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SEX, WHEELS & RELATIONSHIPS

Rediscovering your sexuality after a spinal cord injury can be difficult, and getting your groove back after secondary complications can be equally challenging. REGAN LINTON shares success stories and strategies from wheelers who broke out of the "body ruts" that inevitably come with SCI and figured out how to revive their sensuality and sexuality. EMILY HUPÉ picks up the story there and looks at how couples keep the flame of passion burning as the years roll by.

Cover and Contents Photos by Bear Gutierrez



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BULLY PULPIT

By Ian Ruder

THE SECRET AMTRAK FARE

After 20 minutes of frantically pressing buttons and shouting my answers into my phone, I'm beginning to think Amtrak is holding out on me. All I want is to sign up for the special \$25,000 wheelchair ticket I've been reading so much about, and Julie, Amtrak's automated agent, isn't being helpful.

We had no problem finding the train and time I wanted, but when it comes to choosing what type of ticket I want she refuses to offer me the \$25K wheelchair special. I figured Amtrak might not want to publicize something this pricey and elite, but this is getting ridiculous.

I've tried asking about custom fares. I've requested more information on how they calculate fares. I've asked for fare details. I honestly feel like I could probably write the Amtrak fare guide after listening to Julie repeatedly explain the unwavering minutiae of their policy.

My immediate frustration is tempered by my growing respect for Adam Ballard. Ballard is the Chicago policy analyst/railroad sleuth who discovered Amtrak's secret fare when he tried to book a January trip from Chicago to Bloomington, Illinois. Instead of the regular \$16 coach fare or the \$35 business class fare, Amtrak hooked him up with the \$25K wheelchair special.

My mind begins to wander as I dream about the secret luxuries that must come with such an exorbitant price. Amtrak said the fare simply reflects the cost of taking a train out of service to remove regular seating and create space for a wheelchair. They're not fooling me.

Nobody charges that kind of upgrade fee simply to take something out. For \$25K, I'm expecting the lap of luxury: bottle service, caviar, massages — think first-

class international travel, only fancier.

I get that Ballard was pissed about an unexpected \$25K bill, but I've got a plan. I just opened up an Amtrak Guest Rewards World Mastercard and I have a code for a 20% discount. That code knocks \$5,000 off the cost, and with the card I'll be getting triple points on every dollar of the \$20,000 — plus 20,000 bonus points for spending \$1,000 in the first 90 days.

On top of that, my card comes with one complimentary companion coupon, meaning a friend can experience the high life alongside me. By my count, that's \$30,000 in savings, not even considering how loaded my new card will be with rewards.

"For \$25K, I'm expecting the lap of luxury: bottle service, caviar, massages."

"I'm sorry," Julie's friendly automated voice snaps me out of my daydream, "but I couldn't understand what you said."

Yeah, right. Julie understands me. I've told her everything I can and punched in every code possible. She's no dummy. She's just holding out.

I wonder how Ballard got Julie to give it up. Is there a secret option I'm missing? Did he sweet talk her with just the right words when she asked him to say his answer? Is there a password we wheelies have to drop to unlock the premium options?

I'm beginning to think Amtrak may be discriminating against us ...

BEHIND THE STORIES

With Ian Ruder

I'd like to thank Wendy Crawford from mobileWOMEN.org for urging **Emily Ann Hupé** to reach out and consider writing for us. Thanks to Crawford's suggestion and Hupé's inquiry last May, she is making her New MOBILITY debut with this month's excellent "How to Keep the Flame Burning." An English major with a lifetime love of writing, Hupé, who runs an industrial laundry equipment business with her husband, committed to getting back to writing two years ago. "It was a little bit of a scary thing, but it's always been my passion and I wanted to give it a shot," she says. I'm thrilled she did and I think you will be too after reading her feature.



Steve Wright has been fighting for disability rights and access for decades, and in this issue he has distilled his years of wisdom into a beginner's guide to advocacy. After a career as a journalist and stints in city government, architecture, marketing and business development, Wright has seen it all and is still baffled by the paternalistic and ignorant attitudes civic leaders all too often embrace when it comes to enforcing the ADA and other disability-related policy. "It confounds me that there are people that are otherwise smart and educated who still look at these issues as a sympathy thing or a 'good deed,'" he says. "Enforcement is simply the right and legal thing to do."

Every once in a while, during my procrastination ... er ... research breaks, I stumble across an article or an essay that stops me dead in my tracks as both an editor and a paralyzed person. **Michael Franz's** Sept. 9 essay "SCI Burnout" on [backbonesonline.com](#) didn't just grab my attention — I wanted to meet Franz and get his voice and clear, honest prose into New MOBILITY. Apparently I wasn't alone, as the article went viral over the next few days. Fresh off his newfound internet fame, Franz kicks off our new Products column in this issue. I'm looking forward to sharing his insights, reviews and much more in the months to come.



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SHARE

“Thank you for giving us exciting ideas to think about and share.”

Refreshing Perspective

I liked the article “How to Compare (and NOT Compare) Your SCI to Others” (December 2019) and thought Rick Hayden’s observations were right on the mark. I’ve read article after article about people with SCI playing sports and doing all sorts of physical activities, and it gives the “normals” the impression that having an SCI is virtually no obstacle at all. It is very frustrating.

Mike Robinson
Johnstown, Ohio

Questions to Consider

You’ve given me lots to think about (“Vulnerability Catch 22,” December 2019). Can I be vulnerable and keep my dignity? Can I be more comfortable asking for help without feeling like a prima donna or a loser? Is struggle my karma and my penance? I’d like to stop acting like everything’s OK and under control when it isn’t, but how do you tell people without scaring them away? I am newly disabled and have a lot to learn.

Vibha Thompson
Newmobility.com

Get a Job

None of them will make a difference (“Inclusion and Access: Beyond Campaign Slogans to True Paradigm Shift?” December 2019). There are too many people with disabilities on public benefits, and although this will not make most in the disability community happy, the best remedy is to get a job! I’m a C5 quad and started working after college in 1982 (diving accident

in 1975) and recently retired after 36 years. I have a nice nest egg from maxing out my 401(k). Throughout my career, I’ve met numerous people with disabilities that give up looking for a job too soon or don’t want to work. Sad but true.

Richard Keeling
Newmobility.com

Diva Evolved

Terrific! You showed the painful evolution of your fashionable evolution (“I Will Never Wear a Sweatsuit,” December 2019). I commend you and related to your thoughts about fashion and image issues. Well done.

Kate Wilson
Newmobility.com

Making a Difference in India

This article (“Possible Side Effects of Long-Term Spinal Cord Injury,” December 2019) has enriched my knowledge and will be of great help in educating others. I am a peer counselor at Indian Spinal Injuries Centre in New Delhi, India.

Shivjeet Singh Raghav
Newmobility.com

Food for Thought

Your reflection on inspiration (“Beyond Inspiration: A New Narrative,” August 2019) shared what I have been trying to convey to my family and friends for many years without much success. Thank you for giving me the guidance to try again.

Your Big Ideas issue (September 2019) was groundbreaking. We



all need to become visionaries for ourselves and those around us, and your writers have given us the ideas to share with others.

