

thespin

SPINAL CORD INJURY BC

SUMMER 2013



Good Medicine

Cannabis is being increasingly recognized for its medical potential, and British Columbians with SCI are reaping the benefits



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Three-Way Victory

The results of the 2013 BC election were historic for a number of reasons. How so? Well for one, they sure fooled a lot of people. But the history I am interested in is that three candidates with physical disabilities were elected to represent their ridings in the BC Legislature. All three happen to be politicians with SCI and all three are BC Liberals. In addition, all three have been connected, in one way or another, to SCI BC.

Who are these three? They are none other than former SCI BC staffer and co-founder of our formal Peer Support Program, the Honourable Stephanie Cadieux, Minister of Children and Family Development (Surrey-Cloverdale); the incomparable Sam Sullivan (Vancouver-False Creek); and Paralympic champion Michelle Stilwell (Parksville-Qualicum).

A fourth candidate with a physical disability, Ken Kramer, narrowly missed being elected in Burnaby-Lougheed. Ken would have made an exceptional MLA but I know he will continue to be a positive contributor to the political process. I hope he runs again in the next election.

I know that Stephanie, Sam and Michelle consider themselves politicians and not people with disabilities first. I think of them the same way. They were elected because of their accomplishments, not because of their SCIs. They are there because of their abilities, not their disabilities.

But I do think the fact that people with disabilities can run for office and be elected to it is pretty significant and a positive indicator of the opportunities for all British Columbians to participate in all aspects of our society.

As excited as I am for Stephanie, Sam and Michelle, I am truly disappointed in the 48% of eligible voters in BC who did not bother to cast a vote. Voting is both a privilege and a right and more needs to be done to increase voter interest and participation. Personally, I think all of that negative campaigning and conduct throughout the political process only serves to increase voter discontentment and disengagement. Our political system matters, its work affects our lives. So for all those who didn't cast a vote, don't complain about anything government does or sets in motion. I figure not voting negates one's rights to complain.

With the election over, it will be time to get to work on pushing for policies that will help people with SCI, their families (and those with related disabilities) adjust, adapt and thrive, and that will make for more inclusive communities throughout BC. True, we don't have the resources to fully engage in "formal advocacy" with government, but we are doing what we can with what we have.

When announcing her new cabinet, Premier Clark tasked the new Minister of Social Development & Social Innovation with making BC "the most progressive province for people with disabilities." Let's hope their actions and money are where their mouth is. And let's hope their mouth is where it is supposed to be.

— Chris McBride, Executive Director, SCI BC



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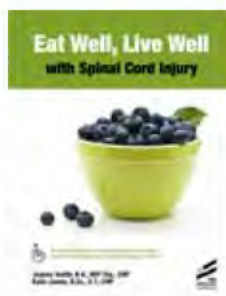
The Freedom 6x6 is a six-wheeled, all-wheel drive power wheelchair that's designed to handle a wide range of rough terrains, including sand, snow and wooded trails. It features a rugged powder-coated steel frame, twin high-torque motors, weight capacity of 350 pounds, and two 100 amp batteries that provide up to three hours of continuous running time.



Control is via a joystick with interchangeable positions for left or right hand, and the chair can turn 360 degrees in a stationary position. Aluminum rims, sealed bearings, seat belt, cup holder, wheelie bar, trailer hitch and 12 volt accessory outlet are all standard equipment. Made in the USA, the Freedom 6x6 is sold in Canada by Chilliwack-based Discount MediQuip—visit www.dmediquiprecycle.ca for more information.

EAT WELL, LIVE WELL

Eat Well, Live Well with Spinal Cord Injury explains the role that diet and nutrition can play in managing secondary health complications of SCI, including pressure sores, UTIs, osteoporosis, pain, fatigue, respiratory infections, anxiety, fatigue, and cardiovascular disease. Each chapter explains why a specific health condition may develop after SCI and provides information on how nutrition may help prevent and manage the health issue through specific foods, supplements and herbs. There are also easy-to-prepare, nutrient-dense recipes, along with reference charts of specific nutrients and supplements recommended for each health condition. The book was written by Joanne Smith, a registered nutritionist with an SCI, and Kylie James, a nutritionist and occupational therapist specializing in neurological disorders. Look for details at www.eatwelllivewellwithsci.com.



gear & gadgets



THE MORPH WHEEL

The Morph Wheel folds in half to make wheelchair travel easier. The wheel size is reduced from 24 inches in diameter to 32 x 12.5 inches when folded. Originally conceived for use with folding bicycles, the Morph Wheel was adapted for wheelchair use by U.S. company Maddak. Each Morph Wheel tips the scales at 3.4 kg, and when used in a pair can support up to 136 kg. It's constructed from glass-filled nylon, with a polypropylene hand rim, and solid tire. Maddak states that the Morph Wheel can fit into overhead bins, closets, car trunks, and even under an airplane seat during flights. It features a safety mechanism which prevents folding unless desired by the user, and will fit on any existing wheelchair able to accommodate a wheel with a quick release axle. The folding mechanism is said to be easy to master, not requiring any special tools. See www.maddak.com for details.

Innovations

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



ROWHEELS

Invented by Salim Nasser, a NASA engineer and quadriplegic, RoWheels is a wheelchair wheel that incorporates a planetary gear in the hub. This gear reverses the direction of the handrim so that users employ a rowing or pulling motion to move forward. The company says this is a more bio-mechanically efficient method of propulsion because it relies on larger and more capable muscles in the upper back and arms, reducing repetitive stress related injuries in the shoulders, triceps, and wrists. Rowheels' patent-pending design includes a gear ratio that decreases cadence while increasing acceleration and speed. It also incorporates a hill assist feature that prevents rollback as the user goes from one pulling stroke to the next. Rowheels are lightweight and have a quick release mechanism, making them easy to remove and stow with one hand during unassisted car transfers. They can be retrofitted to most manual wheelchairs. Visit www.rowheels.com for more details.



Hop on the bus.

This August 17th, The Bus Stop Hop, SCI BC's signature Peer event in Vancouver, is back again. Teams of four participants (including two able-bodied and two people who use mobility aids) will be racing across the city using everything TransLink has to offer. They'll be scoring points at each pit stop by answering trivia questions and completing a wide range of activities. To get onboard for this year's Bus Stop Hop, contact Shelley at smilstein@sci-bc.ca to RSVP.



Tee it up for a great cause.

This July 15th, the annual Doug Mowat Memorial Golf Tournament returns to the Point Grey Golf & Country Club in support of the BC Paraplegic Foundation (BCPF). Participating golfers in this fundraiser will compete for excellent prizes while helping British Columbians with SCI adjust, adapt and thrive post-injury. Proceeds support BCPF scholarships and SCI BC's provincial programs. More information is online at www.mowatmemorial.com.



Camp and play outdoors.

This August 24th and 25th, the Community Recreation Initiatives Society (CRIS) and SCI BC are partnering to offer two days of camping and adaptive outdoor activities in the beautiful 10 Mile Lake Provincial Park. In previous years, CRIS has helped peers discover adaptive kayaking, handcycling and trailriding. This is a free event and all Peers in Northern BC are invited to attend. To RSVP, please contact Brandy by email at bstiles@sci-bc.ca or phone at 250.563.6942.

ask the SPIN DOCTOR

M.J. from the Cariboo asks, *"I'm a healthy, active 42-year old para who hasn't had a UTI in more than five years. Why does my doctor insist that I go for a yearly urodynamics test?"*

To answer this question, we turned to Dr. Claire Weeks, a recently retired SCI physiatrist who many of our readers know from her work at G.F. Strong.



"There's more—much more—to bladder health than avoiding or treating bladder infections. And, unfortunately, some of the things that can go wrong may cause no symptoms for a long time, until it's too late to deal with them.

