consultation was also available for those unable to participate in person.

In all, 995 people contributed their experiences, wisdom and ideas through the consultations and workshops. Importantly, participants included Canadians with disabilities who are hard to reach or whose input is infrequently captured. Another 60 people shared their stories and ideas on the *Rant, Rave & Recommend* feature of the project's website, include-me.ca.

Through a structured research process, CAIP's academic research partners then analyzed the input and identified common sets of barriers and areas in which changes could make Canada more accessible and inclusive.

A lack of public awareness, knowledge, and training were consistently identified as barriers. So too were insufficient infrastructure and services. As well, a need for national standards and equity, accountability, transparency, and representation by people with disabilities and indigenous people in the legislative processes were identified. Lack of housing and transitional barriers (as youth age into adulthood) were brought to the fore in the First Nations community workshops and the youth consultation, respectively. Employment was brought forward as one of the top priorities by participants in the youth consultation.

The results of phase one will now be used to inform the plan for phase two, which will focus on how the identified priority issues faced by Canadians with disabilities can be addressed with new legislation. In addition, CAIP's partner organizations will participate in a think tank aimed at exploring bold and innovative ways of changing attitudes to improve access and inclusion in Canada.

The government asked for input, and through CAIP we provided it. By we, I mean SCI BC, SCI BC members, and hundreds of other Canadians with a connection to disability. I'm pleased to report that the government is listening closely and welcoming our input. We expect new federal accessibility legislation to be developed over the next year and new programs that promote access and inclusion are likely to be launched over a similar time frame. We will stay vigilant to ensure they reflect all of our common input in the process.

To view the report and all of the input received from each of the 62 consultations and workshops, visit include-me.ca. While you're there, fill out the *Rant, Rave & Recommend* feature on the site to include your voice in the process.



- Chris McBride, PhD, Executive Director, SCI BC



The Spin is the quarterly magazine of Spinal Cord Injury BC. An online edition of The Spin is available on the SCI BC website www.sci-bc.ca.

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Publications Mail Agreement #: 40684573

ISSN #: 1922-9445

Return undeliverable Canadian addresses to:
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To update/change delivery address, email thespin@sci-bc.ca or call 604.324.3611.

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AMAZON ECHO DOT

The Amazon Echo Dot is a small, hands-free, voice-controlled device with a built-in speaker. It's made for the mainstream public, but at just \$49 USD, it's a very inexpensive and easy way for anyone with an SCI to automate their house. The Echo Dot can control lights, fans, switches, thermostats, garage doors, sprinklers, and more with compatible connected devices. It connects to Amazon's Alexa Voice Service to play music, provide information, news, sports scores, weather, and more—instantly. You can also instruct Echo to play music from Spotify or other online services. You can even connect Echo to your universal remote to control a TV using voice commands. You can't buy it in Canada just yet, but apart from the function that allows you to order products by voice from Amazon, the US version seems to work just fine here. Visit www.amazon.com and search for "Echo Dot".



Innovations

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Room for Debate

■ opinion

FAIR FARES? Recent hikes to transit pass fees around BC have led to tightening budgets for many people living and getting around with a disability. But is the suggestion that people with disabilities can't or shouldn't pay for transit doing more harm than good? Given rising financial pressures and the already-existing stigma around "disability" as "inability", many of our Peers have questioned whether public transit for people with disabilities should be full price, subsidized or absolutely free. So we asked our SCI BC Facebook community (facebook.com/SpinalCordInjuryBC) to weigh in: Should people with disabilities have to pay for public transit?



Children and seniors get different rates. Does that mean they are not equal? Having a disability should not change your value as a human. I also think, though, that it depends on what the disability is. Being in a wheelchair, for example, does not make you worth less than someone who walks. Providing subsidized or free access to public transportation actually contributes to the equality, in my opinion, because it's giving someone independence and a mode of transportation they may not otherwise be able to afford. There are lots of subsidy programs for people who struggle financially. I think if someone is struggling financially because they are unable to work due to disability for example, then yes. Give them free transit. Isn't this why I pay taxes? — **K.E. Liv**

No. Equality does not mean everyone getting or paying the same thing, Equality is equal opportunity — so no, it should not cost the same. — **Susan Dehnel**

Transit should be free for people with disabilities. — **Doug Hlady**

I agree. Transit is free for people with disabilities in many EU countries. — **Vince Preap**

It's already way cheaper for us—we can't expect to be treated any differently than people without a disability. I wouldn't want to be. — **Brianne Elizabeth**

There have been many studies to determine if transit could be free for everyone. Most have concluded that it would be better in the long run to have "free" transit. The fares only make up a small percentage of the budget anyway, and at the end of the day, we all pay for transit through taxes, etc. — **Roger B. Jones**

The answer isn't one-size-fits-all. I am hemiplegic, use an electric wheelchair and currently qualify for reduced fare public transportation. I feel that if somebody is living on social security, regardless of ability status, there should be no fare. If a person is able to make their own money, and live above the poverty line, their fare should be proportional to income. This way, we as a community support the value of individuals, and their ability to move around their communities and be as independent as is reasonable. — **Brianna Cooper**

Yes. People with disabilities want to be treated the same as everyone else. I feel weird whenever I'm given special treatment. — **Axel Jonsson**

Yes, but subsidized. After rent, long-term disability only gives a little over \$600 to pay for everything else. We still live below the poverty line. — **Robyn Artemis**

There are many, including myself, who can pay regular transit rate...People who make good incomes, have money, etc., should get treated equal to people without disabilities who make similar wages, have money, etc. There is too much contradiction in the disabled community to want to be treated equal yet get concessions where many don't qualify financially but, because they have a disability, continue to get and expect reduced rates! ...it's about equality and dignity, and not being free just because someone has a disability. This is not equal and it compromises dignity! — **Patty Clarke**

...transit should be free for persons with disabilities, according to their income. MDs no longer make house calls, and many have no other means of transportation to medical appointments. If they do not have to pay for their medical services according to their income, then the same standard should apply to how they get to their appointments, in my opinion. — **Kim Heck**



Wind in your sails.

The 27th Mobility Cup, Canada's international regatta for sailors with disabilities, is coming to Lake Okanagan from September 11 to 15. Hosted by the Able Sail Network and Kelowna Disabled Sailing Association, the competition will take place at the Kelowna Yacht Club's spectacular new facility. As usual, sailors will compete in one of two fleets depending on experience. Learn more at www.mobilitycup.com.



Athletics, rugby & tennis.

How about all of them? From July 21 to 23, the Kamloops Legacy Performance Games will feature thrilling competition in wheelchair athletics, rugby and tennis. This is an excellent opportunity for Peers and readers in the BC interior to come out and cheer on the athletes and learn more about these exciting wheelchair sports. For up-to-date information, visit www.bcwheelchairsports.com and click on the news+events section.



What's in your man-cave?

Last year's SCI BC Guys' Garage was such a great success that we're bringing it back for year two. This a chance for local guys with SCI to hang out together for a fun-filled day of food, drink, entertainment, and motorcycles—this year's event takes place at the awesome Deeley Motorcycle Exhibition on Boundary Road in Vancouver. Guys' Garage happens on July 8. Find out more at sci-bc.ca/events or email Ryan at rclarkson@sci-bc.ca.



Talk to:
Program Coordinator Stephen Street
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Looking for work?



TAP INTO ONE-ON-ONE MENTORSHIP SUPPORT

The Employment Mentorship Support Project offers eight months of one-on-one volunteer support for people with physical disabilities in Metro Vancouver who want to explore work, social and leisure options. It's a partnership between the Connectra Society and UBC that aims to reduce barriers to employment and increase social involvement for people with disabilities.