I feel like I learn something from each of your columns and editions. And after using a chair for 67 years from polio, that’s a wonderfully humbling feeling!

Thank you for giving us exciting ideas to think about and share.

Susie Haake
Newmobility.com

Disappointing Doc

Thanks for the Bully Pulpit (“It’s Not SCI, It’s HBO,” December 2019). That’s exactly how I felt, but I didn’t know how to say it.

Lisa Barlow
Newmobility.com

Thank You for the Community

Your lifestyle has been mine, too, in many ways since I first became paralyzed from polio in 1953. Speaking out and joining others to demand a fulfilling life makes us powerful and heard!

Phyllis Bannister
Newmobility.com



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By Seth McBride

COMPLEX REHAB TECHNOLOGY: BATTLE WON, FIGHT RAGES ON

On December 20, President Trump signed into law H.R. 1865, which funds the federal government through the end of September 2020. Tucked into the legislation was language that will have a much longer-lasting impact for a large number of wheelchair users. It exempts complex manual wheelchairs permanently from Medicare's competitive bidding program, replacing temporary exemptions that were set to expire this year. It's a policy advocates have been fighting years to secure.

Without digging too far into the weeds, the exemption will keep the highly specific, custom fitted manual wheelchairs that people with permanent disabilities need from being lumped together with lower quality ones. Power wheelchairs and components received a permanent exemption from the competitive bidding process in 2017, but the temporary exemption for manual chairs was set to expire this year.

Even with the exemptions in place, there is still a huge range of wheelchair styles that are listed under the same reimbursement rates. For example, the Medicare code for an Invacare MyOn folding wheelchair, which weighs 29.65 pounds and retails for \$1,799, is the same one used for a TiLite TR titanium wheelchair, which weighs 9.3 pounds and retails for \$4,595.

"When you have a chair that has a lot more engineering into it, higher quality components, higher quality materials, and it's lumped into a reimbursement code that's the same as a chair with off-



the-shelf components and much lower quality components ... what happens is the higher-end equipment ends up being something that a dealer can't make a living providing," says Dave Knight, territory sales manager for Permobil. If Medicare had put manual wheelchairs into the CBP, it would have further reduced the reimbursement rates for these chairs, making an already bad situation worse.

Furthermore, the bill has language that makes the Centers for Medicare and Medicaid Services reimburse manual wheelchair accessories at their regular rates instead of the lower competitive bid rates that they had been using. Congress had already exempted

"Anyone who pushes a wheel, sits on a cushion and leans against a backrest all day knows how misleading a term like 'accessories' is for these vital pieces of equipment."

power wheelchairs and accessories from competitive bidding, but had failed to include manual chair accessories, so suppliers were being paid different rates for the same accessory, depending on what type of chair it went on.

And anyone who pushes a wheel, sits on a cushion and leans against a backrest all day, everyday knows how misleading a term like "accessories" is for these vital pieces of equipment. You also know that a ROHO isn't a 2-inch foam cushion, and a wire-spoked wheel with metal pushrims might as well be square if you have limited arm strength and no grip. Given how different every wheelchair user's body, functional abilities and daily lives are, there is no single cushion, wheel or backrest that works for all of us.

But under the CBP, suppliers were being paid a set, artificially low rate for these specialized pieces of equipment. Depending on the specific product and how it was coded — say a cushion for someone with a high-risk of skin breakdown who is also active and moves around a lot — a DME supplier might only be reimbursed pennies on the dollar. Either they provide the product the user needs, at a loss, or they steer the user toward a "similar" but suboptimal product on which they can stay in the black. It was a lose/lose/lose. Suppliers face ever shrinking profit margins; manufacturers get squeezed because of declining sales; wheelchair users can't get the equipment they need to stay healthy and independent.

With the new legislation, Medicare will have to reimburse for manual wheelchair accessories at the same, higher rate as for power chairs, hopefully improving manual wheelchair users' access to specialized equipment that meets their needs. Organizations like United Spinal Association, the National Coalition for Assistive and Rehab Technology and dozens of others have spent years fighting for this change. This was an important step, but there's a lot of fighting left to do.

Moving Forward

Don Clayback is the executive director of NCART, an advocacy organization that represents CRT suppliers and manufac-

turers. He says the major priority moving forward is legislation to require Medicare to carve out a separate benefit category for CRT so that reimbursement can better reflect the actual costs of equipment.

There is already precedent — custom orthotics and prosthetics have their own benefit category. The goal of moving CRT into its own category "is better safeguards, better coverage and more appropriate payment rates for both current technology and new technology," says Clayback.

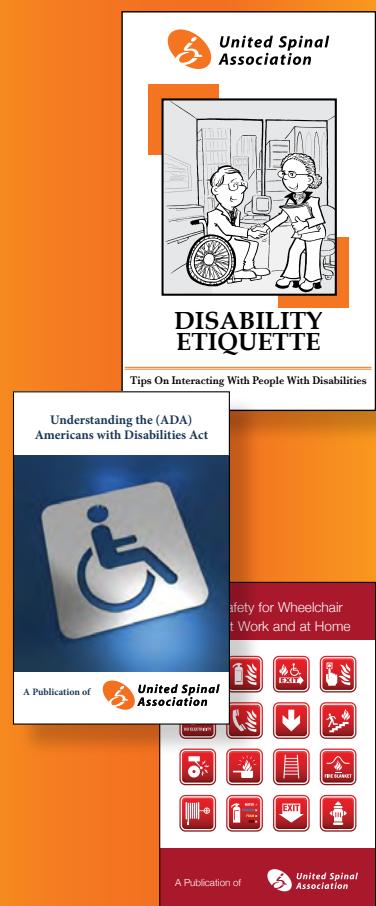
At NEW MOBILITY, we receive more comments from readers about the skyrocketing costs of adaptive equipment than possibly any other subject. As wheelchair users ourselves, we feel your pain. But these days, things aren't easy for manufacturers or suppliers either. Materials, regulatory approval, R&D — everything is more expensive than it used to be. The pressures brought by increasingly stingy reimbursement rates for Medicare and private insurance alike are making an already shaky business environment even shakier, leading to further consolidation in the industry. When margins are tight, only the big survive, further reducing wheelchair users' already limited access to essential equipment.

Getting new legislation passed isn't easy — battling legislative inertia takes years of constant, coordinated advocacy. But the considerable effort spent advocating for CRT exemptions has already educated congressional offices on the value and the necessity of making sure wheelchair users have access to adaptive technology that works for them.

The recent legislation "solves a big problem for people who use complex manual wheelchairs," says Clayback. "But it was also a big win because we've proven that Congress will respond to us. We've proven that Congress understands the difference in CRT. And I think we've proven that if people are willing to send emails and make some phone calls, and in some cases, come to Washington, it'll pay off."

For information about how to get involved, visit: unitedspinal.org/separate-medicare-crt.

Did You KNOW...



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United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.



NEWS FROM UNITED SPINAL

THE FUTURE IS HERE, AND SO IS UNITED SPINAL

New Technology Access Initiative connects members with leading tech companies and resources

Autonomous vehicles are coming. Virtual reality is here. These and other cutting-edge technologies have the potential to dramatically improve the quality of life for people with disabilities, and United Spinal Association is committed to ensuring that the voices and experiences of its members are heard and heeded to maximize that benefit.