In particular, it's essential for your long-term health that pressure doesn't build up in your bladder, either while it's filling or while you're urinating. You may even be able to completely empty your bladder every time you urinate and, therefore, have a low post-void-residual (PVR) volume. But the bladder muscle might have had to work very hard to generate high pressure in your bladder in order to do that. And even when the bladder is simply filling, the pressure inside can be too high. You'll likely

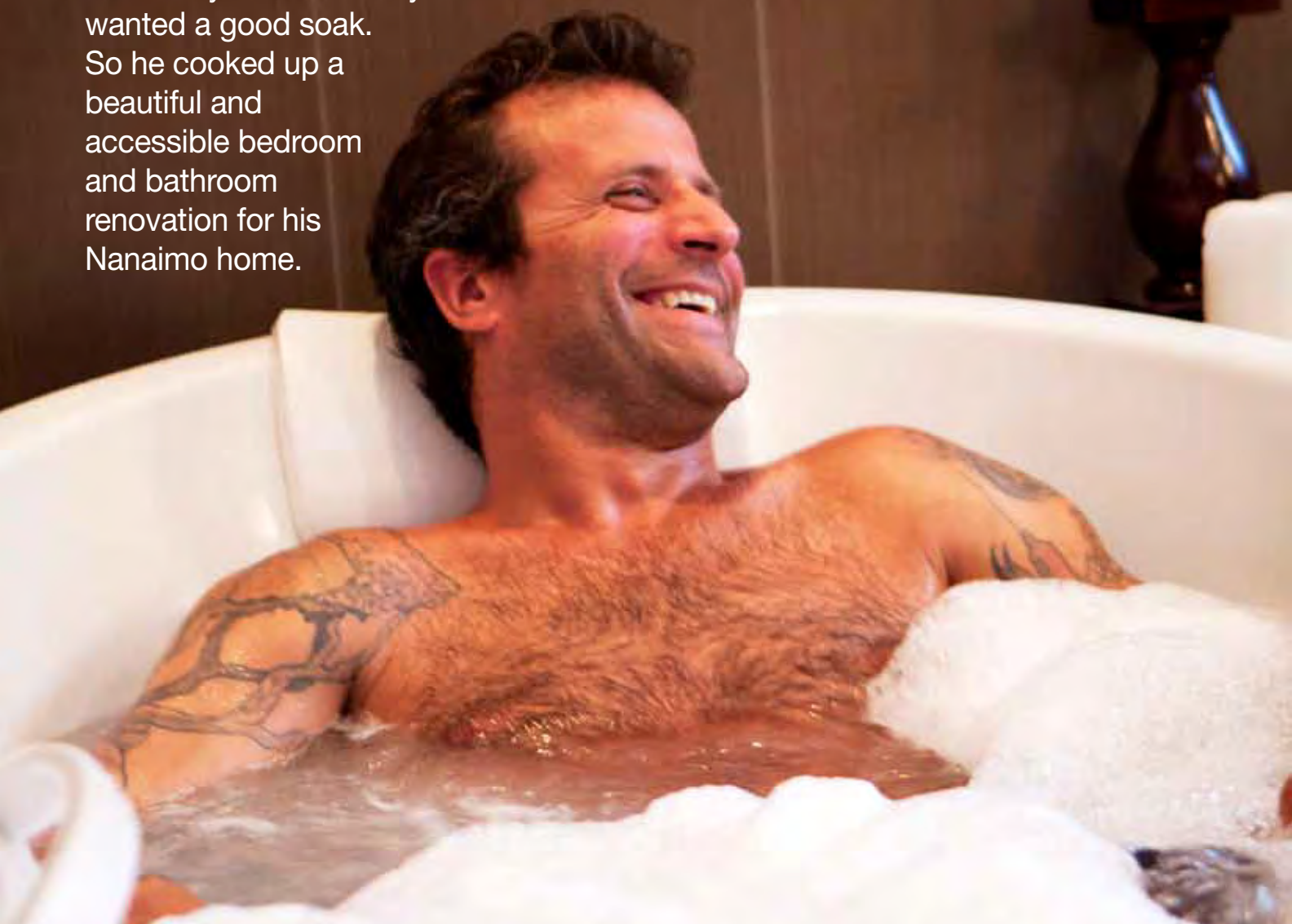
have no symptoms to suggest that pressure is building up, unless your lesion is at T6 or higher—in which case you might develop symptoms of autonomic dysreflexia (another story). But high pressure bladder filling and/or bladder emptying over the course of months to years can lead to kidney damage, and you may only start feeling unwell when your kidneys start to fail. By then, it could be too late to reverse the damage.

The only sensible way to deal with high-pressure bladder problems is to prevent them. And the best way to prevent them is to undergo a bladder pressure test, urodynamics, on a regular basis. In some centres, it's recommended that this be done annually; in some centres every two years. Your physiatrist or your family doctor can refer you to a urologist—a bladder expert who can perform the test. Be sure you understand the results and discuss them and their implications with your specialists."

Got a question for The Spin Doctor? Email it to Brad Jacobsen, our SCI BC Peer Program Coordinator (bjacobsen@sci-bc.ca), who will recruit the most appropriate SCI expert to provide an answer. Remember, the advice provided is general in nature and is not intended to replace advice specific to your personal situation provided by your family physician or SCI specialist.

Form & Function

Chef Cory Parsons really wanted a good soak. So he cooked up a beautiful and accessible bedroom and bathroom renovation for his Nanaimo home.



A modest Nanaimo rancher has been Cory Parsons' home for most of the 14 years that have passed since he became quadriplegic in a diving accident.

Parsons, chef and author of the highly successful *Cooking with Cory* cookbook, bought what he describes as the "small but quaint" house for many reasons. "It was built on a fairly level lot, had some updated features, and the garage had been renovated into a living area with an

attached small ensuite," recalls Parsons. "Immediately I could see the potential of this home and, with a lot of hard work and lots of hard-earned money, I knew it could be the place I would be happy in."

Soon after he bought the house, he used a small grant to complete a modest renovation of the garage area, incorporating an accessible kitchen, bachelor bedroom, and attached bathroom with potential for a roll in shower.

"Since then, I made my small rancher

home work well enough to just barely meet the accessibility requirements that my SCI brought," says Parsons. "But 10 years later, I began to realize it simply did not meet my needs anymore. The bathroom was small—I mean very small—and so I accepted the fact that it was time to once again go through the renovation process."

In particular, what Parsons really wanted was the ability to take a good, long soak. "There was always something

missing, something I had always enjoyed prior to my injury but have had to go without since—a tub. If you have an SCI, I'm sure you'll understand. And even if you don't, I'm sure you can imagine how good it feels at the end of the day—or the beginning, for that matter—to soak in a tub of hot soapy water. Constant spasticity and neuropathic pain leaves me feeling exhausted most days, so the new renovation design was not going to leave out a tub this time."

Parsons set his sights on a hydrotherapy tub that would give him the restorative soak he craved. Due to his level of injury, he knew that he would also need a ceiling track lift to get in and out of it safely. "As I got to work with my designer on the construction plans, it was necessary to include information like this at the design phase in order to ensure that weight loads were properly compensated for and sturdier construction would be built-in at the framing stage."

Also on his wish list was a roll-in shower, accessible sink and counter

space, a pocket door to save precious space, windows and skylights, an open floor plan, and extension of the existing master bedroom.

"I worked very closely with my designer because I knew that it was going to take some planning to make this design work to meet my needs, not only functionally, but aesthetically," he says. "Just because I have a disability doesn't mean my home has to look like an institution or sterile hospital room, and I made it my goal to include beautiful fashion with sleek and streamlined function."

Another consideration was that the design had to include enough space to manoeuvre and store both a power wheelchair and manual wheelchair.

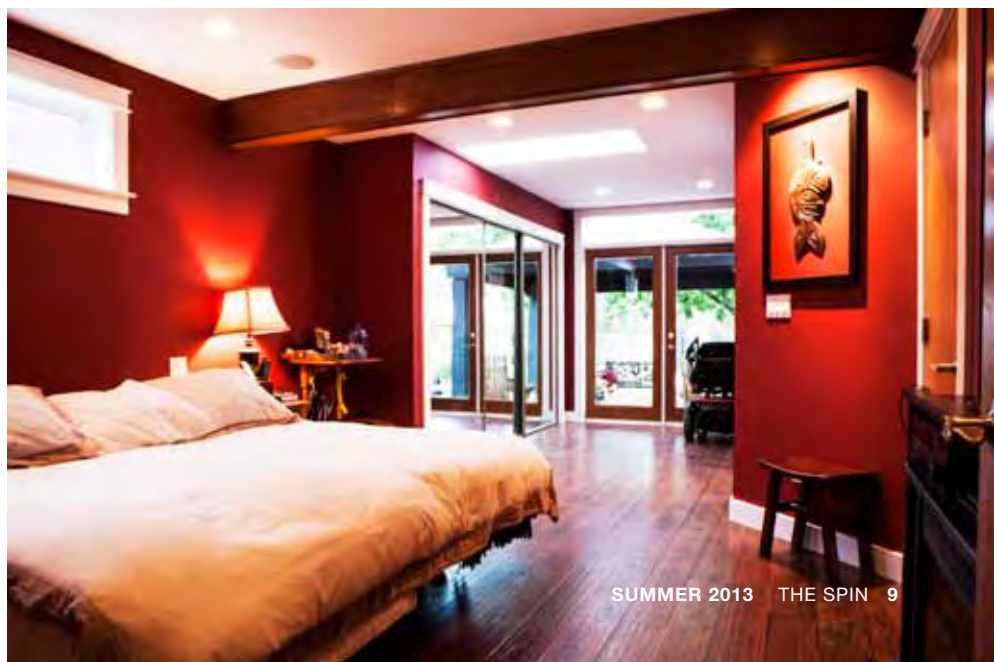
"Accounting for the space needed at the beginning of the design phase will save you headaches later," he says.