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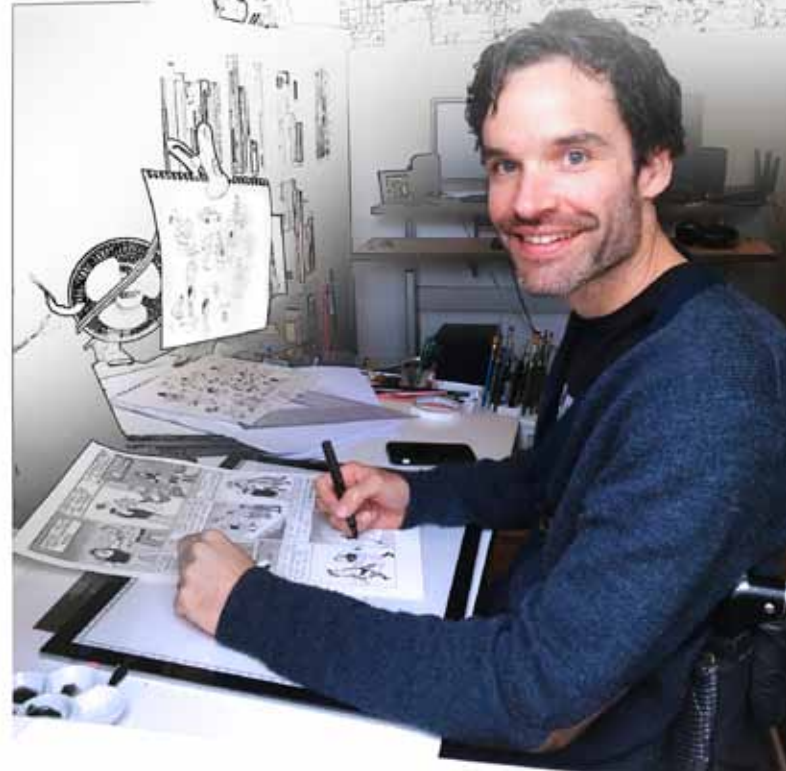
COMIC RELIEF

When the cartoon character Ted the Terrible Superhero suddenly started using a wheelchair, there was no warning or explanation—and few people realized that, behind the scenes, Ted’s creator was working through an SCI of his own.

Oregon’s Mat Barton is a graphic designer by day, a cartoonist by evening, and a T5 paraplegic by accident. He works mornings and afternoons from his Portland home. At lunch, he sometimes takes his handcycle out for a spin. Occasionally, he shrugs off inspired onlookers at the grocery store.

“It’s funny,” he says, “people think you’re finding a cure for cancer just by getting out of your house in a wheelchair.” Often, he files away these interactions for future use in his work.

In the evenings, Barton draws. And, because he’s a procrastinator, on Sunday, Mondays, and Tuesdays, Barton draws *a lot*. On Tuesday evenings, Barton and his college friend Adam Cooper, who collaborates on captions, send as many as ten single-panel cartoons to *The New Yorker*, America’s iconic weekly magazine since 1925 and a holy grail for cartoonists. Their drawings,



signed with a simple CAB (short for Cooper and Barton), arrive and join a stack of hundreds of others, just in time for the cartoon editors’ weekly Wednesday morning meeting.

It’s often said that imperfect childhoods make for comic gold; the unique observations of a kid on the fringe can breed a lifetime of imagination and punchlines. But given Barton’s fanciful viewpoint, his childhood was pretty normal. He grew up in Louisiana, then moved to Central Valley, California at the age of 13. His worldview was shaped by books, movies, and music—and, of course, comics. Ninja-turtles and Simpsons doodles populated the margins of his grade-school notebooks, and cartooning became a constant pastime.

In college, Barton enrolled in the animation program at California State University, Fullerton, and went on to intern at both the Cartoon Network and Warner Bros. But at both studios, he found the drawing style, along with a lack of artistic freedom and creativity, stifling. The focus on kids’ content didn’t help either.

So Barton decided to get into the world of single panel comics—a format that’s been popularized thanks to the work of such art-





ists as Gary Larson (*The Far Side*) and Dan Piraro (*Bizarro*).

"I like looking at a drawing where you can see the artist's hand behind it," says Barton. "It's a little looser. It's drawn in his or her style, and you can see some of their personality in that loose doodle. It's not overworked, just kind of raw, which really appeals to me."

In 2007, Barton moved north up the I5 to Portland where his girlfriend, Jessica, had decided to go to university (they got married in 2008). His graphic design career went with him, but his cartoon collaborator, Cooper, stayed behind in Los Angeles. Despite the distance, the CAB partnership flourished, and the duo continued to crank out cartoons. Online, their comic strip, *Ted the Terrible Superhero*, gained an impressive following.

But in the years that followed, his passion for drawing acquired some competition: competitive biking.

As a child, Barton was an avid BMX racer. After his move to Portland, he got

back in the saddle, road biking, mountain biking, and cyclocross racing at a local pro level. He began leaving his sketchbook behind to make room for his growing obsession with the sport.

Then, in 2012, everything changed. During a mountain bike race, Barton lost control through a particularly fast section. He flipped headfirst over his handlebars and landed on his back.

"I could tell right away something was wrong," says Barton. "I didn't know if it was going to be permanent, but I knew right away. But, laying there, I could tell that I could still move my hands. I immediately thought, 'I can still draw.'"

In rehab, he drew—a lot. Pen and paper offered an escape, and a way to help Barton better accept and understand his altered life. New cartoon characters emerged in situations mimicking his own, and old ones were soon reliving the funnier aspects of his new daily life. *Ted the Terrible Superhero*, the quirky cartoon kid from Barton's online comic strips,

suddenly began using a wheelchair. The comic strip hinted at an accident, but no clear explanation was given.

"Drawing my cartoons definitely helped with my adjustment to my injury," says Barton. "It was nice to have something to take your mind off things. It was very therapeutic. I think if you're in a wheelchair, you go through a lot of stuff that isn't very natural and you aren't prepared for, so you have a right to get a little angry and sad at times."

On the rehab ward, when he wasn't drawing or being treated, Barton found comfort in getting to know the work and life of someone he'd always admired: the late John Callahan, a quadriplegic who, following his own accident, became a successful cartoonist who drew by clutching a pen between both hands. Though he'd never met Callahan, Barton had long been a fan of the artist's hilarious and often irreverent portrayal of disability, and his autobiography proved to be a big support (Barton's wife, Jessica, by

this time an occupational therapist, was another).

After a month in rehab, Barton was out—and back to the drawing board.

He continued to work as a graphic designer. But, with competitive cycling no longer viable, he found himself once again filling his spare time with comics and doodles—and, with his old friend Cooper, working hard to get those cartoons out into the world.

In 2014, a breakthrough—after 60 plus CAB submissions to *The New Yorker*, the weekly's cartoon editors finally liked one they saw and published it (though Barton concedes that, since then, 400 to 500 other cartoons painstakingly crafted by the duo have been methodically rejected). Barton and Cooper's work has appeared elsewhere, too—the *National Lampoon* may pay only \$100 US per single strip (compared with *The New Yorker's* \$700 US), but Barton says it's easier to sell to.

These days, with fewer magazines running cartoons, and more artists vying for those spots, Barton says cartooning isn't

quite the profession it used to be.

Still, he's happy to see the world of cartoons evolving. *Archie Comics* recently added Harper Lodge, a fashion designer and blogger who uses a hot pink wheelchair, to its cartoon family. And over at *The New Yorker*, diversity also seems to be catching on.