To facilitate those conversations and the inclusion of individuals with mobility disabilities in technology innovations, United Spinal has launched the Technology Access Initiative. The initiative is a far-ranging effort to connect the organization and its 50,000 members to the technology industry through the formation of direct partnerships with leading companies, the creation of resources and much more.

At the heart of the initiative is the Tech Access Group. This cohort of tech-savvy members from across the nation will work with leading tech companies and designers to help guide the direction of new technologies and the policy surrounding them.

"We want the unique user experiences and feedback of our community to carry weight and inform tech product service and design from the get-go, and not be an afterthought," says Brook McCall, the woman charged with leading the TAG. "We are challenging tech thought leaders to solve the problems we face daily."

A high-level quadriplegic herself, McCall is intimately familiar with technology's vital role in increasing independence. "With limited mobility, access is everything," she says. "Tech offers unparalleled potential for independence, autonomy and opportunities for participation and success in areas where our members have faced logistical barriers in the past."

The TAG team will meet regularly for subject-specific tech accessibility discussions. It will also engage with stakeholders to develop use cases and opportunities for technology engagement and access for United Spinal members.

"We've already had some great collaborative discussions about the good, the bad and the ugly when it comes to the state of tech in our lives," says McCall. "We are passionate about generating real change that equates to improved ease-of-use, simplicity of design and processes, affordability, product access and awareness, and education and training, both for users and tech employees on all levels, about the solutions that we need."

TAG is positioned to elevate the tech industry's awareness and commitment to individuals with mobility disabilities as valued customers. The team will serve as consumer advocates, speaking out for our community's needs in tech places and spaces where our voices have been previously lacking. Some of the technologies and fields TAG plans to focus on include connected health, smart homes/offices, smart cities, mobile offices, machine learning and AI, rehabilitation and mobility tech, robotics, prosthetics and transportation/autonomous vehicles.

If you are interested in getting involved with TAG, either as a member or tech partner, contact McCall at bmccall@unitedspinal.org. You can also find out more on United Spinal's website, unitedspinal.org.

— IAN RUDER

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HOW WE ROLL

TECH NERD AND RADIO PERSONALITY

Paul Amadeus Lane



Paul Amadeus Lane is a velvety-voiced brand ambassador, accessible gaming consultant, keynote speaker and TV and radio personality who, as a C6 quadriplegic, has climbed the ranks high enough within the broadcasting industry to call his own shots.



Always in the Zone

Lane, 49, was always a nerd. Even pre-injury, when he was a musician and an EMT, he spent his spare time gaming, indulging in sci-fi and comic books and drooling over the latest in futuristic gadgetry. Then, following the multi-car pile-up in 1993 that made him a quadriplegic, he taught himself HTML and started a business selling cellphone accessories and contracts.

"I'm a sci-fi guy. I was always into Star Wars, Star Trek and Battlestar Galactica. I would see all the technology on those shows and I'd think how cool it would be if we could have it," says Lane.

But how does a guy using a wheelchair go from selling cellphone accessories, to not just working in radio, but having his own show?

"I looked at my options and I thought, what can I do that wouldn't take a lot of physical strength where I could just open my mouth and let it rip?" he recalls. "I have an older cousin, and she said I had the gift of gab. This always resonated with me, so I thought, let me just try. I wasn't going to be denied."

The radio bug bit him in 2000 when Lane heard that a friend

had his own radio show. Lane asked him how he did it. Turns out, the guy just called up the station and was paying for time, so Lane tried that too, even though it quickly got expensive. He didn't give up and enrolled in the Academy of Radio and TV Broadcasting in Huntington Beach, California, in 2006.

"They were kind of apprehensive about letting me go to that school at first because it wasn't always wheelchair-friendly and they worried about my ability to do stuff as a low-level quad," he says. "I talked to the administrator, and he said there was a module on the final where I'd have to cut tape with a razor blade. Let's just say my GPA was so high, I didn't even need that last module and I still graduated with honors."

Coming out of school, Lane thought he was hot stuff. But he'd send in his demo and resume, and as soon as stations heard he had a disability, he wouldn't get a call. Then CBS Radio KFWB took a chance on him as their part-time news production assistant.

"I worked there overnight from 3 a.m. to 11 a.m. It was crazy. I had to get up early and switch my bowel program," he says.

FAVORITE ADAPTIVE TECHNOLOGY:

My Mieron VR. It puts me in a virtual reality environment, so I can pop balloons and fight dinosaurs while I work out. No one wants to work out. But when it's fun, it's pretty cool.



DREAM X-MEN MOVIE CAST DEAD OR ALIVE:

Yul Brynner as Professor X, Jack Nicholson as Wolverine, and Iman as Storm.





Agents of S.H.I.E.L.D.'s Ming Na Wen and Clark Gregg share the spotlight with Lane.

Then one of his classmates working at NBC radio affiliate KCAA 1050-AM in San Bernardino, California, told him about an opening the station had for an announcer. "So I had an opportunity to be on the air," he says.

He got the job and worked for both stations at the same time before he really took off as host of KCAA's morning show, eventually becoming its news bureau chief. In 2015, he moved to ABC KMET 1490 AM in Los Angeles, and in January 2016 he got the opportunity to start his own talk radio show. He called it *The Tech Zone* — a place where he interviews celebrities and industry insiders about tech, gaming and sci-fi news and how it affects all of us, including those of us with disabilities. *The Tech Zone* has since spun off into *The Entertainment Zone*, covering geeky pop culture, and *The Ability Zone*, covering adaptive technology.

"I've been blessed to have bosses who look beyond the chair and admire my hustle," says Lane. "They always say, 'Man, you work harder than everybody.' The one thing I want people to know is I am dependable, and that's what makes me really push in that area. Even if it is an emergency situation, I will be there."



NEXT CAREER MOVE: I'm putting together a framework for a reality show called *Paul on Wheels* that will chronicle me going on different adventures and give a behind-the-scenes look at my life.

BREAKING IN TO SHOW BIZ An Extra Set of Hands

Paul Lane details a creative way he overcame a barrier while interviewing for his first job in radio.

“ My wife took me to the interview. When I met the guy he said, 'Here's an application, a clipboard and a pen — meet me in the quad.' I looked down and thought, how the hell am I going to fill out this application?

The guy went upstairs, and while he was gone, I hurried out to my wife who was waiting for me in the van. I said, 'Hey, look, I need you to fill this out really



Lane interviews *Brooklyn Nine-Nine*'s Terry Crews and Joe Lo Truglio.

quick. Can you do it?' She filled it out as fast as she could and gave it back — it must've taken her only a few minutes — then I roll to the quad, and the guy is waiting for me and says, 'Hey, what happened? I was worried about you.'

'Oh,' I said. 'I had to go to the bathroom.'

So, I did my interview. The guy was really cool, but still when I left there I thought he was just being nice. He's not going to hire me or anything.

Well, to make a long story short, I got hired as a news production assistant for KFWB.