Taking all of his needs into account, it became obvious that he needed more space. So the plan grew to include a small extension at the back of the house.

Armed with a finished plan and approval from HAFI, the provincial government grant program which offers up to \$20,000 to offset the costs of renovating for wheelchair accessibility and safety, Parsons prepared to get to work.

"Prior to my injury, I spent many years building houses and working with concrete foundation construction," says Parsons. "So I was quite comfortable taking on the role of general contractor. This helped to keep some of my costs

FACING PAGE: Parsons finally gets to enjoy a hot soak. RIGHT: A huge roll-under vanity and a spacious, glass-enclosed wheel-in shower offer beauty and true accessibility. BOTTOM RIGHT: The stunning and spacious master bedroom. BOTTOM LEFT: access to the hydrotherapy tub is provided by ceiling track lift.





down. I pulled in some favours from some of the sub trades I'm still friends with, allowing me to stretch my dollar a little further. At the point that I got work underway, I had saved some money in a trust account, and with the assistance of HAFI, my budget was about \$45,000."

The renovation would include a new foundation, slab floor, perimeter drain, wood framing, insulation, roofing, windows, flooring, exterior doors, electrical, and plumbing. "All city building permits had to be applied for and a permit given before construction could begin. It's a detailed process that is in no way different than brand-new construction of a home. Also, construction quotes must be submitted in triplicate for HAFI grant approval. Only once you've been approved can you begin construction. I highly recommend timing the entire process so that you're working during the summer drier months—this makes it easier to keep the moisture out of the construction of your home and the mud and dirt to a minimum."

Over the course of several months, the work was completed. Parsons says it went smoothly, but concedes there were a few hiccups. "Everyone in the construction and renovation business will tell you that you need to factor in a 15% buffer for unexpected expenses," he says. "Believe me when I tell you that you need it. Especially when working with older homes and opening up walls—there will always be something unexpected and costly hiding around the corner! This was indeed the case with my renovation and expenses pushed my total cost near \$50,000—things like the excavator accidentally pulling out my electrical ground,

and construction material prices to suddenly skyrocket. These things are not in your control, and none of my unexpected expenses were anyone's fault. But I will always tell people to have some extra money for those 'just in case' situations."

Parsons adds that getting to know your construction personnel is paramount for people with disabilities—you are the best person to help them understand your needs and encourage them to go that extra mile to ensure your satisfaction.

And Parsons is immensely satisfied with his end result. "I truly enjoyed the process, and I believe you can see from the photos that I achieved what I had set out to: create a space that works both functionally and aesthetically. It takes a lot of planning and time, and probably more money than you'll originally plan for, but if you prepare properly, follow the regulations properly, practice the mantra

of 'do it once, and do it right', then you too can have a beautiful addition to your home that will allow you to enjoy and be productive in the environment you live in.

"Never doubt your abilities to do something great. All it takes is to make a plan. Remember, it's never a matter of 'if', it's always a matter of 'how'!" ■

With his reno complete, Cory Parsons is moving on to other projects. Cooking, nutrition, and fitness are his greatest passions in life, and he's working hard to pass on what's he learned to others in his community. He's still avidly cooking and writing recipes for a future second edition of Cooking With Cory, which he says will showcase his love of organically gardening. He's also embarking on a business as a personal trainer and cooking instructor. Visit www.coryparsons.com to learn more about his work.

Bylaw Will Ensure Basic Accessibility of New Housing

Thanks to a new proposed bylaw, the City of Vancouver is poised to become the first city in Canada to require housing to be accessible and adaptable.

For the past two years, the City has been developing the next edition of its Building Bylaw, and one of the biggest changes will be the mandating of basic interior accessibility and adaptability of all new housing—houses, townhouses, duplexes, and apartments. Specific requirements of the new bylaw will include wider doors, stairs and halls; level door thresholds; easy to reach/use switches, controls and faucets; lower drain pipes so counters can be lowered easily; accessible bathrooms; accessible shower drains or ability to install an accessible shower without undue expense; and bathroom walls reinforced so grab bars can easily be installed. All of these things can be easily done with minimal cost added to construction.

Here at SCI BC, we believe this will make a huge difference for people with disabilities, along with seniors. Not only will it make it possible for people to find housing they can actually live in, it will make it possible for them to more easily age in place.

The City's Persons with Disabilities Advisory and the Seniors Advisory Committees are to be commended for their two years of work to develop this new bylaw.

If there's any criticism of the proposed Bylaw, it's that it only requires good accessibility and adaptability on the inside of housing, with no requirement for an accessible way to get to or from the street to the entrance of the housing. Advocates worked hard to lobby for this addition, but weren't successful.

The bylaw is currently being considered for approval by City Council as this issue

of The Spin goes to press. If Council adopts the bylaw, there will likely be a grace period before the new bylaw is enacted in the Fall of 2013.

If you are looking to buy, rent or sell an accessible home, or just want to learn more about accessible housing, check out our AccessibleHousingBC.ca website.





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Reuse & Recycle

With their fledgling but thriving business, Jim Miller and Dee Friesen have solved two longstanding problems in the disability community

Jim Miller has worked in the mobility equipment business for the past 26 years. He's also been paraplegic for the past 29 years. So when he started a business specializing in quality used wheelchairs and other mobility equipment, it's a pretty safe bet that he had done his due diligence.

"The idea germinated as many as 10 years back," says Miller, a former SCI BC board member. "Being in the new equipment business for so many years, I was always frustrated at what families and individuals with no funding had to spend to get equipment. Along with that, new equipment dealers aren't in a position to help out their customers and families when a piece of equipment is no longer required, so where do they turn to sell that equipment?"

Enter Discount MediQuip (formerly D's MediQuip Recycle), which opened its doors in Chilliwack in December 2010. The business, which is owned by Miller and fiancé Dee Friesen, has operated since inception with a simple philosophy: try hard to get a family or individual the proper mobility equipment at approximately half the cost of new—and help them sell it or dispose of it when their equipment is no longer needed.

The company has twice moved into larger settings since 2010—a clear indication that it has found its sweet spot.

"It's a total confirmation of the need for this type of service," says Miller, who works full-time at nearby Sidewinder Conversions as an adaptive vehicle sales specialist, leaving the daily management of Discount MediQuip to Friesen and helping out as time permits. "Dee and

I started out three years ago in a condo and the rest is history."

The company's new location is 45672 Airport Road in Chilliwack, the former site of A-1 Wheelchair Unlimited.

"We felt that, with the great exposure and the previous 10 years of a similar business in that location, it was a great opportunity—particularly since we had grown to a level where we needed a larger facility," says Miller.

Their competitive advantage, says Miller, is bringing much-needed expertise and accountability to the world of used mobility equipment sales. "Before we existed, families who could only afford used equipment—or chose that option over buying new—could only buy privately using classified ads, with no trial period or advice from anyone experienced to help them make sure the equipment is appropriate for the user," he says. "Also, once they purchased it, they owned it—there was no returning it."

In contrast, Discount MediQuip offers expertise to fit the equipment, a trial if needed, and 10 business days to return or exchange it if it's not working out.

"We also tell our customers that if and when a day comes when they no longer need the equipment, we'll take it back

on consignment and get them 50 percent of their money back depending on the condition at the time," adds Miller.

The company's products are a combination of consignment items from existing customers, along with items that are purchased from or donated by individuals and institutions. Miller and Friesen pride themselves on being able to find appropriate products for customers if there isn't anything in stock that meets their needs. As word has spread about them, the company increasingly finds itself shipping equipment well beyond the Lower Mainland to individuals living all over BC and Alberta.

The company also has a philanthropic side. "When equipment isn't suitable for re-use in our marketplace, we donate it to a local charity, Hope Haven, which distributes equipment to third world countries," says Miller. "It's hard to believe, but there are many people in the world who require a basic wheelchair, and have no other way of getting one."

For Miller, all of this adds up to a very gratifying experience.

"I have always enjoyed helping people out in our world of disability, and it feels great to offer a service that was previously unavailable," he says. ■

For more information, call Discount MediQuip at 604.392.2929, or check it out online at www.dmediquiprecycle.ca.



yoga for every body



How Mary-Jo Fetterly transformed her yoga practice to reconnect with her body post-injury

Mary-Jo Fetterly is at the top of her game when she decides, one fateful morning, to take a break and go for a ski.

One day earlier, she was posing in a photo shoot for a news story about her thriving yoga studio. It's 2004, and Mary-Jo spends most days juggling her own business and taking care of her two teenage daughters.

With her business partner, Jennifer Steed, Mary-Jo runs Trinity Yoga, which offers one of the only yoga teacher training programs in Western Canada. Since they started offering classes, they've been barely keep up with the demand. From 2001 to 2004, they taught more than 1,500 yoga teachers from Vancouver and across Canada.

"Things were just picking up steam," says Mary-Jo.