"*New Yorker* cartoons have historically been very 'white' but that seems to be changing," Barton says. "Bob Mankoff, the (recently retired) cartoon editor, is striving to show more diversity in the magazine's cartoons, and I think that's evident in the cartoons they've been publishing."

But he believes more can be done. "I think most cartoonists shy away from this type of content because most artists—myself included—grow up copying other artists and cartoonists. If most of the cartoons published are of white, able-bodied men, then the aspiring cartoonist gets comfortable drawing this type of character. I still struggle with drawing women, but it's something I'm aware of

and I'm constantly working at drawing more of them and getting better at it."

Barton is forthright about his achievements. Getting published in *The New Yorker* was the proudest moment of his career; marrying Jessica was the proudest moment of his life. He's less certain about his future—maybe he'll attempt to create another comic novel, perhaps he'll go back to cartoons about disability. He's been toying with the idea of a short story about an older, grumpy person in a wheelchair, but he's not yet committed.

"Honestly, drawing wheelchairs is a pain in the ass," he says. "If you keep it simple and loose then it's not so bad, but there's a lot going on with a wheelchair. But of course, the more you draw them, the more comfortable you get."

No doubt, the same can be said for using one—after all, doesn't art imitate life? ■

You can see much more of Mat Barton's work online at www.matbarton.com or matbarton.tumblr.com.

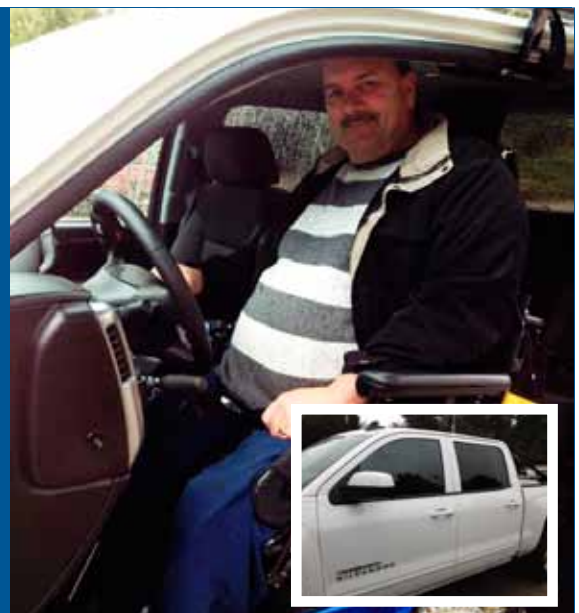
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From writing, travel and sports, to board games, woodworking and cooking, our SCI BC Peers share their passions, pastimes and expertise

In April, Peers from across the Lower Mainland showcased their hobbies and handiwork at our annual SCI Forum. Our workshop-based event, aptly titled “How We Do Stuff,” shone the spotlight on our most valuable SCI experts—you!

Prior to the event, SCI BC put a call out to Peers across BC, asking, “What do you love to do?” We received more than 40 submissions of passions and pastimes, all of which we compiled into “Hobby Cards” for our event—and some of which we’ve managed to squeeze into the next few pages so that readers from other areas of the province can check them out. All of the Peers featured on our Hobby Cards are more than willing to share their knowledge with you, wherever you’re located—look for email addresses on the bottom of each card. The complete list of Hobby Cards is available on SCI BC’s new online hobby database at sci-bc.ca/hobbies.

And the hobby hunt is far from over! If you have an activity you’d like some advice on, let us know. If you have a passion or pastime that’s made a difference in your life, why not share your tips, tricks, and experience with other Peers around the province? Email mpankalla@sci-bc.ca to promote your hobby—and get your very own hobby card made, too!

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singer-songwriter
T10 paraplegic

Music is my passion – the art of it, the science of it. It's bottomless.
salttotheearth@riseup.net

ask me about



MODEL BUILDING

Hello, I'm
DEAN STONE

wood model builder
paraplegic

I enjoy the challenge and creativity. We all need a creative outlet.
wingrider21@hotmail.com

ask me about



SOCIAL MEDIA

Hello, I'm
GABE CHESMAN

writer & communicator
C3/4 quadriplegic

Social media to me is more than just posting selfies, it's a living.
gkchesman@gmail.com

ask me about



SOLO WORLD TRAVEL

Hello, I'm
GERRY BURNS

solo adventure traveller
C1/2 incomplete quad

It's all about freedom, independence, and pushing limitations.
burner5353@gmail.com

ask me about



TABLE GAMES

Hello, I'm
HILARY BROWN

unabashed strategist
T8 paraplegic

Games provide a unique type of social engagement.
hjbrown@shaw.ca

ask me about



SEWING & QUILTING

Hello, I'm
KAREN HODGE

counsellor & parent
T1 paraplegic

I love to take pieces of fabric and turn them into new items.
k_meadow@hotmail.com



Hello, I'm
KEVIN PRIEBE

designer & sculptor
paraplegic

I take pride in being part of a team and in the creative process.
kpfx@me.com



Hello, I'm
VINCE PREAP

dancer & athlete
L5 quadriplegic

Dancing is fun, social, and integrates a wheelchair user and standing partner.
vpreap@gmail.com



Hello, I'm
SYDNEY SPRAGGS

fearless paddler
Multiple Sclerosis

Paddling is amazing upper-body exercise and the highlight of my week.
smspraggs@gmail.com



Hello, I'm
LINDA MCGOWAN

intrepid traveller & writer
MS paraplegic

I love to explore new cultures, new habitats, and new countries.
lin@shaw.ca



Hello, I'm
MARNEY SMITHIES

woodworker & artist
T5 paraplegic

Frames to small furniture – my list of projects keeps getting longer.
marneysmithies@gmail.com



Hello, I'm
MARNI ABBOTT-PETER

retired paralympic athlete
T4 paraplegic

It's amazing how much can be grown in a small, raised, accessible plot.
peterabbott@shaw.ca



Hello, I'm
MARY-JO FETTERLY

yoga pioneer
C4/5 quadriplegic

I love yoga because it's a science, philosophy, and technology for living well.
maryjofetterly@gmail.com



Hello, I'm
MONICA GARTNER

author & public speaker
Osteogenesis Imperfecta

I love to travel, and share stories, ideas, and thoughts.
dynamicmg@gmail.com

ask me about



WILDLIFE PHOTOGRAPHY

Hello, I'm
RICH GREEN

nature photographer
T12/L1 paraplegic

I prefer to hunt with my camera, showcasing the beauty in nature.
greenlensphotos@gmail.com

ask me about



ONLINE WRITING

Hello, I'm
ARNOLD CHENG

blogger & web writer
T9 paraplegic

I love using words to help others discover the world around them.
arn.cheng@hotmail.com

ask me about



SKIING

Hello, I'm
SANDY HAWKSHAW

mountain lady
C4 incomplete quad

Skiing permits me to be where I love to be: outdoors.
amtnlady@yahoo.com

ask me about



ROADTRIP CAMPING

Hello, I'm
RYAN CLARKSON

primitive camper
L1 incomplete paraplegic

I like to push myself physically and mentally, to feel like my old self.
rclarkson@sci-bc.ca

ask me about



ART THERAPY

Hello, I'm
SUZAN JENNINGS

author & speaker
Guillain-Barré Syndrome

My passion, art therapy, has helped me through various health battles.
psuzanjennings@gmail.com

ask me about



OCEAN SPORTS

Hello, I'm
SHIRA STANDFIELD

outdoorswoman
T12 paraplegic

My favourite outdoor hobbies are ones where I leave my wheels behind.
shirastandfield@gmail.com

ask me about



COOKIES

Hello, I'm
SHERRY CAVES

cookie artist
paraplegic

My new art medium (and hobby business) brings people joy.
bayheron@telus.net

ask me about



KNITTED CRAFTS

Hello, I'm
TABASSUM CHAGANI

creative crafter
Post-polio syndrome

I like to move my creative bone. Knitting improves my manual dexterity.
tchagani@yahoo.com

ask the SPIN DOCTOR

“How can I get it across to my family doctor, ambulance personnel, or staff at my local emergency room that I believe I’m having an episode of autonomic dysreflexia (AD)?”