”

WHY I JOINED UNITED SPINAL: I joined the Triumph Foundation's Golden State chapter in August 2019 to inspire others to never give up and keep reaching for great things.



EXTREME SPORTS, EXTREME PASSION

BY SETH MCBRIDE

Darryl Tait is hanging off the uphill side of his snowmobile, wedged in a chute at the top of a mountain and hoping against hope that the weight of his upper body is enough to keep the 500-pound machine from tumbling back down the slope and taking him with it. As he tries, unsuccessfully, to release the straps that hold his paralyzed legs to the vehicle, one thought keeps passing through his head: *I've already been crushed by my own machine once; I really don't want it to happen again.*

That previous incident happened in 2011. Tait had been hustling for sponsorships at a snowmobile exposition in New Hampshire. He had all the skills needed to go professional, but because he grew up in Canada's remote Yukon territory, nobody knew who the hell he was. He figured that landing a backflip — which back then had only been done by a handful of riders — was the best way

to get people's attention. He had already landed a few on a backcountry feature near his hometown of Whitehorse and was confident he could pull it off.

At the last session of the expo, Tait hammered the throttle wide open and hucked himself backwards off the lip

"I guess the feeling I get out of it is just ... joy."

of the jump. "As soon as I got upside down, my snow machine sputtered, quit and stalled on me," he says. The centrifugal pull of the track stopped, which stalled his rotation. The tips of his snowmobile dug in on landing and "like a mousetrap going off, the snow machine bit me from behind." The re-

sult was a T4-5 spinal cord injury.

Clinging to the side of the mountain, Tait is fully aware of the potential consequences should gravity exert its dominance again. "I was exposed to other types of spinal cord injuries and quadriplegics in rehab," he says. "I realized that if I do break my neck,

I'd be starting from square one all over again."

After a few nerve-wracking minutes, one of Tait's friends is able to get to him and pull him off the snowmobile without it rolling. He was about one degree of slope away from another really bad day but manages to make it out with his remaining function still intact. "If anything would have happened, it would have been a heli [evacuation] for sure," he says looking back.

If your immediate reaction is, "What the F are you thinking Darryl? Didn't you learn your lesson?" I get it. But bear

Left: Darryl Tait flies off a jump at the B-Line indoor bike park.
Below: Snowmobiling will always be one of Tait's passions.

with him. Tait did learn a lesson, just not the one you might expect him to.

"I stopped doing extreme sports after my accident for a little bit ... just to play chess or fly a kite or try to do more chill activities, but I was so depressed," he says. "I realized that it's my identity and it's who I am. I can't stop doing it — I just need to do it within reason."

Tait isn't alone. Getting back to doing what they love is priority number one for many athletes who sustained spinal cord injuries in the pursuit of high-risk sports. In the process, they're pushing extreme adaptive sports to an entirely new definition of "within reason."

GETTING BACK TO NORMAL

"I guess the feeling that I get out of it is just ... joy," says legendary motocross racer Doug Henry.

Henry started riding dirt bikes at age 5 and racing motocross at age 15. "I had a rough learning curve. I had my fair share of crashes, but with that I was maybe able to push it a little bit more than some of my competitors," he says. That ability to push it led to three motocross national championships, an Eastern supercross championship, and induction to the Motocross Hall of Fame in 2005.

Being around dirt racing his entire life, Henry was well aware of the risks of his chosen vocation, but he never doubted they were worth taking. He says that he knew the kind of injury his actions could cause. In fact, he had already broken his back once while racing, though without any nerve damage, and after multiple surgeries and a long recovery process, had gone back to racing. "So I really felt like I couldn't use the accident as an excuse to stop doing what I was doing," he says.

Henry wound up in a wheelchair

as a result of another racing accident — in 2007 he broke his back again, this time resulting in a complete SCI at T12. Shortly after his spinal cord injury, a friend showed him a video of Ricky James — another motocross rider who had been paralyzed a few years before — riding an adaptive motocross bike. "It looked to me like something that I could do, and something I wanted to do," says Henry. He



If it is fast and has wheels, Doug Henry will ride it. This bike has a metal frame around it to hold his legs in place and give him a little protection if he rolls.

Photo by Paul Buckley

had family support and friends across all levels of motorsports, and not long after he got out of rehab, Henry began adapting equipment — from dirt bikes, to snowmobiles, to bulldozers and excavators — to make them usable for his new body. "I just kind of kept moving forward," he says.

He had made a living racing motorcycles, but now he had the time to pursue other activities — everything from snowmobiling to mono-skiing, snow

biking, dirt biking, mountain biking and road cycling. Henry already had X Games medals (a gold and a bronze in Supermoto, a hybrid dirt/road motorcycle competition) in his trophy collection, and he's since added a host of others. "I go out and push myself in a certain area or a certain section and try to get a little bit more out of myself, and when I'm able to do that, that's just an achievement that I can't seem to fulfill anywhere else," he says.

DIFFERENT, BUT AWESOME

Everything lined up for Henry to re-integrate into the sport he loved, but for many people a number of factors can make getting back to normal more complicated.

In 2017, Quinn Brett fell while speed climbing El Capitan in Yosemite. Brett was part of an elite subset of big wall climbers that ascend multi-thousand-foot rock faces as fast as humanly possible. In 2012, Brett and another woman had set the woman's speed record on El Cap, climbing a route called The Nose — which usually takes teams two to three days — in only 10 hours and 19 minutes.

She still doesn't know exactly what happened when she fell. She says she was distracted and probably not in the right frame of mind to be on the wall, and somehow, she came off. Whether she forgot to place protection or it failed, Brett fell 100 feet onto a

ledge, bounced off the rocks and landed on another ledge 10 feet farther down — she had multiple broken bones and an incomplete SCI at T11.

Brett is still figuring out her new reality. After her SCI, she says, she didn't really miss rock climbing as much as some other parts of her nondisabled life. "Yes, I love rock climbing, but mostly I

outlet for cardiovascular activity, and a friend immediately ordered her a Reactive Adaptations off-road handcycle to get her back out into the wilderness. Her first trip was eye opening. "I was just so grumpy. Like, I used to speed-run up hills and kick everyone's ass, and here I am barely moving forward," she says.

Slowly though, her perspective started to shift. Part of it was realizing that handcycling was a new sport, requiring new muscles and new techniques. When she was climbing, she'd spent years working her way up harder and harder difficulty ratings. Understanding that same commitment was going to be required for adaptive sports helped get her over her initial grumpiness.

Another turning point was meeting other adaptive athletes and starting to plan rides with them. "The part that I

"Oh, this is cool, I can plan adventures again."

was an endurance athlete," she says. She missed the freedom and the mental and physical satisfaction of being able to move herself through wilderness and difficult terrain.

Post-injury, swimming gave her an



Quinn Brett embraced handcycling when she realized it could be as demanding and difficult as rock climbing was for her.

miss about rock climbing isn't necessarily the rock climbing, it's scheming the big endeavors — like what kind of gear do we need and how can we be efficient and ... where can we stash food so we don't have to carry it, she says. "That really started spinning my head around, like, oh this is cool, I can plan adventures again."