But on this sunny, January afternoon, one of her skis gets caught on a branch, the other is diverted by a rock, and that's all it takes. Three vertebrae in her neck are crushed when she lands.

"At the moment I hit the ground, I couldn't breathe, and then I could feel my whole body going paralyzed, like sand draining from an hour glass," recalls Mary-Jo.

Her instincts immediately kick in: she closes her eyes and focuses on breathing. It was something she had done so many times before through years of yoga practice. Just breathe.

Slowly, laboriously, her lungs jerk back to life and fill up once more.

So begins Mary-Jo's long discovery of a new, completely different yoga practice, one that would take her from full paralysis as a complete C4/C5 quadriplegic to a place of renewed movement and mobility.



When she landed at GF Strong Rehabilitation Centre, Mary-Jo could just barely move her right arm and right wrist. Everything else below her neck was paralyzed, and the doctors were cautious in their prognosis. "You will do well if you can maybe use your right arm," they told her.



Fast forward nine years, and Fetterly can lift her arms and move her torso up and down and side to side. She can crawl on all fours, and she can even swim with a flotation device around her neck. She no longer uses a catheter, and she hasn't had a UTI in seven years.

But much like the initial breath she took after her accident, her journey back to health hasn't been an easy one. In many ways, Fetterly's positive attitude at first worked against her.

After eight months of rehab at GF Strong, Fetterly didn't miss a beat: she went right back to work travelling across BC and Alberta teaching yoga. But after two years of living at her pre-injury pace of life, her health was in serious decline.

In 2006, she registered as an outpatient at GF Strong, where doctors found that she had developed scoliosis from poor chair posture, along with a syrinx, a dangerous type of cyst, near her spine. Surgery was being considered, and after having refused to take pharmaceutical drugs for two years, Fetterly finally caved. When she overdosed on prescribed medication two weeks later, she knew her approach had to change.

"I hadn't taken myself back to the drawing board yet, and it took its toll on my body," she recalls. "I realized that I had to stop and take some time to learn how to heal. I couldn't keep battling or avoiding my spinal cord injury; I had to learn to work with it."

That's when she remembered watching a documentary about Molly Hale, a Californian woman with a black belt in Aikido who became a quadriplegic after a car accident. Fetterly tracked her down and asked her for advice.

"She told me to get out of my chair and imagine that I'm in a baby's body—to start moving from there, and relearn how to move and think about it from a developmental perspective," says Fetterly.

Hale also told Fetterly that, if she didn't want to take pharmaceutical drugs for pain and spasticity, she should try cannabis to reboot her nervous system.

Fetterly took the advice to heart. She now spends at least two and a half hours

each day outside of her chair—stretching, exploring her range of motion, and making vibrations with her mouth as a way to massage her body. Combined with massage, meditation, cranial sacral therapy, cannabis, acupuncture and hydro therapy, Fetterly says she's noticed "nothing but improvements."

She still experiences a lot of spasticity, but Fetterly has stopped seeing it as a negative side effect. "I have lots, but I can work with it. It's how the body communicates in this altered state."

Fetterly says that, in finding harmony with her altered body, she's not doing anything that's not available to or possible for anyone else. "It's not rocket science. I'm doing things that are intuitive for me. I don't do this to walk again

someday; I'm doing this for quality of life every day."



Today, Fetterly still teaches yoga to able-bodied people as a volunteer. She's also been developing a new kind of practice that encourages people with SCI to get out of their chairs and reconnect with their bodies in a whole new way.

"It's about taking people on a journey through their own body," says Fetterly. "It's just a matter of stepping out of that box of what you think your body is capable of. Anything is possible—the things I've seen students do and the benefits they get, it just amazes me."

Shira Standfield is one of those students. She is a T12 paraplegic, and she's

DVD Review: Beyond Disability

The revered yogi T. Krishnamacharia used to say, "If you can breathe, you can do yoga."

Matthew Sanford couldn't agree more. Paralyzed from the chest down, Sanford is passionate about introducing people with disabilities to the world of yoga.

Although Sanford wasn't a yogi when he was injured at the age of 13, he became one soon after when he discovered how yoga could heal the gap between his mind and body.

He has since become a pioneer in the field of adaptive yoga and has developed a program for healthcare professionals, caregivers and yoga teachers, which he delivers through his yoga studio in Minneapolis.

"Disability is best understood, lived with, and approached as a mind-body issue, and deepening the connection between mind and body positively transforms the experience of living with a disability in practical and tangible ways," says Sanford.

In his DVD, *Beyond Disability: a yoga practice with Matthew Sanford*, Sanford and his students practice a yoga flow that is appropriate for people of all abilities. They guide you through seated centering, grounding, balance, rhythm and balance relaxation practices. Viewers can do one section at a time or enjoy the 50-minute practice in its entirety.

The great thing about having a DVD like this one is that you can practice it on your own time and pace in the comfort of your home. I found this DVD to be very well laid out, the direction to be clear and simple, and the poses and sequencing to be something that anybody could do, while still offering challenge and interest.

As good as this DVD is, it has its limits. Perhaps one of the most important things to consider when beginning yoga is to have a teacher to initially help you understand the poses, practice and proper alignment. This is a difficult thing to convey on a DVD unless you have prior experience, so I strongly recommend for those of you who are considering beginning a yoga practice to consult with your local qualified yoga teacher—of which there are many—and have them help you with the initial setup.

Beyond Disability is for sale at www.mindbodysolutions.org for \$24.95 plus shipping.

—Yoga teacher Mary-Jo Fetterly





Fetterly led a well-received yoga session at Spinal Cord Injury BC's recent Women's Tea event.

been learning yoga with Fetterly as a way to deal with her chronic pain. "Mary-Jo has a really good understanding of how the body works, especially a body with SCI," says Standfield. "She has some really good techniques that deal with the root of the problem rather than just deal with the symptoms with medicine. In the traditional system, it's just 'Oh, you have SCI so you can expect to have chronic pain.' But with Mary-Jo, I've learned to understand what's causing it and why it happens, and it makes it easier to cope."

"It's really about being happy with where you're at with

your body and learning how to work with it," says Fetterly. "Yes, it's functioning in a different way, but it's nothing to consider as an enemy—it's something you need to learn to manage."

Today, Fetterly's biggest challenge is finding a venue where she can teach group classes for people with SCI. For now, she volunteers for events and develops her techniques through private classes in a small studio, but her dream is to offer her alternative therapy to more people, more often—and then to train yoga teachers and care-aids the adaptive yoga she's developing.

"It takes them to a richer, more fulfilling place with connection," says Fetterly of her students, "Their whole attitude about who they are in their body changes; it becomes less antagonistic and less disconnected."

"The other day, I got Shira into a child's pose, where you start on all fours and then push back and rest on your knees and relax into the ground. She said to me, 'I don't feel paralyzed right now, I feel like a normal person.' That comment just popped for me. That's what this is all about." ■

Spinal Cord Injury BC is planning a special yoga workshop with Mary-Jo Fetterly this fall! If you're interested, please RSVP with Shelley (smilstein@sci-bc.ca). Meanwhile, you can learn more about Fetterly's story on her website (www.mary-jo.com).

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Good Medicine

Thanks to a growing body of research and an increasingly powerful legalization lobby, cannabis has emerged from the murky shadows of the criminal underworld into the limelight in recognition of its powerful medicinal qualities.

The best medicine Chris Marks has ever found for SCI is cannabis. Every day, the 38-year-old marketing student from Victoria either smokes or vaporizes cannabis as a treatment for neuropathic pain and spasticity, and to help him relax and sleep.

"When I was first injured, I was on amitriptyline, Baclofen, gabapentin, dantrolene, tizanidine, Dilaudid, topical creams with ketamine for nerve pain, as well as a myriad of antibiotics," says Marks, an incomplete C5 quadriplegic since 2005. "After a couple years, I asked myself, 'Do all these pills do anything for me? I still have extreme spasticity.' I weaned myself off the pills after talking to my doctor, and have not taken a single pill from the above list in over four years—just cannabis."

Marks says he still has spasms, hypertonicity and mild dysreflexia every time he voids his bladder. "But not to the extremes I had before," he says. "I experience almost zero nerve pain these days."

Marks is among the growing legions of Canadians who are discovering the medicinal qualities of cannabis. Cancer patients, people with SCI and other neurological disorders such as MS, and those looking for relief from anxiety, depression and insomnia are among those who are reaping the benefits of this ancient remedy.

Cannabis Through the Ages

Make no mistake—cannabis is an ancient remedy. It was described in a Chinese medical compendium dating some 2,700 years B.C., and it appeared at the top of the list of the Zend-Avesta, a sacred Persian medical text dating from 550 B.C.

It was only in the 1930s that marijuana was vilified, with the prohibitive Marijuana Tax Act being signed into US law in 1937. According to some historians, marijuana was the victim of a successful lobbying effort and smear campaign by DuPont and other synthetic materials manufacturers, which then proceeded to reap vast profits by filling the void conveniently left by the criminalization of industrial hemp. At the time, cannabis was being prescribed by physicians for many common ailments, and researchers were just beginning to explore its therapeutic benefits.