Here at SCI BC, we often hear various versions of this question from SCI BC Peers. For some professional advice, we turned to physiatrist, UBC professor and ICORD researcher Dr. Andrei Krassioukov, one of the world’s leading experts on AD.



While SCI specialists have a thorough understanding of AD, many medical practitioners who don’t often come into contact with patients with SCI have limited knowledge of this potentially lethal condition. In fact, our recent study to assess knowledge among emergency room personnel in Canada and the USA demonstrated that up to 80 percent of physicians and paramedics weren’t familiar with AD. That’s why I see my efforts and those of my colleagues to educate healthcare providers about AD as critically important.

Meanwhile, as we continue with that work, there are some things that you can do as a person at risk of AD.

The first is to be knowledgeable about AD and be prepared to explain it to any healthcare professional who seems confused with your symptoms. Let them know AD is very common in SCI, involves dangerously high blood pressure, and is caused by a wide range of stimuli including bladder distension, undiagnosed infection, fecal impaction, a piece of clothing that is tied too tight, and even sex.

Second, carry your AD card at all times and present it to healthcare staff. This card is shown at the right, and you can also find a downloadable, printable version at our website (search for “Autonomic Dysreflexia Wallet Card” at www.sci-bc.ca). This card will help you convey the basics of AD to whoever needs it—particularly if you’re having problems speaking or organizing your thoughts.

Third, tell whoever is treating you that GF Strong Rehab Centre in Vancouver offers a 24-hour emergency response line for healthcare professionals. The number is 604.875.4111. Healthcare professionals unfamiliar with AD can call this number any time to get connected with me or one of my many colleagues who have specialized knowledge in AD.

One final thought: I’ve worked with other Canadian AD specialists to develop an online AD course for physicians and other community healthcare professionals. Please consider helping us spread the word about this course—ask your doctor to check it out at www.abcofad.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



G. F. Strong Rehab Centre

SCI-BC Infoline 1-800-689-2477

TREATMENT

Autonomic Dysreflexia

For caregivers and clinicians

1. Raise the head of the bed by 90° or sit person up-right.
2. Take blood pressure every five minutes 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 minutes after initial dose.

Attention ER physician:

If you have any questions phone VGH 604-875-4111 and ask for the GF Strong physician on call.

Road Warrior

For SCI BC Peer Program Coordinator Ryan Clarkson, there's nothing better than the adventure offered by an open road, an unexplored destination, a remote campsite, and the challenge of days and weeks of solitude.

Ryan Clarkson loves a good road trip. In the past six years, Clarkson has driven more than 109,000 kilometres, visited 43 national parks and monuments, and pitched his tent more than 200 times in two provinces, two territories and 29 US states. Along the way, he's endured breakdowns,

poisonous snakes and insects, treacherous driving conditions, and costly repairs. But the reward has been a front row seat to some of North America's most remarkable natural scenery—and a renewed sense of confidence and independence that he admits flagged in the first few months after he became paraplegic.

The irony is that Clarkson's injury occurred during a road trip. After graduating from high school in Aldergrove, he was bit by the travel bug. By 2009, he'd backpacked around Europe twice. Seeking to finance a similar trip to Asia, he took a job working on a crew that repaired structural cracks in BC highways.

"I took that job because we travelled all over the province for work, which was a bonus," says Clarkson, who is now 30. "About a month in, we were going up to Stewart, BC for a couple weeks. I was ecstatic because I knew the area was beautiful and ripe with glaciers. And the town borders an Alaskan ghost town which I would be able to check out and say I had been to Alaska."

Just 12 hours after arriving in Stewart, Clarkson's plans were dashed when



he swerved to avoid a black bear and flipped the tanker truck he was driving.

He was pulled from the bush by a fellow employee and airlifted to Vancouver, where he was diagnosed with an L1 incomplete injury.

Initially, he was told he might never walk again. But over the course of rehab and physio sessions, Clarkson gradually regained the ability to walk for short distances with canes. He soon settled into a routine of using a wheelchair for day-to-day activities, but found a way of carrying his canes under his seat chair for use when stairs or obstacles prevented him from wheeling.

During that time, he found himself thinking again about adventure travel.

"Aside from wanting to challenge myself, I felt like I had unfinished business, because I made it within two kilometres of the Alaskan border but never got to cross it because of the accident," says Clarkson. "Aside from being told I would





most likely never walk again, this ate at me the most. I would sit in my bed at GF Strong and look at pictures of Alaska and northern Canada and get bitter thinking I would never be able to go there.”

Clarkson reasoned that travel was a way to challenge himself—and other people’s perceptions of him and his abilities. His resolve to embark on an adventure road trip grew. “I’ve always loved road trips and driving, so deciding on that was easy. And I was honestly scared to get on a plane and check out other parts of the world, so I focused on driving and camping because my vehicle could double as my home.”

His destination, not surprisingly, was back to Stewart, and then on into Alaska and northern Canada. He planned for a two-week trip, and packed everything he thought he might need into his Jeep Patriot, including a pop-up tent that takes all of four seconds to set up, a Thermarest self-inflating sleeping pad, a sleeping

bag, and some basic camping tools such as a short-handled axe.

He never contemplated asking anyone to join him.

“I’ve always preferred to travel alone,” he says. “I went to Europe twice with friends, but after a week, I split up with them to go solo. I love the independent feeling of not answering to anyone and doing what you want, when you want. It’s also a fantastic way to meet new people. But these reasons aren’t why I did my first camping trip alone. I opted to go solo because I wasn’t sure I could do it. If I had to concede and turn around, I would feel like less of a failure than if I had to quit while with my friends.”

Looking back, Clarkson admits the trip started poorly. “Before I left, I was scared and had little clue on how to do anything because of my new disability,” he says. “Then, the first four nights, I was almost in tears regretting my decision because the weather was so poor—all it did was

rain. I thought I wasn’t physically or emotionally ready for such a trip.”

Fortunately, that’s when Clarkson’s “Aha!” moment arrived.

“The day I was driving to Stewart was the day that the sun decided to make an appearance. It was almost as if Mother Nature was lighting the way for my return. I thought it would be an emotionally-charged moment of sadness for me to return to the area of my accident, but it was the exact opposite. I had tears starting to form in my eyes because of the flood of joyful emotions that I was experiencing—pride and joy in the fact that I was able to make it back to such a beautiful area after I was told I would most likely not be able to walk, even with canes.”

That night, alone at his campsite, he celebrated. “I brought up a very good bottle of wine with me for the occasion, a pricy ‘04 Bordeaux I believe, and I drank it while playing the harmonica

and watching the sun set. That's when it dawned on me that I could truly do it, and that I would never let my injury be an excuse to stop me from doing the things that I love. Even though I had a ton of mosquitoes floating in my wine, it was the best bottle I ever drank."

That epic first trip ended up covering about 14,600 kilometres. Clarkson made it up to Inuvik, the farthest drivable point in Canada, Denali National Park in Alaska, and Yellowknife. Not surprisingly, two weeks turned into five.

The journey was a powerful catalyst. Since then, he's taken dozens of road trips, always by himself, always to a destination he's never seen before, and always well off the beaten path.