When you are really good at something before your accident, it can be hard to accept that you aren't automatically going to start an adaptive sport in the same place you left off. Roy Tuscany was an aspiring pro skier when he broke his back at T12 and sustained partial paralysis. After the accident, he says, "I was always trying to find what would make the sensation most like what I remember, and actually, the best thing I've done is get into a sport that I didn't do prior to my injury."

He found a new outlet in adaptive surfing. One of the best things about surfing, he says, was that he didn't have any idealized experience from before his injury to compare it to. He was free to enjoy the experience as is, instead of being bummed out that it wasn't the same as before. He says that step number one for getting involved again is to let go of expectations.

When asked what advice he gives to newly injured athletes looking to get back out there after a spinal cord injury, he shares a phrase that has become a mantra, both for him and the foundation he started (see sidebar): "It will never be the same. But it will be awesome."

THE PROGRESSION IS REAL

You only need to spend a few minutes on Instagram to realize how far extreme adaptive sports have progressed in the past few years. Whether its Trevor Kenison airing into Corbet's Couloir on a sit ski, adaptive surfers paddling into some of the gnarliest waves on the planet, Tait breeching 20 foot gaps on his Bowhead mountain bike, or any number of other stomach-clenching feats, today's athletes are doing things that remained the domain of elite-level nondisabled athletes only a few years ago.

One key factor driving this progression is the growing availability of highly-engineered adaptive equipment. Unlike the gear of 20 years ago, today's equipment can mimic some of the natural functions

HIGH FIVES FOUNDATION

Roy Tuscany started the High Fives Foundation to support athletes who've sustained life-changing injuries. Their Empowerment Fund provides funding to help with everything from physical therapy to living expenses, bodywork, travel, adaptive lessons and equipment for athletes pursuing a dream in the outdoor sports community. They also run B.A.S.I.C.S., which teaches injury prevention and smart decision-making strategies in the mountains. For more info, visit highfivesfoundation.org

"It will never be the same," Roy Tuscany tells newly injured athletes. "But it will be awesome."

Photo courtesy of the High Fives Foundation



Getting back to doing what they love is a priority for most people with SCI. Well ... this is what Darryl Tait loves.



LIFE ROLLS ON

Jesse Billauer started Life Rolls On in 2001 to provide opportunities for people with a variety of disabilities to try adaptive surfing and skating. The organization currently hosts WCMX and surfing events in 12 cities across the country, from California to Texas, New Jersey, Georgia and more, each with an army of volunteers ready to make your experience as safe and enjoyable as possible. Check out the website at liferollson.org for a full event list and info on how to get started.

of the human body and withstand the extreme forces that come with such extreme pursuits. “Ten years ago, one of the best sit skis was the Freedom Factory. You weren’t jumping that into Corbet’s Couloir,” says Tuscany. “That thing would break upon impact and you’d end up with the shock somewhere between your thigh and your midsection.”

The advent of long-travel suspension and CNC-milled aluminum frames is helping today’s sit skiers launch the largest jumps in the terrain park, drop backcountry cliffs and charge just about any slope on the mountain. Similarly, with off-road bikes like the Bowhead Reach, adaptive surfboards shaped to respond to the unique weight shifts of seated and prone riders, and custom carbon-fiber seat buckets that can make snowmobiles, snow bikes, two-wheel mountain bikes and just about any other vehicle rideable by wheelchair users, today’s adaptive equipment is allowing

athletes to push themselves and each other, instead of holding them back.

Henry has been a driving force behind many extreme adaptive sports — designing and fabricating new gear and pushing the limits of adaptive snowmobiling, motocross, snow-biking and bucket biking, among others. He says that in addition to the improved equipment, “extreme sports are more accessible to get into as an adaptive athlete these days. ... There are a lot of resources now — just reach out through social media and you can find out pretty much everything you need to know.”

Whether through Instagram and Google searches, or through foundations (see sidebars), would-be adventurers are able to find out what equipment is available, see what others with similar levels of function are able to do, connect with like-minded individuals and receive quality instruction more quickly and more easily than ever before.

ANATOMY OF RISK

Those who get to the highest levels of extreme sports tend to have a slightly different brain chemistry than most humans, and they tend to view risk in different terms. As “This Is Your Brain on Adventure,” an article in *Outside Magazine* that looked at the brain chemistry behind thrill-seeking, explained it: “Thrill seekers tend to be open-minded, intelligent, and curious. They invent new sports, run for office, work on Wall Street, and perform high-stakes surgery. They’re also more likely to bust their skulls open or get hooked on crack.” As it happens, Tait gave himself a pretty nasty concussion last summer when he smacked his head while trying to drift his Bowhead under a steel gate in a Calgary parking lot.

When those without the risk-taking genes see a video of someone riding a monster wave or clinging to the side of a cliff, they tend to focus on the potential consequences, whereas when risk-takers see the same footage, they remember the rush that those activities deliver. A traumatic accident can give a first-hand lesson in consequences, but adventurous types still often view risk as something to be managed rather than avoided.

Even though the inherent risks of speed climbing a 3,000-foot rock wall may be obvious, Brett says she didn’t view her climbing as particularly risky. “For me, risky things are like doing backflips or climbing certain routes that have shitty protection or a really high fall consequence,” she says. “People can diminish risk physically, by preparing and physically getting better, but also by mentally doing things over and over and getting more comfortable.” After her injury, Brett says she doesn’t feel like she’s taking risks as big as “people in wheelchairs who are doing backflips in skateparks.” But still, she was recently out riding Moab’s famous slick rock with Tait and a few other Bowhead riders, and she almost tipped over backwards on one section. “That would have been a pretty high consequence,” she says.

YOU ARE WHAT YOU LOVE

It's safe to say that while spinal cord injury may alter your physical function instantly, it does little to alter the brain chemistry that led you to take risks in the first place. After Jesse Billauer was thrown from his surfboard into a sandbar and sustained a C6 SCI, he wanted nothing more than to get back out into the water. It was 1996 and there weren't many paralyzed surfers, especially quads. He'd been months away from going pro before his injury, but it took years of riding smaller, manageable waves to grow his skills and dial in his gear. Eventually, though, he progressed onto bigger and bigger waves. "After my accident, I didn't stop. It didn't matter whether I was paralyzed or not — I was going to surf what I wanted to surf."

With the help of friends pushing him into the waves, he was soon back

riding waves — like Cloudbreak in Fiji and Sunset Beach on Oahu's North Shore — that were bigger and more dangerous than anything he'd ridden before his injury. In 2015, he won his

"It didn't matter whether I was paralyzed. I was going to surf what I wanted to surf."

first world championship as an adaptive surfer. When asked about any particularly close calls or sketchy situations he's found himself in since his injury, Billauer laughs. "Too many," he says. "I wouldn't call them close calls, I'd call them bad calls." Billauer says he's broken leg and hip bones multiple times riding big waves, each with a six-

month recovery period, and is now a lot more selective about when and what he surfs. "Through injury and age and growing up, that's when I started dialing back a little more."

Henry has had a similar experience. It wasn't the accident, but experience and maturation that caused his mindset to shift. "As I get older, I'm more precise with a lot of the decisions that I make, and I try to be safer. I try to constantly improve my equipment to make it safe. And I still have so much fun with it," he says.