Some 60 years of cannabis prohibition ensued, but medical science wouldn't be denied. In the late '70s and early '80s, even as cannabis was still widely-regarded as a criminal substance, researchers began discovering its beneficial effects. Today, a growing tide of research is contributing to the increasing recognition of cannabis as legitimate medicine—recognition by Health Canada, many other countries, and many US states.

And the research is compelling. Cannabis has been scientifically validated to relieve eye pressure in people with glaucoma, reduce nausea and improve appetite in people undergoing treatment for cancer and HIV, and control insomnia and depression.

Even more intriguing is what's coming down the research pipeline. Preliminary findings indicate that cannabis has promise as a treatment for a long string of diseases and disorders. Among these are Crohn's, migraines, fibromyalgia, ALS, arthritis, asthma, diabetes, epilepsy, hepatitis C, Huntington's, Parkinson's, psoriasis, sleep apnea, and anorexia.

Perhaps most exciting is the recent discovery that cannabis appears to have powerful cancer-fighting abilities.

Researchers working in animal studies are providing new evidence that cannabidiol (CBD), one of the active compounds in cannabis, fights cancer and tumours in at least five different ways.

All of this is great news. But our focus in *The Spin* is the ability of cannabis to provide relief from the most debilitating secondary health complications of SCI.

Cannabis and SCI

Basic research conducted over the past two decades has revealed that the human nervous system contains widespread cannabinoid receptors. In fact, the cannabinoid receptor system is the most widespread receptor system in the human body.

Cannabinoids are proteins that bind to and activate cannabinoid receptors. Once activated, the receptors repress the release of neurotransmitters by the brain cells that they are attached to. Because cannabinoid receptors are so widespread, they play a role in pain, movement, appetite, memory and mood, to name a few.

The body's own cannabinoids are found throughout our body and it's believed they play an important role in regulating function in our respiratory, reproductive, digestive, immune and other systems. But cannabinoids from external sources such as cannabis also bind to the cannabinoid receptor system and, in the process, modify our body's processes.

As the sidebar to the right explains, the two most important cannabinoids found in cannabis are D9-THC and CBD. When they bind to receptors, they get us high—but do much more as well.

First, they relieve neuropathic pain—a common and excruciating by-product of SCI and other diseases that often can't be effectively controlled with pharmaceutical approaches. While the exact nature of the mechanism isn't yet understood, D9-THC has been clearly demonstrated in many studies to provide relief for people suffering from neuropathic pain, including people with SCI.

One of the more recent and credible studies was a double-blind trial con-

Cannabis at a Glance

- Cannabis, or marijuana, is the cured and dried flowers of the Cannabis plant that are smoked, vaporized or ingested for their psychoactive and medicinal qualities.
- Cannabis contains at least 85 diverse chemical compounds that are referred to as cannabinoids. Cannabinoids activate cannabinoid receptors in our nervous system that repress neurotransmitter release.
- Of all the cannabinoids, the most abundant and important are delta-9-tetrahydrocannabinol (D9-THC) and cannabidiol (CBD). D9-THC is the principal psychoactive cannabinoid—it gives us a euphoric high and appears to be instrumental in relieving neuropathic pain and spasticity. CBD is less psychoactive and more sedative than D9-THC, and is also thought to contribute to relief of chronic pain and spasticity. As well, CBD is the subject of much new research focusing on its antioxidant and cancer-fighting properties.
- Isolated pharmaceutical forms of D9-THC and CBD have been developed for specific purposes, but there is a growing body of evidence that suggests the two have a complex, intertwined relationship that creates a viable argument for consumption of natural cannabis that has a balance of D9-THC and CBD.
- Indica and sativa are the two main varieties of the cannabis plant. Sativa cannabis has a greater ratio of D9-THC to CBD and provides an uplifting, euphoric high. Indica strains have more CBD resulting in a narcotic “body stone” effect, making them appropriate for relaxation and sleep.
- Most cannabis today is a cross of the two varieties, with growers experimenting with hybrids to achieve specific combinations of results.

ducted by Dr. Mark Ware at Montreal's McGill University. The conclusion of Dr. Ware's study, which was published in the August 30, 2010 issue of the *Canadian Medical Association Journal*, stated, “A single inhalation of 25 mg of 9.4% tetrahydrocannabinol herbal cannabis three times daily for five days reduced the intensity of pain, improved sleep and was well tolerated.”

Results from another credible and more recent study led by the University of California's Dr. Barth Wilsey were published in the February 2013 issue of *The Journal of Pain*. This was also a double-blind study involving 39 people with SCI suffering from neuropathic pain. “Vaporized cannabis...may present an effective option for patients with treatment-resistant neuropathic pain,” concluded the authors, who also noted the effectiveness of using a low dose of THC, which didn't result in significant cognitive impairment. “As a result,” they wrote, “one might not anticipate a significant impact on daily functioning.”

The second benefit of cannabis is

relieving spasticity. The majority of research focusing on cannabis and spasticity is targeted toward MS—not surprising, given the much greater prevalence of MS compared to SCI. But an online search does reveal that there is a significant amount of anecdotal and subjective evidence (for example, surveys of people with SCI) that point to the effectiveness of cannabis in reducing SCI-related spasticity. There are also at least two objective studies.

One of these was done in 2003 by Swiss researchers at the Center for SCI and Head Injury in Basel. In the final phase, 13 subjects were given either a placebo or dronabinol, which is a pharmaceutical formulation of D9-THC. “The results demonstrate a significant therapeutic effect of (dronabinol)... in patients with SCI,” concluded the authors. “THC is an effective and safe drug in the treatment of spasticity.”

Closer to home, another objective double-blind study by University of Manitoba researchers was completed and reported in the May 2010 issue of

the *Archives of Physical Medicine and Rehabilitation*. The 11 subjects who completed the trial were given either a placebo or nabilone, a synthetic cannabinoid which is intended to mimic D9-THC. The researchers saw a significant decrease in spasticity using one form of measurement, and concluded, "Nabilone may be beneficial to reduce spasticity in people with SCI. We recommend a larger trial with a more prolonged treatment period and an option to slowly increase the dosage further."

One of the researchers involved was Dr. Karen Ethans, and she is currently recruiting subjects for a larger trial.

While more research is needed, a clearer picture of cannabis' effect as a treatment for SCI neuropathic pain and spasticity has emerged. And there are other benefits. A small dose before bed often helps some people with SCI get a good night's sleep. Others find it helps control overactive bladder (a small study seems to corroborate this). And, be-

cause cannabis in small doses increases serotonin, it has a similar effect to antidepressants, acting as a mood elevator.

Making Good Use of Cannabis

We suspect that most medical users still consume it the old-fashioned way—smoke it, either rolled in joints or in a pipe. Smoking is quick and effective. But is it safe? Early research raised alarm bells, suggesting that smoking cannabis increases the risk of cardiopulmonary disease or cancer. However, more recent—and arguably more credible—research contradicts this, asserting that even habitual cannabis smoking doesn't create a significant health risk.

Nevertheless, if there's even a shadow of a doubt, and a safer alternative exists, why not try it? That better method is using a vaporizer, which creates only enough heat to vaporize D9-THC and CBD into gases. The result is that you're inhaling a more benign vapour which is readily absorbed into the bloodstream,

as opposed to inhaling smoke containing carbon monoxide and tar from a large number of burnt compounds. Studies demonstrate that vaporizing cannabis is more efficient when it comes to cannabinoid delivery, and that using a vaporizer could even help to reverse damage done by smoking. And because it's more efficient and less stressful on lungs, vaporizers are reported as being that much better for people with quadriplegia, who may have reduced lung capacity or more easily-irritated lungs.

Another popular and benign method of consumption is eating cannabis. Edibles—mainly in the form of treats and brownies made from cannabis-infused butter or cooking oil—are available pre-made from dispensaries or concocted in your own kitchen. Edibles introduce cannabinoids into your body through your gastro-intestinal tract. It's then processed in your liver before entering your bloodstream. One thing to keep in mind is that, when D9-THC is processed by the

Cannabis: Real Benefits for Three British Columbians

We asked three SCI-BC peers about their experiences with cannabis.

Cory Parsons is a Nanaimo-based chef, author, C5/C6 quadriplegic and long-time Health Canada licensed user and registered grower.

"I use medical cannabis to counteract the nausea affects of my pain medication," says Parsons. "I also find cannabis an excellent sleep aid—it allows me to remain asleep throughout the night. Ingesting medical cannabis



aids greatly in the reduction of the strength and frequency of my spasticity, again allowing for an undisturbed night's sleep. Without it, my spasticity becomes unbearable. I've also become aware of the anti-inflammatory properties medical cannabis provides, as I've found a decrease in shoulder pain due to reduced inflammation."