There have been low moments—clouds of mosquitoes, poisonous critters in his camp, flat tires, broken windshields, treacherous terrain, empty gas tanks with no service stations in sight, burns and insect bites.

"My worst moment was in 2013," says Clarkson. "I had three flat tires in less than 72 hours while on the remote 750 kilometre Dempster Highway in the northern Yukon. The tow bill was around \$450. Between that, two new tires and all the repairs, it cost me around \$1,200. Huge mistake as I had no business going back on that highway with the terrible tires I had. This was a huge WTF moment for me and also a valuable lesson about not biting off more than I can chew."

Clarkson has always scraped through these mishaps, sometimes discovering in the process the kindness of complete

strangers. For example, there was the first and only time he ran out of gas, thanks to a remote gas station on the route to Dawson City being out of order. "I had to pull out in a scenic overlook," he says. "It must have been weird seeing a wheelchair user wave an empty jerry can around in northern Yukon, because the third vehicle that drove by pulled over—they siphoned some of the gas out of their tank and refused any payment!"

But the rough patches, says Clarkson, are insignificant when he looks back and considers the countless highlights of his road trips. Notable among these was his trip to Alaska's Denali National Park.

"When I drove in the park it was around 15 degrees; the next morning I woke up to snow. It was mid-August! During my drive in Denali I saw moose, caribou, grizzly bears, black bears, elk, mountain sheep. The sheer beauty of that place is unmatched. I remember saying out loud to myself, 'This is insane!' as I made a turn on the dirt road in time to see a herd of caribou thundering at full speed on the open tundra. Denali National Park was one of the most amazing experiences of my life. I remember eating a can of beans watching the sun dip behind the tallest peak in North America (Mount Denali) while a moose drank from a creek within a stone's throw of me. I felt ten feet tall at that moment."

There are other highlights, including his voyage on BC's inside passage. On the final leg, he took the overnight ferry from Prince Rupert to Haida Gwaii.

"This was one of my favourite nights of



SAFETY FIRST: Clarkson's constant companion on his road trips is bear spray. Note the quick release, non-adhesive hockey tape.

the trip as I slept on the passenger deck between the seats with a bunch of other travellers. I felt like I was in Europe staying at a youth hostel again! A bunch of us drew straws and the short straw, which was me, was tasked with waking everyone up just before dawn so we could all go on the deck and watch the sun rise on the Pacific Ocean. Haida Gwaii itself was awesome as it felt like I was on the other side of the planet. I truly gained a new respect for our province and the First Nations people who live in it."

Another highlight was seeing the northern lights on the Alaska Highway. "This was last November, right after I got hired by SCI BC. I decided to celebrate the new job by driving up to the BC/Yukon border and camping along the Alaska Highway in order to see the northern lights. At this point in my adventures, I had driven around 91,000 kilometres and thought I'd been everywhere and seen everything. The drive up was brutal because of snow and I regretted it the whole time. I eventually made it to the Alaska Highway by Muncho Lake and put the seats down to sleep in my car. It got down to minus 18 that night, and I was not loving life. Then I woke up around 1 AM and poked my head out of my Jeep to see the most amazing northern lights dancing above



ROAD HAZARDS: Clarkson has had his share of setbacks during his road trip adventures.

ROAD TRIP ADVENTURES

1. Setting up camp in the Nemaiah Valley, east of Bella Coola, BC.
2. Winter camping in Jasper National Park, Alberta.
3. Wide open camping on a hot day in Oregon's Alvord Desert.
4. On board the ferry up BC's Inside Passage, en route to Haida Gwaii.
5. Dusk approaches at Clarkson's campsite in Kansas.

If you'd like to see more of Clarkson's road trip photos and videos, search for "ryanwclarkson" on Flickr (www.flickr.com).



1



5



4



2



3

me. I felt like the only person on the planet, as everything was covered in a sparkling sheet of fresh snow, and the stars and northern lights exploded in the night sky."

Yet another memorable trip was down the Pacific Coast Highway, from Vancouver to San Diego. "Everyone knows this is a beautiful drive, but that wasn't the amazing part for me. The Pacific Coast Highway is one of the highest density tourist drives in the world, but I managed to find free camping sites the whole way down—and most of the spots had amazing views. These five days confirmed to me that I was getting adept at trusting my gut and scouting areas to camp."

Beyond the cost, Clarkson has adopted a few more criteria for choosing a campsite: potential for a great sunset, a unique feature such as a spectacular view or rock formation, protection from the wind, no ponds or small lakes that can be breeding grounds for mosquitoes, and no proximity to other people.

"I almost always look for spots where I can listen to my music and sing until the late hours of the night," he explains. "I don't want to disrupt people's camping experience, and I don't want them to disrupt mine as well."

Safety is also top of mind. "I feel safe nine out of ten times. Even on that tenth time, I don't feel like I am in *real* danger.

I strap bear mace to the side of my chair with (tear away) hockey tape, so I can grab it easily. As far as animals go, music is my best defence. When I have my music blasting, I feel invincible. When the batteries die and it goes silent, I feel vulnerable. A couple times I thought I was alone for miles and then would hear younger people shooting guns and smashing bottles pretty close by. On one of these occasions, I packed up my tent in the middle of the night because I didn't want some drunk lunatics rolling into my camp in the middle of the night and robbing me. Ultimately, the best defence is common sense. Keeping all food and wrappers in your closed vehicle is the number one priority. After that music and bear mace are key."

Perhaps you're reading this and feeling the tug of the open road and everything it brings—the sense of adventure, the windows rolled down and the road trip playlist cued, an intriguing but unknown destination waiting at the end of the trail. But you find yourself wondering, "Can I really do this?"

Clarkson believes you can—as long as you’re realistic about how far off the beaten track you should venture. “I wouldn’t be able to do the style of camping I do if I couldn’t use canes to get around,” says Clarkson. “The terrain is often very rough, and a lot of places in remote locations do not offer accessibility at the most simple of places like gas stations. Being able to use canes allows me to visit anywhere no matter how inaccessible it is. Having said that, there are still thousands of spots to check out that don’t require canes to get around.”

The key, he says, is to know your limits and work within them. “It’s very hard to say what everyone’s specific limit is, as that will depend on what their needs are, both physically and mentally. I’ve seen quadriplegics in the middle of the desert and it seemed to be no big deal because they had a few members of their family with them. So essentially I say support is everything. A high-level quad might not be able to go to the closest provincial park and camp by themselves, but with

the proper support he or she could make it up the tallest mountain. Build a good support system and trust in that system.”

But for Clarkson, road tripping is likely to remain a solitary endeavour.

“I honestly love and thrive on some of the struggles of camping alone. Nature discriminates against everyone, and using my disability is just an excuse to justify getting a hotel or heading home early. I know it sounds terrible, but rolling into camp after an eight hour drive, digging a fire pit, chopping firewood, setting up my tent, cooking dinner, and keeping an eye out for scorpions and snakes, all while going on day 11 without a shower, all add up to such an amazing feeling of independence. You get an amazing feeling of being truly connected to nature when you’re the only soul around for hours. I love my friends and family, and have had offers from them to join me, but I think I’ll stick to solo camping.”

Not surprisingly, Clarkson enthusiastically encourages his peers to hit the road this summer.

“You have no idea how rewarding it is to get out of your comfort zones and challenge yourself. Driving into a new region and sleeping outdoors is the best way I know to do that. I honestly feel like I can do anything—as well as overcome anything—now that I’ve experienced such highs and lows while on the road. When I’m visiting some amazing places, my disability is the last thing I’m thinking about. And you know, you don’t have to go deep into the bush or high up in the mountains to get that rewarding feeling— I still get that by camping an hour from home.