For all of these athletes, risk is a part of their sports, but adrenaline isn't the only goal. The experiences — whether it's the sensation of being completely present and focused, the pleasure communing with the natural world, the satisfaction of rising to a challenge or the simple joy of connecting with your friends — are what keep bringing them back. **MM**



Champion surfer Jesse Billauer is doing his thing at Cloudbreak, Fiji.

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BEYOND THE TYPICAL:

Off-the-Path Parks We Think You'll Love

The dead of winter might not seem like the best time to be thinking about your next domestic adventure but with 62 national parks and over 10,000 state parks spread across the U.S., there is bound to be somewhere you want to visit to escape the cold weather doldrums. It's also a perfect time to book your spring and summer trips before the accessible lodging options fill up. With that in mind, we turned to some of our trusty travel correspondents to turn up some destinations that may be off your radar, but in your wheelhouse.

Explore the Forts of Savannah

BY ASHLEY LYN OLSON

It's said that during his March to the Sea, Union General Sherman spared Savannah, Georgia, because the city was too beautiful to burn. Still, it's hard to go anywhere in Savannah without passing some kind of monument or plaque commemorating the hardships of the Civil War. Large outdoor spaces that were once battlefields today remain open as reminders of what was gained and lost. On the banks of the Savannah shoreline, you can visit the still-standing Fort McAllister, Old Fort Jackson and Fort Pulaski and experience their eerie, ghostly vibes.

It's funny to say that I have a favorite fort, but of the three, Fort Pulaski National Monument really has great accessibility. If you only have time to visit one, this should be it. Located on Cockspur Island, between Savannah and Tybee Island, Fort Pulaski offers a lot to explore, starting with the prisoner burial ground you'll see as you leave the parking lot and head toward the fort.

You'll navigate over a moat on a chained, wooden bridge, and then pass through a short, dark, stone hallway that opens into a piercing bright light, like entering a sports arena. The magnitude of the space is impressive, as the fort



Ashley Lyn Olson enjoyed Fort Pulaski's eerie, ghostly vibe.

is larger than it appears from the outside.

You won't find an elevator to take you to the second floor, where the gun deck is located. But then again, you may not care because completing the loop around Fort Pulaski will take time. Watch out for the deep tracks in the pathway that are used for irrigation and ventilation.

While meandering, it is impossible not to imagine the lives of the people who lived here and the realities they experienced. The architecture of the building alone is incredibly impressive, but don't forget there is a whole system of trails on the other side of the parking lot. A pedestrian path takes you from the paved Nature Trail to Battery Hambright, Old North Pier and the Wesley Memorial. All are camouflaged by palm trees and dense with Georgia wildlife.

Old Fort Jackson National Landmark is smaller and a little less accessible, but certainly should not be overlooked or underestimated. Constructed between 1801 and 1812, Old Fort Jackson was in charge of protecting Savannah from being attacked by sea. The fort has no inclines, and portable wooden ramps are placed along the pathway of travel. Reenactors are often there, sporting traditional attire and weaponry. Furthermore, every day throughout the spring and summer a Dahlgren cannon is fired. With a 9-inch smooth bore and weighing 9,000 pounds, this cannon was designed to take on wooden warships but was powerful enough to be effective against the ironclad vessels introduced during the Civil War.

Fort McAllister Historic State Park rests on Savage Island, just 10 miles south of Savannah, and the fort itself is situated on the banks of the Ogeechee River. Thick wetland brush and intricate waterways made this location harder for the Union Army to defeat during the Civil War.

At Fort McAllister you can see the best-preserved earthwork fortifications of the Confederacy. My first thought when I saw them was that they would also make incredible hobbit holes for denizens of the Lord of the Rings' Shire, and I had a little laugh, but the seriousness of their past was heavy. It was also a little painful that I couldn't get down to the entrance of the earthwork fortifications, and I wished the park offered a wooden ramp instead of a wooden staircase. But I could see them just fine and feel their impact.

Since Fort McAllister is a Georgia State Park, a fee is required and there's no discount for disabled visitors, despite limited access. The property is at sea level and the trail involves wheeling over dirt, crushed rock and grass. When the weather is wet, the trail gets muddy, and the accessible bathroom is across a thick, large lawn. Otherwise, plan ahead and use the one just outside the museum/office. The Magnolia Trail is pretty flat but rocky and connects with a mile-long nature trail. There is accessible camping and a fishing pier as well.



Photo courtesy of the National Park Services

tribe originally named Badlands "mako sica," which translates to "land bad" because of its high temperatures, exposed terrain and lack of water sources. What's not lacking is wildlife.

As you drive into the park, you're happily greeted by hundreds of prairie dogs standing over their burrows. Don't be surprised if you run into a traffic jam! Sometimes herds of bison take over the road. Bighorn sheep can be spotted climbing the breathtaking rock formations. As the sun sets, open your ears to hear the coyotes howl.

It's not only the wildlife thriving in the park. During springtime in the prairie, your eyes are drawn to the vivid purple and yellow wildflowers. A few months later, the summer flowers are as incredible as the spring flowers. As the year winds down, fall is your last option to visit because winter, well, winter is cruel and unbearable.

Badlands Loop State Scenic Byway has multiple accessible trails or lookout points. Some aren't marked as accessible on the park's map but that doesn't mean you can't stop to explore. I was able to maneuver the terrain with minimal support using my lightweight TiLite wheelchair. I was also using the Freewheel attachment to make things a bit easier. For those who are new to the outdoors or don't have good off-road mobility, there are multiple accessible trail options, many with accessible restrooms and parking.

The Not-Bad-at-All Lands

BY MATT TILFORD

When most people think of taking a trip to South Dakota, the first thing that comes to mind is Mount Rushmore. The famed sculpture is definitely worth a stop, but to really connect with nature you can't miss Badlands National Park. Not only is the landscape diverse and astonishing, but the land's history is also fascinating. The native Lakota

Fully Accessible Trails

Fossil Exhibit Trail: This is a half-mile accessible boardwalk loop trail with a 13 foot elevation gain. Along the trail, you'll see evidence of fossils and signage to tell you all about it.

Window Trail: This quarter-mile accessible boardwalk out-and-back trail has a 6-foot elevation gain. There is an amazing skyscraper window view at the end of the trail, hence the name.

Door Trail: This out-and-back trail is a little under a mile



The Badlands boast a stark beauty, such as that seen in its striated rock formations.



Matt Tilford enjoyed many of the park's accessible trails.

long. The first section is on an accessible boardwalk, and after that your wheels touch the earth. The complete trail isn't rated accessible but with the right mindset, equipment, and a spotter, I was able to accomplish it in my everyday wheelchair with my Freewheel and a nondisabled hiking companion.

Cliff Shelf Trail: This is a half-mile loop with sections of boardwalk and 65 feet of elevation gain. It's another trail to get your wheels dirty on.

One of my favorite trails at Badlands National park is the trail I created on my own. You can do the same because a lot of the park is a level hard surface. I wouldn't suggest going off-trail alone unless you know the park and have that type of experience and the right resources/gear. Just know it's possible, and remember to leave the land as you found it.