Parsons gets congested from smoke, so he uses a vaporizer or eats edibles. "I've found the very best method is to make a healthy protein smoothie," he says. "Over the past 14 years, I've experimented with strengths and quantities of medical cannabis dosages and I find that a little bit evenly spaced throughout the day works best for me, rather than large single doses, as I don't enjoy the 'cloudy head' feeling. Too much at one time impairs my ability to keep my thoughts focused and my day productive."

Parsons believes that cannabis offers him far greater medical benefits with the least negative side effects compared to the drugs

doctors had prescribed. "It would seem like they would give me one pill for one thing," he says, "and two more pills to combat the side effects of that pill, and then even more drugs to combat the negative side effects of those pills! With medical cannabis, I was able to cut my pharmaceutical drug intake by three quarters, and I still feel that this drug is by far the least toxic and its side effects are all positive ones—which is the exact opposite of the pharmaceutical world."

As for negative side effects, Parsons admits that his short-term memory isn't as good as it once was. "But," he says, "there's an app for that."

While he believes cannabis should be used respectfully, it should be decriminalized or legalized. "Research has shown that it is not the devil's weed that we were told it was growing up," he says.

Chris Marks is a 38 year-old incomplete C5 quadriplegic who lives and attends college in Victoria.

"I use cannabis for neuropathic pain management, spasticity, relaxation and recreation," says Marks, who is a licensed Health Canada user. "I smoke cannabis, vaporize it, and sometimes eat products infused with cannabis oil or butter."

Marks used cannabis recreationally before his 2005 injury and thought he would give it a try post injury. "I obtained a health Canada exemption to possess marijuana and found a designated grower to breed and grow some custom strains for me," he explains. "My grower has mailed me my marijuana monthly via Canada Post for the last few years."

liver, it's converted into another form of THC which has more of a longer-lasting sedative effect. That means it may be great for sleeping, but perhaps not as ideal for reducing pain and spasticity. Another common complaint about edibles is that it takes much longer for the effect to be noticed, and it's also more difficult to find an appropriate dosage.

Yet another method is tinctures—usually an alcohol-based solution of dissolved cannabinoids that can be taken as drops, or added to food and drink.

What are the side-effects? Again, new evidence suggests that even habitual smoking doesn't increase risk of lung cancer. And the assertion that cannabis is a "gateway" drug to more powerful narcotics has pretty much been relegated to the urban myth category. For the moment, that leaves a couple of side-effects. First, some studies have suggested that long-term use may lead to some memory impairment. Second, as advertised, cannabis gets you high. That's fine—unless, of course, you've got a job to do, a degree to get, or anything else that re-

quires a clear head such as driving. Yet, as many users report, it is possible to reap the medicinal effects without being a stoner. Most people with SCI who use medical cannabis have gone through a trial and error process to find what form of cannabis, at what dosage, works best. Many have found that a combination of methods, usually smoking or vaporizing small amounts during the day and taking edibles before bed, works best. For most, the goal is to find a balance that provides the medicinal effect without resulting in a "high" that curbs productivity or the ability to work and function daily.

Getting Your Medicine

The cannabis prohibition is clearly crumbling. Around the world, access to medical cannabis is steadily improving, public attitudes towards cannabis are becoming more enlightened, and even cannabis laws for recreational use are loosening. Indeed, in the last US election, two US states—Colorado and our neighbours across the border in Washington—voted to legalize cannabis.

In Canada, legalization seems more like a question of when, not if. Liberal leader Justin Trudeau has already indicated his support for decriminalization, with his party's official position being support for full-blown legalization.

But, for the moment, by virtue of its inclusion in the antiquated Controlled Drugs and Substances Act, cannabis is illegal. The only way you can possess it legally is to be licensed by Health Canada's Medical Marihuana Access Regulations, or MMAR (why the federal government chose this antiquated spelling is a mystery to us).

You need to apply for an MMAR license and update it annually. Your completed application needs to include a declaration of support from your doctor. Once authorized, you have three options to get your medicine: access Health Canada's supply of cannabis (heavily criticized for its poor quality), obtain a license from Health Canada to grow your own, or obtain a license from Health Canada to designate someone to grow on your behalf. (Note: these options are changing

Like Parsons, Marks has discovered many benefits of cannabis as a medicine. "Cannabis has not cured my SCI, nor has it taken away every symptom of the injury," he says. "But neither did the 20 plus pills I used every day."



One of the greatest benefits he's found is that it eliminated the need to take Baclofen for spasticity. "Now, I don't have to worry about having a seizure when I forget to take my Baclofen," he says, adding that weaning himself off the drug was "extremely difficult."

He uses cannabis daily, but tries not to use large amounts, particularly before exams or public speaking engagements. "Smoking is messy, stinky and possibly dangerous, so I try to use the vaporizer the most. I invested in a Volcano vaporizer—it appears to be the safest method of cannabis usage.

The downsides of cannabis usage Marks sees are social stigma from people with outdated views, and the cost of it for people with low or fixed incomes.

"Most of the downsides I see with cannabis stem from poorly-conceived public policy and misinformation by lumping cannabis in with other highly dangerous and addictive drugs like cocaine or heroin," he says. "My experience with a compassion club with well over 1,000 members is that it improves quality of life for many people, including myself."

Arren Hahn is a 37-year-old from C4/C5 quadriplegic from Vancouver. Since his injury in 2005, Hahn has experienced extreme neuropathic pain and spasticity. These days, he's playing wheelchair rugby for Team BC, travelling, and living a healthy lifestyle. He credits much of his ability to deal with pain and spasticity to cannabis.

"I've been using medical marijuana for five years now," says Hahn. "I prefer to eat it—I find this is the most effective way to use it for sleep and nerve pain. Pain and spasticity affect my sleep habits very much—sometimes I'm up for days at time even with medical cannabis. But without it, when I travel abroad, I have an extremely hard time sleeping and getting rest."

Hahn is also a Health Canada registered user who receives his cannabis from his own designated grower. "I like to make brownies or cookies for the main part of my medical use," he says. "I also smoke a little bit throughout the day and smoke a full joint at night."

For Hahn, some of the side effects of his cannabis usage are dry mouth, eyes and skin, and sometimes being tired in the morning. But he says the benefits far outweigh the negatives. "Eating and smoking cannabis both work well for my nerve pain and sleep problems. Although they don't fix the problems completely, they seem to work better than the pharmaceutical medications that I use or have used for these same problems."



next year—more on that in a few paragraphs.)

Getting a doctor's support has proven to be a problem for some MMAR applicants. Many doctors and their representative organizations are openly unhelpful. No doubt, abuse by patients seeking to exploit the system has contributed to this. This is probably a major reason why statistics point to the vast majority of medical cannabis users simply purchasing their medicine illegally.

Here at SCI BC, we urge peers to use the legal route—protect yourself at all costs. Police have demonstrated a reluctance to seek out and prosecute unlicensed medical cannabis users, but that doesn't mean you won't be one of the unlucky few.

Good scientific evidence led SCI to be one of the first conditions that qualified for MMAR approval (it was approved for SCI spasticity and pain relief in 2001). As a result, it's a condition that's a no-brainer for even the most conservative of physicians. The bottom line is that, if your doctor won't approve you—a person with an SCI—for a MMAR license, it's probably time to find another doctor.

There is a third route to obtain medical cannabis, and that's through one of BC's many compassion clubs or dispensaries. These exist in a murky grey area. Canadians have a constitutional right to use cannabis for medical reasons. So when Health Canada was unable to produce enough cannabis of sufficient quality to meet demand, compassion clubs and dispensaries emerged.

The federal government maintains these are illegal. But police, for the most part, seem to look the other way. The result is that many people choose to bypass the complex and time-consuming Health Canada route in favour of dispensaries. Convenience (Vancouver alone has an estimated 30 dispensaries), confidentiality and expertise are some of the reasons for this. The latter is important—dispensary staff are often experts that can suggest strains, methods of consumption and dosages that are appropriate for a client's medical condition.

Technically, however, buying from a dispensary is illegal, even for MMAR license holders.

Adding to the confusion is that Health Canada has announced it will change the rules for medical cannabis on April 1, 2014. The most radical and heavily criticized of these changes is removing licenses to grow your own cannabis. Instead, production will be steered into larger facilities. And the price per gram is projected to skyrocket, from about \$4 per gram to up to \$9 per gram.

Critics say that Health Canada's changes are driven by the desire to profit from a burgeoning industry, and will drive licensed users back into the realm of illegally-obtained cannabis. Yet another criticism of the changes is that they presented a perfect opportunity to integrate dispensaries and compassion clubs, arguably the closest thing to a pharmacy that medical cannabis users have access to. Instead, the new rules seem to suggest a crackdown of dispensaries is imminent.