“There are two major events in my life that made me incredibly humble. One was the accident that left me paraplegic, and the other was freeing myself to see what this great land has to offer and realizing I can go see it anytime I want.” ■

Need some sound road trip or camping advice? You can reach Ryan Clarkson by email at rclarkson@sci-bc.ca, or check out his top road trip tips at sci-bc.ca/blog.



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Not far, just next door!

148 West 6th Ave.

tel: 604.872.5496
web: www.macdonaldsHHC.com
email: info@MacdonaldsHHC.com

The Elephant in the Bedroom

No, we're not referring to your latest sexual escapades. We're talking about sleep—lack of it, to be specific.

University of Washington researcher Dr. Donald Fogelberg explains that it's a big problem with potentially serious consequences for many people with SCI, and believes more could be done to pinpoint its causes and treatments.

We know you talk about it—the lousy sleep you had last night, how tired you are at work today, your newest strategy to sleep like a baby. But do any of us ever do more than talk about our sleep issues, or view sleep as a critical factor that can help determine our overall health? Or do we simply resign ourselves to our various forms of sleep deprivation, instead of digging deep for answers and looking to our healthcare providers for solutions beyond a routine prescription for sleeping pills?

We believe that, for most of us, it's the latter. We also believe it's high time for all of us—people with SCI, rehabilitation professionals and other healthcare providers, and researchers—to have a conversation about sleep, with the goal of seeking some better answers to the questions of why so many people with SCI have sleep issues, and what can be done about them.

We were pleased to learn that one of the world's few experts on sleep disorders in people with SCI and other neurological conditions plies his trade just down the highway in Seattle. We reached out to Dr. Donald Fogelberg, an assistant professor at the University of Washington's Department of Rehabilitation Medicine, who readily agreed to give us an overview on the scope of the problem and some possible solutions.

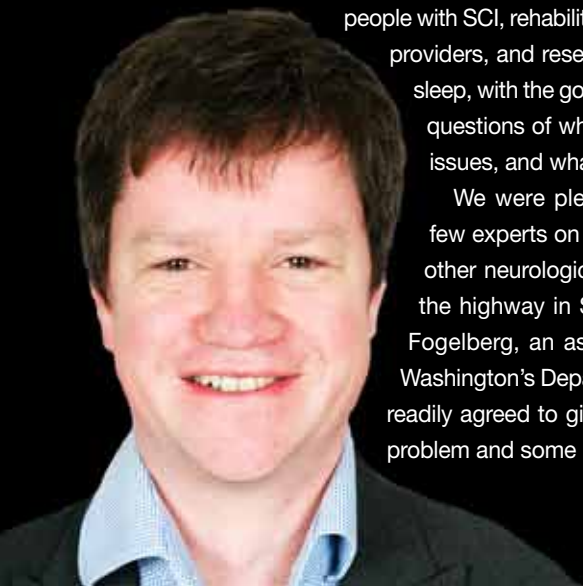
Dr. Fogelberg, can you tell us how and why you made the decision to specialize in sleep problems for people with SCI?

I first got interested in this topic in 2008 when I was working on my doctoral dissertation at the University of Southern California. I was reviewing interview data collected during a study focused on daily experiences of people with SCI who develop multiple, serious pressure ulcers. I was particularly interested in the idea that many of the behaviours that could lead to pressure ulcer development were habitual in nature, because changing habits requires a different therapeutic approach than changing intentional behaviours.

The combination of focusing on repeated, semi-automatic behaviours and the fact that I myself was fairly sleep deprived (very common among PhD students!) helped me to notice that many of the participants in the study talked about having serious, ongoing problems with their sleep. At the time, I assumed that other researchers must have noticed this as well, and was surprised that the topic was largely neglected in the scientific literature. There is, however, a very robust and consistent body of research about the many problems that can be caused when people don't get enough sleep.

Just how big is the problem of insomnia and poor sleep for people with SCI? We understand that there has been little research done in this area, but even an educated guess would help.

You're correct that there is still very little research that has been done about sleep problems that people with SCI experience, but almost all of the work that has been published suggests that it's very, very common. Keep in mind that insomnia, which is one category of sleep disorder, is one of the most common chronic complaints in the general population. What we're seeing, both from our own research and that published by other groups, is that sleep problems are even more common for those with an SCI than the already high levels in the general population.



Can you describe the various health risks, physical and mental, of ongoing compromised sleep—for the general public, and for people with SCI in particular?

Poor sleep can lead to a wide range of problems, both directly and indirectly.

Physically, poor sleep has been associated with cardiovascular disease, weight gain, diabetes, and a range of immune and endocrine system dysfunctions.

Poor sleep can also cause problems with a range of cognitive and other mental functions, such as decreased levels of alertness, memory problems, poor attention, impaired judgement, and poor decision-making. Ongoing sleep problems are also associated with problems

regulating mood, and those with them are more likely to be clinically depressed and have more problems with anxiety.

Finally, poor sleep seems to make people more susceptible to pain and increases fatigue.

Can you describe the most common sleep difficulties for people with SCI? For example, are problems falling asleep most common, or is it length/quality of sleep?

This is another area where we really need to do more research to be able to say much definitively, partly because much of what has been published to date relies so much on people's descriptions of their own sleep problems, and it's very diffi-

cult to diagnose your own sleep problems very adequately. Based on what has been published, it looks as though almost all aspects of sleep are somewhat worse in SCI than in the general population; they're more likely to report problems falling asleep, having sleep that's disturbed or restless, and getting adequate amounts of sleep. Sleep-related breathing problems, such as sleep apnea, also appear to be more common for those with SCI than the general population.

So what are some of the most common SCI-specific barriers to sleep?

Again, the research in this is pretty preliminary at this point, but it seems as

PEER SLEEP HACKS

12 SCI BC PEERS OFFER THEIR BEST TIPS AND TRICKS FOR A BETTER NIGHT'S SLEEP

Arnold "Bucky" Cheng, T9, Steveston

I'm a total nerd so I have nerdy ways of falling asleep. For example, I think of three former players of each NHL team, without repeating a player who has played for more than one team. I go through each team alphabetically, and usually I'm asleep by the time I hit Minnesota. Another one is naming as many countries as possible. Like I said...nerd.



Glenda Gain, C4/5 Incomplete, Victoria



I listen to CBC radio's *Ideas* podcast. It runs for an hour, and it's so interesting it puts me to sleep! I also eat only a light meal three to four hours before bed, and a chunk of cheese later if necessary.

Teri Thorson, C6, Vancouver

I usually fall asleep pretty easily but I need some kind of background noise. Writing down the things in your head helps too.

Bert Abbott, T6, Nanaimo

Listening to something soothing works well for me. I have a couple of favourites. The first can be found on YouTube—search for “waves on a beach with a palm tree”

and you'll find a short and long version of a very peaceful soundtrack featuring gentle waves. The second is any live concert



by Journey, The Alan Parsons Project, AI Stewart, or Emerson, Lake & Palmer. Make sure the device you're using is covered so there's no light from it to disturb your sleep cycle, and have the volume just loud enough so that you can hear it (if it's too low, you'll find yourself straining to hear it, which will keep you awake). I had to play with that a bit to get the right level for me

I was told by doctors at GF Strong to eliminate all light in your bedroom. This includes your alarm clock out of the room, which I've found takes away my urge to look at the clock every time I wake—and then getting anxious about the time.

If anxiety does get the best of me, I sometimes eat something—just a few raisins or grapes, or a teaspoon of peanut butter.