For those of you who want to stay overnight to experience the park when it's most lively, there are a few accessible options. Badlands National Park has four accessible cabins: one single king, one duplex king and two double queens. Roll-in showers and lower bed heights are some of the ADA accom-

modations that come standard. Site 12 and 20 at Cedar Pass Campground are both ADA RV sites with electricity and water hookups.

If you're not worried about accessibility and looking for an adventure, you're in luck. Badlands has several established drive-up campgrounds with hard-packed, flat surfaces, and backcountry camping is allowed as long as you aren't visible from the road and at least half a mile from the trail.

Badlands National Park is the perfect destination for all ability levels and truly offers something for everyone, no matter where your interests lie and what accessibility options you desire.

Hell's Half Acre Lava Field

BY KARY WRIGHT

Hell's Half Acre Lava Field covers about 150 square miles on the Snake River Plateau in Idaho. Geologists estimate this field, with its large lava chunks and deep holes and cracks, was created just over 5,000 years ago by a fissure vent that opened when the North American tectonic plate passed over a fixed hotspot in Earth's mantle.

The name of the field is thought to have come from early fur traders who used the term Hell's Half Acre to describe any rough terrain. The rocks are made of basalt, which can cool into different shapes and textures. Scientists say the heat that created this lava field is still close to the surface, and also fuels the Yellowstone geysers.

The easiest access to Hell's Half Acre is via a rest stop, about 20 miles south of Idaho Falls and five miles east of Blackfoot, along Interstate 15. As my wife and I traveled along the freeway, the landscape suddenly changed from tillable farmland to huge rectangular boulders the size of houses as far as you can see. "What's all that?" my wife asked, looking at the huge dark boulders that cover the land.

"Let's pull over and see," I said. We pulled into the rest stop, and with my dog in tow, we headed down the Lava Trail System. For the next hour, we were immersed in a totally foreign ecosystem. There was very little soil, and huge rocks were everywhere. The slow-growing junipers, grasses and lichens are small, hardy and can tolerate the extreme summer and winter temperatures.

Off to the side of the trail were deep holes where the lava drained away, and plants could be seen down in these. We saw very little wildlife, but it was daytime, and nightfall is usually much better for wildlife viewing. There were lots of interesting interpretive signs on the trail that shed some light onto the harsh life of plants and animals here.

There is a wheelchair-accessible trail that's a quarter of a mile long, and another half-mile loop that was no problem in my power chair, but its 12% grade may be hard for manual chair users. The trail surface was solid and quite level. The rocks, crevasses and plants are very close as you wind between the ancient lava flow. You can imagine it being very

hot and flowing like a river before cooling and breaking up.

There was even a geocache — essentially a GPS-based treasure hunt location — if you are into that.

Bryce Canyon National Park

BY KARY WRIGHT

While we were camping and exploring some of the out-of-the-way places in Utah, a tip from a local led us to Bryce Canyon National Park. The drive to Bryce Canyon took us through Red Canyon, and we enjoyed spectacular views of the red cliffs and ancient formations. There was even an archway carved through rock that the highway followed.

Once at Bryce Canyon, you can choose to drive around the park yourself or take the shuttle that operates from April through October. The area is busy, and there are quite a few tour busses, especially on weekends, so some drivers may not want to brave the traffic. We chose to drive ourselves around the park for the handiness of loading and unloading my chair. Having a disability placard helped with the parking.

There are 13 viewpoints in total, with four main viewpoints within the first few miles of the park. You need to leave your vehicle to get close to the canyon, but when you do, the scenery is absolutely spectacular. Bryce Canyon is known for having the most stunning sandstone scenery in the American West. The viewpoints have accessible paved trails along the rim with fences for safety. As I wheeled along the trails, it was overwhelming to look out over the cliffs at the amphitheatres (or bowls) carved into the edge of the plateau, with their red, orange and white rock.

The Bryce amphitheater is 12 miles long, 3 miles wide and 800 feet deep. There are hundreds of hoodoos, or rock spires, everywhere. They are found on every continent, but Bryce has the highest concentration anywhere in the world. Hoodoos are formed when erosion wears away softer rock, leaving behind a thin layer of harder material.

There's a lot of wildlife in the area including deer, elk, bears, foxes, coyotes, eagles and condors. Among the plant species are pine trees, junipers, aspen, blue spruce and Douglas fir, to name a few. There are two campgrounds in the park if you wish to stay, and part of the North campground is open year-round. The park also has one of the darkest skies in North America, making it perfect for stargazing, and clear air offers views ranging from 90 to 160 miles on most days.





Hell's Half Acre Lava Trail is a lot more inviting and accessible than the name makes it sound.

Valley Forge

BY JOSIE BYZEK

Over the summer our family rented a cabin at French Creek State Park, located about an hour west of Philadelphia. We thought we'd spend the week hiking, kayaking or swimming, but found ourselves in a history hot spot, as we were close to Valley Forge National Park.

In December 1777, General Washington marched 12,000 tattered, undernourished and meagerly-equipped soldiers into Valley Forge. The war for independence wasn't going so well, and our new nation had lost a string of battles and then its capital, Philadelphia, that fall.

The weather improved in February. In March, General Nathanael Greene became head of the commissary, and provisions started flowing into camp. April saw Prussian officer Friederich Wilhelm Baron von Steuben begin drilling the men into a fit fighting force. By the time the army marched out in June, it's estimated close to 2,000 had died from disease, and more had stolen back to their home states. Those who remained were forged into a disciplined fighting force capable of winning against the British Army.

But on this cheery summer day, the sidewalk leading up to the Valley Forge Visitor's Center has a street fair feel to it as docents in 18th century-themed costumes spin tales to children at story-telling benches and families wander by. The current facility is a temporary fill-in, while the original Visitor Center undergoes a \$12 million upgrade that promises increased accessibility among other new benefits. It is slated to open this spring.

While at the Valley Forge Encampment Store, we purchased tickets for a 90-minute trolley tour. The lift-equipped trolley stops include the Muhlenberg Brigade huts, General Washington's headquarters and the National Memorial Arch. There are parking lots at these sites, but we enjoy guided tours. The Arch was built in 1910 as a simplified version of the Arch of Titus in Rome, but we could see as much of it as we wanted to from the trolley, so we didn't get out.

Muhlenberg Brigade Huts

Upon his arrival at Valley Forge, one of the first things Washington did was order a contest to see who could build huts the fastest. The finished products, smaller than most one-car garages, featured six bunks on each side wall and sheltered 12 men.

The originals are long gone but you'll find replicas scattered throughout the park, and a few rows of them are open to the public at the Muhlenberg Brigade Area, which is named for the long-ago encampment of General Peter Muhlenberg. In addition to huts, you can see the field where the soldiers were drilled until they were no longer merely Pennsylvanians or Virginians or New Yorkers but Americans. If you come at the right time, you can catch reenactments of Revolutionary War-themed events ([calendar at valleyforge.org](http://calendar.valleyforge.org)).

This is my favorite place in Valley Forge to visit. I appreciate that although no battle was fought here, this is where the war was won. A sorry lot arrived at this site in December 1777, but a world-class Army marched out in April.