If opinion polls are to be believed, all of these proposed changes—and indeed, the entire Health Canada regulation of medical marijuana—may be irrelevant in the future. Last November, Angus Reid published results of an extensive two country public opinion poll on cannabis. In the US, 54% supported outright legalization. Here in Canada, the figure was 57%. It's likely that these numbers will continue to grow as new evidence emerges about the medical potential of cannabis.

The message is simple: politicians who

avoid the topic or maintain support for prohibition do so at their own peril. In BC, an opportunity to put public opinion to the test is coming this fall, when the Sensible BC campaign will have three months to collect 400,000 signatures and force a BC referendum to decriminalize marijuana in 2014.

The Bottom Line

The body of evidence is far from complete, but the picture is becoming more and more clear: when used appropriately, cannabis can be good medicine for people with SCI. No doubt, we're preaching to many of the converted in this story. But we also believe that many other readers may have never considered it. Others might be sitting on the fence, unwilling to move forward because of outdated social stigma, conservative values or moral beliefs.

Our hope for all readers is that they see cannabis in a modern context. It's so much more than a recreational drug like alcohol. It's not a cure-all, and it won't be effective for everyone. But it is medicine, with clear benefits for some people with SCI already confirmed, and more emerging as research moves forward.

If you suffer from excessive neuropathic pain, spasticity or even insomnia, and you're finding pharmaceutical drugs ineffective or too hard on your body, perhaps you should consider cannabis. Ask your medical professionals for their thoughts. And show them this story if you don't get an enlightened response. ■

SCI BC Staff Member Headed to Hall of Fame

Vernon's Sonja Gaudet, Canada's most decorated wheelchair curler, will be inducted into the Canadian Curling Hall of Fame during the Canadian Curling Association's (CCA) annual meetings in June. Gaudet, who is Spinal Cord Injury BC's Peer Program Coordinator in Vernon, has won gold medals at the past two Paralympic Winter Games in Torino, Italy and Vancouver. She played lead both times. She's also helped Team Canada win three world wheelchair curling championships, the most recent coming in February in Sochi, Russia.

Gaudet becomes the first athlete inducted into the Canadian Curling Hall of Fame based on her wheelchair curling achievements.



Update: Botox

PharmaCare's recent announcement that it's now providing coverage for Botox for neurogenic bladder is good news for people with SCI

On March 28, 2013, PharmaCare announced it will reimburse Allergan's Botox treatment for people with neurogenic bladder due to SCI or MS. Up to this point, people had to pay for it out of pocket, at a cost of approximately \$800.

Here's PharmaCare's criteria: "For the treatment of urinary incontinence due to neurogenic detrusor overactivity (NDO) associated with multiple sclerosis (MS) or subcervical spinal cord injury (SCI) in patients who have experienced treatment failure and/or intolerable side effects to a specified anticholinergic."

Treatment failure of anticholinergic drugs (for example, Ditropan and Oxytrol) is defined as "using optimal doses of at

least one anticholinergic for a minimum of three months without a reduction of symptoms." Second, the treatment covered is one dose of Botox injected into the detrusor muscle of the bladder. PharmaCare may cover additional treatments every 36 weeks, providing that your urologist provides documentation showing that you've experienced 50 percent reduction in the frequency of "urinary incontinence episodes."

Botox is a powerful, bacteria-produced neurotoxin which, when injected into the smooth muscle of the bladder, can result in a long-lasting (up to ten months) relaxation of the bladder, an increase in bladder capacity, and preven-

tion of NDO. NDO is the spasming that inappropriately contracts the urethral sphincter and leads to the type of leakage that countless people with SCI experience.

In several high quality studies, Botox has been shown to result in significant reduction of NDO. Those who benefit from the treatment report a big quality-of-life boost. They may also experience lower risk of UTIs and even bladder cancer, mainly due to lower cathing frequency. Research also indicates that, since Botox reduces high bladder pressure resulting from NDO, it will provide some protection against damage to the upper urinary tract and renal system. Based on these studies, Health Canada and the FDA approved Botox in 2011.

For more information about Botox and its potential benefits and side effects, visit www.allergan.ca or speak with your doctor or urologist. ■



Botox: Two SCI BC Peers, Two Different Results

In the last issue of *The Spin*, we introduced you to 24-year-old Caleb Brousseau, a Paralympic skier who was scheduled to have the procedure on March 15. Brousseau, who is from Terrace, was told by his urologist that he was a good candidate because his bladder is so active. He agreed, hoping that Botox would allow him to liberate himself from a leg bag, while stopping leaks and a disturbing number of UTIs.



"I thought the surgery went well," says Brousseau, who is L1 paraplegic. "There was little pain and not much blood afterwards."

Brousseau waited patiently for results, but they didn't materialize. "The way I feel is slightly let down—I really thought it would work," says Brousseau.

Brousseau's urologist told him that Botox won't work for everyone, but still believes he's a good candidate. "He says there may have been two problems with my surgery," says Brousseau. "First, it may have been too small of an amount administered to me. Second, it may have leaked during the injection."

Despite some doubts, Brousseau will go ahead with a second injection. "I am really hoping that when we try again, that it will have an effect this time," he says.

Chad Tinney's experience couldn't be more different. A

28-year-old with T6/T7 paraplegia, Tinney had constant battles with infection and incontinence since his injury in 2004. "I had to empty my bladder before I did anything out of fear of voiding," says Tinney, who lives in Prince George. "I had dysreflexic bouts and spasms, and was constantly feeling 'off' due to the amount of UTIs I was getting. I felt my bladder was controlling my life."

After researching Botox himself, Tinney approached his urologist, who agreed to do the treatment last December. "It was a very quick and easy procedure—less than half an hour if I remember correctly. There was no pain, discomfort, or side effects."

He says the outcome was life changing. "I have had only one UTI since. I haven't worn a leg bag since, which at times was pretty much a part of my wardrobe. I empty my bladder when it is convenient to me. The control I felt my bladder had over me is gone, physically and mentally. I will most definitely be going back for a top-up when it is due."

Tinney recommends Botox to his peers, but advises cautious optimism. "Obviously, every bladder situation is different and outcomes could be different than mine, so it's not like a person can guarantee results. So I would recommend going at it like I did, with low expectations, and be happy with any kind of improvement."





Careers Carved in Stone

Victoria's Alistair Green and Garry Curry have become reputed stone sculptors, thanks to perseverance, pure artistic skill, and assistive technology.



Alistair Green (left) and Garry Curry in their studio

Painstakingly chiselling and polishing stunning sculptures out of heavy blocks of stone isn't an art form you'd expect to find quadriplegics practicing.

But sculpting stone is exactly what Garry Curry and Alistair Green have made their artistic mark in. The two artists and friends from Victoria have been practicing their craft for almost two decades, with their work today finding homes in galleries and collections around the globe. In the process, they have banished the stereotypical view of disabled artists and dedicated themselves to teaching their craft to other people with disabilities.

Curry and Green's parallel lives as friends and fellow artists began in 1991, when they were injured in separate motor vehicle crashes. Curry, a lifelong Vancouver Islander who was fortunate to survive a rollover in his truck, was left with C5 complete quadriplegia at the age of 22. Green, who was born in the UK and moved with his family to the Comox Valley in 1980, was left with C4 incomplete quadriplegia at the age of 20 after a near-fatal crash.

The pair spent a year in rehab together at GF Strong, learning how to cope with such a devastating injury. After rehab,

they both moved to Victoria, where they struggled to find their new place in life. Both had been fit and outdoors-oriented before their SCIs, and it wasn't surprising that both had a hard time adjusting to post-injury life.

"After rehab, I would spend months in my apartment without going outside," says Curry, who suffers from constant neuropathic pain. "Life was very depressing. Then, in 1994, I saw a video on a local TV station about a stone sculptor—his name is Maarten Schaddelee."

Curry was intrigued with the two beluga whales Schaddelee was working on, and he and Green decided to try their hand at sculpting. Soon they had completed some small pieces.

"The greatest discovery was that, when I was working hard on stone, my pain would disappear," he says. "And at the end of all your hard work, you'd be rewarded with a sculpture."

The third sculpture Curry created was an abstract humpback whale. "That was my 'Aha!' moment," he recalls. "This



sculpture was the beginning of a new life, full of satisfaction and sense of worth."

Green was working with Curry at the time in Curry's apartment, and he was having similar success. "In 1996, says Curry, "we decided to take up stone sculpting as a profession."

By this time, the pair realized they needed a dedicated work space so they could create accessible workstations, with a dust-controlled environment. Curry's sister had a small space available, which was converted into a studio and

How do they do it?

Clearly, stone sculpting is hard physical work. So how do Curry and Green do it?

"Alistair and I often work as a team," says Curry. "I work with my right arm and Alistair works with his left. We're able to help each other to complete sculptures, and we often work on sculptures together. It starts with a rough stone—we'll spend some time collaborating on what to create, with the shape of the stone dictating greatly the outcome of the sculpture. We always try to maximize the size of sculpture from the stone."