(Bert Abbott is SCI BC's Peer Program Manager)

Chris Marks, C5 Incomplete, Victoria

I tie myself in the fetal position on my side with pillows between my legs and under my head, and lie there for eight hours. That and my CPAP can give me five to eight hours of sleep more nights than not. Also, I don't nap, so by the time I go to bed, I'm exhausted and ready to sleep.



Jocelyn Maffin, T10, Vancouver

Sometimes spasms keep me awake. I try to head this off by stretching before bed. I've found a little bit of cannabis in a vape pen is just enough to help my muscles relax before bed and has no side effects except a skunky taste in my mouth. I sleep best when I give myself 30 to 45 minutes to wind down before bed. I also sometimes listen to this goofy sleep podcast on headphones if I'm really stuck and can't get to sleep (www.sleepwithmepodcast.com). It's a free podcast that's just an hour of the most boring stories read by a guy with a really mellow ASMR (autonomous sensory meridian response) voice that keeps



though there are some specific barriers faced by people with SCI to getting adequate amounts of high-quality sleep at appropriate times.

In one study that I did using previously collected interview data, people mentioned several factors: problems with positioning themselves comfortably for sleep; problems changing position during the night; night-time care routines such as bowel and bladder management or pressure relief routines; uncomfortable sleeping surfaces; difficulty controlling elements in the sleep environment like noise, temperature and light levels; muscle spasms; and neuropathic pain.

In your latest study, you've written about the doubled-edged nature of sleep issues for people with SCI, in that many secondary complications of SCI lead to compromised sleep, and vice versa. Can you elaborate?

This is one of the aspects of sleep that I think makes it such a key phenomenon for rehabilitation professionals to understand—specifically, that poor sleep can both be a result of other conditions, such as pain and depression, and a cause of those conditions. To take pain as an example, it's fairly easy to see how pain can cause poor sleep; if you're in pain, it's hard to fall asleep, and you're also likely to wake up fairly easily. There's also an emerging body of evidence that poor

sleep makes it more likely that you'll experience pain the next day. In fact, poor sleep is a better predictor for pain the next day than pain is of poor sleep the following night. The exact mechanism that causes poor sleep to increase next day's pain is still being investigated, but it's a significant finding, because it suggests a reciprocal relationship between sleep and pain that can cause a vicious cycle; the more pain you feel, the worse you'll sleep, and the worse you sleep, the more pain you're likely to feel.

The relationship with depression is similarly complex. For many years, it was assumed that if someone had a major depressive disorder and didn't sleep

your brain busy but lulls you to sleep. Keep in mind that tablet and smartphone screens give off blue light which the brain receives as sunlight and therefore concludes it's time to be awake. See if your device is running with the latest versions of iOS or Android, which have a feature to dim your screen and tint it gold or yellow so it won't keep you awake.

(Jocelyn Maffin is the SCI BC Resource Centre Manager)

Kristina Sheldon, C4/5 Incomplete, Vancouver

Calming teas such as chamomile can be helpful. I've also used the herb skullcap in the past and found it nice and relaxing. Some of my friends with insomnia have told me CBD/THC helps them sleep. Apparently tryptophan is something people also use (the turkey drug). Often I'll read until I realize I'm not reading anymore and then quickly turn off the light and pass out.



Cory Parsons, C5/6, Nanaimo

As a licensed Health Canada organic grower, I know that cannabis can be a powerful sleep aid. But different strains work differently for different people.

Historically, we've been told that indica strains work better than sativa strains when it comes to relaxation and sleep, but I know people who swear the opposite is true. Meanwhile, there's an emerging

body of research that suggests the terpene content of cannabis plays a huge role in whether or not it induces sleep. In particular, cannabis with a high content of the terpene myrcene is reputed to be exceptional for relaxation. And there's more emerging evidence that cannabis that's been allowed to mature for an extended time while still on the plant, and cannabis that has been thoroughly dried to convert THC to cannabinol (CBN), is best



for sleep. My advice is to explore and experiment with the offerings available to you.

I've recently discovered a product called Natural Calm Specifics. I swear by this stuff. It contains a number of sleep-promoting ingredients, but the most important appear to be magnesium citrate and magnesium glycinate, the two forms of magnesium that are easiest for the body to absorb. Magnesium is critical for sleep, and very few people get enough of it in their daily diet. A side benefit is that it's really improved my bowel routine.

Diane Swan, L1, Sechelt

Holistically for sleep, there is valerian and melatonin. For the last 20 years I have used amitriptyline. It's best to start at a low dose 10mg and increase slowly to the amount that works for you. I take 50 mg.



Laurie Edberg, CP/ataxia, Vancouver

I use music apps that feature nature sounds, chimes, medicine bowls, rain or the buzzing of a fan. Two of my favourites are White Noise Free by TMSOFT, and Sleep Pillow Sounds by FIT-NESS22 (easily found using an online search). Also,



you can check out www.everydayroots.com/sleep-remedies for some more great sleep advice.

Trish Rhode, T3, Kamloops

I lie in bed and concentrate on my breathing. When I breathe in, I think "in" and when I breathe out, I think "out". If that isn't working, I count my breaths. Every time I lose count (which is kind of the point) I start back at one. Before I know it, I'm thinking "one" more and more as I lose track of how many breaths I have taken. The goal is to quit counting, of course, and then I am asleep.



well, the poor sleep was just a symptom of the depression and not a problem in and of itself. If this were true, then the sleep problems would go away when the mood problem was resolved. However, there's a substantial amount of research that undermines this understanding of the relationship between sleep problems and depression. For example, poor sleep often precedes the emergence of the depressed mood, and may continue even after the person's mood has improved. However, if sleep problems are successfully treated, then people tend to respond to antidepressant medications faster and at lower doses.

Beyond the usual generic sleep hygiene advice, what are some of the most effective mitigating strategies that people with SCI can employ to improve their sleep?

One of the most important steps to improving sleep is simply to start to take it more seriously as an important part of maintaining your health. The standard sleep hygiene guidelines, readily available online, are a very good place to start, and for most people and most situations, following those guidelines will be enough. Some of the standard advice, like limiting time in bed to just time when you're asleep, isn't really feasible for a lot of people with SCI, so some problem-solving might be needed to adapt the standard advice. If people have tried all of the standard measures and are still having problems, then I would advise that they start keeping a sleep diary and consider talking with a healthcare provider.

Are you saying people should view poor sleep as a potentially serious medical problem? If so, where should they turn to for help, given the common response from GPs to simply write prescriptions for zopiclone?

This is a tricky question to answer. On the one hand, yes—sleep is essential to maintain good health, and if you're not sleeping well, it's important to take it seriously. On the other hand, it's also important to keep a sense of perspective about occasionally having a bad night's sleep; excessive worry about anything,

including sleep, makes it much harder to get a good night's sleep. If you notice that you're consistently having problems with sleep, particularly if it's starting to impact how well you function during the day, it's often helpful to start keeping a sleep diary. This can be as simple as making a note of what time you go to bed each night, about how long it takes you to fall asleep, an estimate of how many times you wake up at night, and what time you get up in the morning. This type of information about your general sleep patterns can be helpful if you do decide to seek help from a healthcare provider.

The sort of prescription you mention often is a first-line of treatment; sometimes a short-term prescription for a sedating sleep medication is enough to get the person through a short-term sleep problem. Often, however, these medications can have unwanted side effects, and they're often not good long-term solutions. I think it's worth emphasizing that there are a number of different types of sleep problems, such as insomnia, sleep-related breathing disorders like sleep apnea, circadian rhythm disorders in which the timing of sleep is a problem, etc., and each can require different treatment strategies. Some of these disorders can be diagnosed fairly easily during a routine visit with your doctor, but others may require specialized investigations,

which may include a sleep study. These typically require referral to a sleep clinic.

Given all this, do you think sleep should be emphasized more in the rehab setting?

I would very much like to see more attention paid to sleep during rehabilitation. It's very likely that poor sleep makes it more difficult to reach rehabilitation goals; one thing we know from studies in the general population is that poor sleep makes it more difficult to learn new information, and also impedes motor learning, so it stands to reason that promoting good sleep will help people maximize their rehabilitation outcomes. In-patient environments are often not all that conducive to good sleep, though, because of ambient light levels, noise levels, temperature, and other factors.

What's next for your research in this area?

In addition to the work I'm doing with sleep after SCI, I'm also interested in how sleep is impacted by other neurologic problems, like traumatic brain injury, multiple sclerosis and Parkinson's disease, and I've got projects in various stages looking at all of these disorders. I'd like to better understand how sleep impacts rehabilitation outcomes, and am starting to look at different strategies for improving sleep—there is still so much work to be done in this area! ■

Table Tennis, Anyone?

Para table tennis is a fast-paced sport that can be played by wheelchair users with only slight modifications to the rules. If you're already a player, or want to have a go, SCI BC hosts drop-in sessions twice a week (Mondays from 5 to 7 PM, and Fridays from 4 to 6 PM) at PARC, located at the Blusson Spinal Cord Centre.

"We have a range of four to 12 people per session," says Richard Peter, SCI BC Peer Program Coordinator. "It's getting bigger, and we've been approached to host a tourney or join in local events. We're now looking into proper coaching opportunities, and attending national events." For info, contact Richard Peter at rpeter@sci-bc.ca.



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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.

Measuring Quality Participation in Adults with a Physical Disability

Overview: The purpose of this study is to develop a questionnaire to measure the quality or 'goodness' of participation in different activities among adults with physical disabilities. The study, led by ICORD researcher Dr. Kathleen Martin Ginis, is part of the Canadian Disability Participation Project (which involves SCI BC as a community partner).

What to expect: The survey will take approximately 30 minutes to complete, and you will receive a \$5 Starbucks e-gift card as thanks for your time.

Who can participate: You may be able to participate in this study if you have a physical disability, are at least 18 years of age, understand English, engage in activities related to employment, mobility, or sport/exercise. The researchers are particularly eager to hear from people who are employed or from people who play a sport either recreationally or competitively.

Why participate: By participating in this study, you will be helping researchers develop a measurement scale that they can then use in various settings (e.g., workplaces, recreation programs, communities) to determine if those settings, and the people responsible for those settings, are ensuring that people with disabilities are able to participate in ways that are satisfying and meaningful.

Location: The survey can be completed online.

For more information or to participate: Please contact the study team by email (cdpp.kpe@mcgill.ca) or call 514.398.4184 ext. 0481.

ProACTIVE SCI: Physical Activity Study

Overview: This collaborative research study between ICORD researchers Dr. Christopher West and Dr. Kathleen Martin Ginis is looking to see if personal training and brief physical activity coaching sessions that are tailored to the individual can improve physical activity participation, fitness, and health.

What to expect: The 11-week study involves two testing sessions of two hours duration at the beginning and end of the study to evaluate fitness, heart health (non-invasive), and psychological factors associated with exercise; nine weeks of weekly 15-minute coaching sessions; and four six-day physical activity monitoring sessions (weeks one, four, seven and ten) using an accelerometer and recall.

Who can participate: You may be able to participate in this study if you have been injured for more than one year, are between the ages of 18 and 65, and are currently doing less than 150 minutes of aerobic exercise (at moderate to vigorous intensity) and strength training twice per week.

Why participate: You'll receive a free personal training session! This includes weekly 15-minute physical activity coaching sessions (these will be different for everyone, but can include advice on how to set goals and monitor your activity, physical activity tips and tricks, and links to resources and other people, etc.) done over Skype or telephone, and an assessment of your heart health and fitness. You can help us better develop strategies for physiotherapists to ensure their clients with SCI remain active. You will be compensated \$150 to thank you for your time.

Location: The study will take place in ICORD labs at the Blusson Spinal Cord Centre, 818 West 10th Avenue, Vancouver, and over Skype/phone.

For more information or to participate: Contact the study coordinator, Jasmin Ma, by email (jasmin.ma@ubc.ca) or phone 613.329.1849.



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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Zero...or Hero?

Have you seen these stickers around the Lower Mainland?

If you don't already know the story behind these stickers, they're the work of Mark Stockbrocks, SCI BC Peer and accessibility advocate extraordinaire.

Stockbrocks, who lives in Vancouver, was hoping to become a firefighter in 2011 when a cerebral hemorrhage changed his plans. Today, he uses a power wheelchair and is paralyzed in both legs and his left arm.

It wasn't long after he left rehab at GF Strong that he began to assess the accessibility of his new world on wheels. He encountered lots of truly accessible public spaces, but just as many bad ones, including many businesses and facilities that promoted themselves as accessible but were, in fact, far from it.

So he vowed to take matters into his own hands and somehow develop a system to publicly acknowledge and identify accessible spaces—and, just as publicly, identify and condemn spaces that presented barriers to wheelchair users.

His solution is Accesstickers—two stickers he had professionally produced. One gives a big thumbs up for facilities and businesses that have excellent accessible features; the other, as you can see, isn't quite so complimentary. He carries these stickers with him wherever he goes, and doesn't hesitate to slap them up wherever he feels necessary.

"This idea was borne by the complete void of anyone involved with the disability community to actually be an assertive and proactive higher-profile voice representing the actual real-life people in our world who have unique accessibility needs," he explains. "I put these stickers in the most high-profile, high-traffic areas I encounter in the community. For example, push-to-open buttons in any type of public entrance imaginable get a thumbs up. Steep ramps, no ramps,



narrow doors, inaccessible bathrooms—these get a big thumbs down. I don't care whose toes I step on. This is the real deal, and it needs to be done."

Stockbrocks self-funds Accesstickers, paying out of pocket for the high-quality, long-lasting vinyl stickers. In the time that he's been slapping them up around town, he's been contacted by angry business owners (he always refuses to apologize). But he's had a lot of gratifying successes.

"The Accesstickers project has scored some major victories," he says. "For example, it's prompted BCIT, London Drugs, the Rick Hansen Foundation, Langley Rugby

club, some Boston Pizza locations, and theatres around the city, to name a few, to make excellent renovations to improve accessibility."

An important goal, he explains, is to clearly identify to other wheelchair users those places that have great accessibility, and those that don't. And he says many other people benefit in the process.

"Although it's primarily intended for people with mobility challenges, it actually helps everyone who enters the premises—notably mothers with strollers, elderly people, and people making deliveries," he says.

The approach may seem confrontational at first, but Stockbrocks says that's necessary to get people's attention. And the end game is to actually trigger a dialogue with people who could potentially improve the accessibility of a space.

"I like to communicate directly with private business owners, educational institutions, theatres, hospitals, restaurants, live performance venues, apartment buildings, arenas," he says. "Places that people tend to go with friends and family, to push real-world inclusion and accessibility."

Once a conversation has been started, Stockbrocks is happy to offer his perspective and some initial advice.

He's also glad when someone in the disability community offers to help him spread the word. That's why he created <http://accesstickers.blogspot.ca>, where he offers Accesstickers on a free, open source basis—anyone interested in be-

ing an accessibility advocate can visit and download high resolution, print-ready graphics files. You can also learn more at Instagram (@accesstickers) and Facebook (Accesstickers). ■



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