The pair have designed many different adaptations of tools to compensate for the lack of grip and strength. Their tools—air-powered impact chisels for initial shaping, and rasps and chisels for fine work—are held in place with arm braces and splints.

The duo found an incredible amount of support from CanAssist, a non-profit University of Victoria program of students and staff who are committed to developing assistive technology solutions for people with disabilities. CanAssist volunteers have worked hard to create specialized splints for Curry and Green that help them control the powerful tools and dissipate the high heat that they create. Another valuable CanAssist contribution was a powerful yet portable electric vise that opens and closes the jaws with the simple press of a button. The vise holds stone up to 100 pounds securely in place, allowing Curry and Green to work with confidence.

"CanAssist has been a great help," says Curry. "If you have an idea, they have a team of engineering students who can solve it."



used for two years. The studio allowed them to create larger sculptures and experiment with different tools, but it was hard to heat and would flood during wet weather. Once again, they needed a larger studio, so Green's carport was converted into a studio with five large accessible workstations. That space remains their studio to this day.

Their early lives as artists were humble—as they honed their craft, they bartered sculptures for badly-needed tools such as high quality chisels, sculptor rasps, an air compressor and air tools. They also donated many sculptures to charities and organizations to help raise funds for their causes.

While they weren't making much money, they were both amazed at the sense of purpose sculpting had introduced into their lives—so much so that they wanted to teach and inspire other people with disabilities. They created the Vancouver Island Society for Disabled Artists, and in the years since, they've taught and mentored several talented sculptors. They've also been the focus of a documentary about stone sculpting that has been seen by millions of people in 32 different countries.

"Our main goal at first was to show other disabled people what is possible, because it has been a life changing experience for us," says Curry. "My most important career accomplishment is my students—to watch them learn as you teach is very rewarding. With every sculpture an artist creates, their confidence grows."

In the past five years, the pair have taken a different, more career-oriented direction as they began to realize their potential as artists. The turning point may have been a sculpture they were commissioned to create for the 2010 Winter Olympics in Vancouver. "It took two years to complete," says Curry, adding that it will soon be on permanent display at a new University of Victoria building, currently under construction.

"At this point, Alistair and I are going to focus on selling our sculptures full-time," he says. "We now have sculptures across Canada—and in Scotland, Germany, USA, Australia, New Zealand, and Japan. We have shown our work in many galleries and museums. It takes 15 years of going to art shows and creating contacts before you really see the possibility of profit. Shipping artwork to museums and shows is extremely expensive—it can cost up to \$5,000 and even \$10,000. But these are expenses you have to make to elevate your artwork. After showing in few museums, the price of your work increases."

While the pair are looking forward to some financial success, Curry says it would only be a bonus.

"Having a disability can leave you feeling left behind. Sculpting has given me something to show for my time spent in a chair. I have a passion for hard physical labour, and working with stone gives you a great sense of being here and now. I look forward with great excitement as I enter the middle of my career. With every sculpture completed, I anticipate the next." ■

For more information, please contact Garry Curry by email (garrycurry@shaw.ca) or by phone (250.472.2917).



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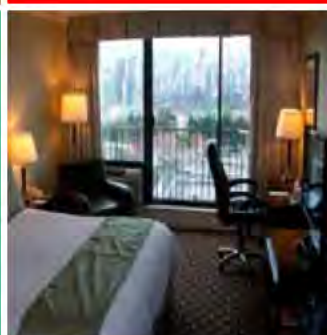
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Sexual Supports

EASE debuts its website; a new guide for supporting sexual intimacy in care facilities

Two new resources offer assistance for people with SCI and other disabilities seeking to explore their sexuality and achieve intimacy.

EASE Canada, which we first told you about in the Autumn 2012 issue of *The Spin*, now has an online presence. EASE, which stands for Equitable and Accessible Sexual Expression, is a Vancouver-based organization that's committed to helping people with SCI and other disabilities achieve their sexual and sensual desires—desires that are just as strongly ingrained and important for wellbeing as in those who are able-bodied.

On the EASE website, you can learn about disability-specific intimacy training that EASE is developing for health care providers, sex workers and people with disabilities. You can also discover how EASE can recommend the services of an appropriate sexual surrogate or other sex worker who are trained to help people with disabilities explore their sexuality and intimacy. While you're there, you can learn about other online resources that promote sexuality for people with disabilities, or read current news stories in the EASE blog.

Check it out at www.easecanada.org.

For the thousands of British Columbians who live in care facilities across the province, achieving sexuality and intimacy may lead to ethical, moral and legal quandaries for health care workers who support them. What are a client's rights? What are a health care worker's responsibilities? And what if these go beyond someone's comfort zone?

These are complicated questions that nurses and health clinicians deal with each day, and for a long time, they were trying to answer them alone.

Fortunately, there is now a short guide that health care providers can turn to for guidance. Written by clinical, ethical and legal experts, *Supporting Sexual Health and Intimacy in Care Facilities: A Pocket Reference Guide* was published by Spinal Cord Injury BC on May 1st.

Based on a much longer document published in 2009,

this new Sexual Health Reference Guide is the first of its kind in the country.

"There has long been a gap in guidance for health care providers and facilities in how to best support residents in their sexual lives, but we have a moral, legal and ethical obligation to support them with this part of their life," says Kate McBride, the sexual health clinician who coordinated the project. "These guidelines were developed to try and close this gap and to create a dialogue in this complex area of health."

The document includes sections to help caregivers assess risk of harm to their patients, determine if consent has been acquired, and outlines when and how to intervene if necessary.

The reference guide also includes a series of case studies based on real-life situations, ranging from residents wanting help to get washed and dressed to go out on a date; to unmarried residents wanting to share the same room; to residents with cognitive difficulties engaging in sexual activity together.

Spinal Cord Injury BC received funding from the Public Health Agency of Canada for the creation of this new *Pocket Reference Guide*. You can download the entire 13-page booklet at www.sci-bc.ca/news/media. ■



A Guide to User-Friendly Trails

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Fishing Hole

Doug Janke wants you to 'fess up about your best fishing spots

Anglers are notorious for keeping their best fishing spots a well-guarded secret.

But Doug Janke, an SCI peer who lives in Hedley in the BC interior, thinks that every fisherman (or woman) who uses a wheelchair would benefit from sharing their knowledge of accessible fishing spots across the province. Spinal Cord Injury BC agrees, and we've dedicated space on our website to make it happen.

Janke, who is quadriplegic, was an avid fisherman before his injury in 1974. After his injury, he got back into the sport. He's been boat fishing a few times, using a rod and reel adapted to meet his needs by CanAssist. But he's had little luck finding quality accessible fishing spots at the lakes and rivers around Hedley—wheelchair accessible spots next to deep water that he could easily visit and would give him a chance to land the big one.

Last December, Janke spoke about

his frustration during a conversation with Joe Basnett, Spinal Cord Injury BC Client Services Specialist. Basnett decided to do something about it, and brought the issue up with SCI BC's information services team.

Pat Harris, our Manager of Information Services, took the next step by digging around for some quality wheelchair accessible fishing spots across the province. He's found quite a few, and those are now listed within our SCI Information Database.

"We've posted the fishing resources in alphabetical order," says Harris. "Where possible, we included a weblink and a map which outlines where the resource is located and information on other nearby amenities such as an accessible washroom."

But Harris says that visitors to the database can do more than simply read about the offerings presented there. "Attached to each of the accessible locations is an 'Accessible Fishing YOU

TELL US feedback form' which will hopefully be used by anglers to tell us where other locations exist that we're unaware of. We've attached this form on each of the accessible sites to make feedback a little easier. Once a visitor fills out the form, they simply hit the submit button and it goes directly to our InfoLine staff, who can then add the resource to the database."

Janke looks forward to other anglers with disabilities sharing their knowledge. "It could be a good, stable dock or platform that's wide enough for a wheelchair," he says. "But it could just as easily be any accessible patch of flat land that's next to deep water, with no weeds in the way."

Give up your best-kept fishing hole secrets at www.sci-bc-database.ca—look under Recreation & Leisure > Outdoor/Adventure. ■

Fishing Resources

There's an incredible number of resources and products available for anglers with disabilities, including many innovations that make fishing an accessible activity for even those with limited hand function. A great example is the Power Fish'n Pro Hybrid Reel, shown below.

A great starting point to learn more about adaptive technology for fishing is www.adaptiveoutdoorsman.com. A Bing or Google search for "disabled fishing" will also yield impressive results. And if you want to see how people with disabilities are fishing, search YouTube—you'll be amazed at the results.

Finally, keep in mind that not all commercially-available products will meet everyone's specific needs. That's where non-profit organizations such as Tetra and CanAssist might be able to help. Learn more at www.tetrasociety.org and www.canassist.ca.



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