General Washington's Headquarters

When we disembarked from the trolley, we weren't exactly sure where General Washington's Headquarters was, since all we saw was an early 20th-century train station, a few huts and a modestly-sized stone house across a broad field that we learned was called the Isaac Potts House. Potts' tenant, Deborah Hewes, rented that stone house to Washington, who used it as his headquarters.

The house itself is not accessible and there's probably no way that it could ever be. You can get close to it by rolling on the balcony past the train station to the very long ramp near the rear. Also, a virtual tour of the house is available at youtu.be/jJeY2rZINvI.

The house is humble, although not as humble as the Muhlenberg huts. A few years back our family toured Revolutionary War sites in Massachusetts, including Battle Road, and they were humble, too. And in Independence Hall in Philadelphia our early legislators sat at tiny round tables in unadorned surroundings. I wonder what the men at Valley Forge or their commander would think of our gargantuan military and super-power status today.



General Washington's Headquarters

SELF-IMAGE AND INTIMACY:

BEATING the BODY RUT

BY REGAN LINTON

I have a confession to make: I'm guilty of perseverance. Since my injury 18 years ago, I've been fortunate that my general trajectory in life has been without insurmountable roadblocks. Following the initial wallop of my spinal cord injury and recovery, I've had the privilege of reaching a place in my life where I'm confident, self-assured, productive, happy and have achieved a lot ... all on wheels.

I was therefore completely caught off guard over the last few years when, seemingly out of nowhere, various circumstances completely knocked me on my ass. I felt uninterested in the activities that had previously made me feel healthy, viable and attractive. I found myself feeling stuck and uncomfortable in what I dubbed a "body rut."

Once I was in this funk, it was easier to indulge in methods of escapism that only made it worse: alcohol, not exercising, oversleeping. It felt like I should be able to bounce back, but I had no desire to engage with a body that was making me feel crappy. Worst of all, in the body rut, my brain immediately gave in, "Well, I guess it's all downhill from here ... might as well just let myself fall apart."

It's easy during these ebbs to feel like all is lost. And it can have a negative impact on the very things that might make us feel better: sexuality, relationships, intimacy and more. It's a vicious cycle: Often the things that make us feel good are the very things we want to push away when we're in body ruts.

But all is NOT lost. We all have the potential — with the right support — to move through these body ruts and back to a place of confidence and power. Specifically, we can prevent them from denying our fulfillment as human beings who are sexual, sensual and have great capacity for loving and enjoying our bodies, alone or with others. Before we can even get to the sex or online dating, we have to get other junk out of the way. And most often it requires starting with ourselves.



Photo of Regan Linton by Ted Tahquiechi

We can become uninterested in the activities that make us feel healthy, viable and attractive. But we all have the potential — with the right support — to move through these body ruts and back to a place of confidence and power.

INCITING INCIDENTS

There are countless ways we can end up in body ruts. Perhaps neuropathic pain that suddenly increases or changes can push us into one, or an unexpected physical issue or a gradual change that eventually catches up to us. Even things that seem more a matter of the head and heart — like rejection, heartbreak, disappointment or loss of a relationship — can manifest in the body and make us feel physically unwell.

Emily Yates, a 28-year-old, full-time wheelchair user with cerebral palsy living in Glasgow, Scotland, has experienced numerous ebbs and flows with her body and relationships.

A self-described lover of travel, cats, gorgeous food and pink hair dye, she experienced the same doubts and fears about her body and sexuality growing up that many of us face in our initial encounter with disability. "I remember being 14 and lying in bed, terrified that I would never get a boyfriend or have sex due to being a wheelchair user," she says. Much of the fear dissipated as she grew older and developed confidence, throwing herself headlong into sex-positive and disability-positive advocacy.

Her body rut started after a relationship breakdown at age 24. "My partner at the time felt more like a caregiver than a boyfriend. This shattered my confidence and the strong disabled identity I was so proud of," she recalls. "For a long time, I struggled to trust anyone,

or believe that they could possibly find me attractive. For the first time, I realized how intrinsically linked my sense of sexuality and my sense of worth are. I felt unattractive and almost fearful of being sexual with anyone, which, in turn, affected how I felt about other aspects of my personality, my capabilities at work, and everything, really!"

Stewart Tucker Lundy, a C5-6 quad from Denver who was injured in a 1982 diving accident, finds that body ruts now de-



“When people say you’re lucky to have such a beautiful wife, I say, ‘Dammit she’s lucky! We’re both lucky!’ It’s not just a sweet lady taking care of a guy in a wheelchair. We’re two sexy people.”

— Stewart Tucker Lundy, pictured with his wife, Marci

velop as a function of aging. "As I get older, there's a transition happening again — my body is changing, and it's new," he says. Lundy admits that often the ruts have developed as a result of comparison. With past sexual relationships, he frequently didn't think he was worthy of being with his partners. "I didn't think I was good enough," he says. "I was comparing myself with able-bodied men. I'm not an able-bodied man."

Arianny Ramirez recently married her beau, Pat, after two and a half years of dating. "Definitely communication is so important — talking about your fears — from the beginning, getting it all out there," she says. "You're giving a person a chance to understand what your life is like and if they want to be part of it."

For Arianny Ramirez, a manual chair user from New York City, it was a divorce. Paralyzed at L3 as a teenager in a fall from

a Ferris wheel, she married in her mid-20s. "I stayed in way too long — largely because of my injury," she says. Her body played into her concept of self as a young person. "When I was younger, I never wanted to show my legs because of the muscle mass. I was very aware of those things, I pretty much had issues with my body for a long time."

Single for two years, she struggled to restart dating. "It can be very scary, especially in New York," she says, "everyone is pretty much single here, with a reputation of not settling down. ... Having a disability is an extra level of obstacles, you don't know the reaction of someone when they meet you, how they will react to your disability. It was harder to open up — I had my guard up."

My body rut seemingly came out of nowhere — a result of a beautiful trifecta of a broken relationship, an anal abscess and a knee fracture. My reasonable side said, "These will pass," but another part of me retreated into a negative place. The medical issues and the required break from normal physical activities impacted my physical state. I felt tired. Nauseous. Gross. Even with success in other areas of life, the body piece was leaving an icky residue. Nerve pain resulted in me neglecting my body and sexuality. It was just too uncomfortable to keep dealing with it.

STARTING WITH NUMBER ONE

When your self-image, body confidence or trust have taken a knock, it's not always easy to bounce back. Even after medical issues have resolved or a broken relationship is finally a memory, it can still feel like a chore to do things like getting to the gym, getting yourself dressed or signing up for that dating app.

Often the first step is acknowledging that these body ruts may have a lot more under the surface than we realize, making it harder to pull out of them. For those of us who have experienced a traumatic life event or change that was body-based, life circumstances that may just be a blip in the road for most people have the potential to immediately plunge us into dark places.

Joby Siciliano, a certified massage therapist at the Chanda Plan in Denver, has seen this with countless clients in his 10 years of practicing bodywork extensively with individuals with spinal cord injury, brain injury and other conditions. "Trauma resurfaces that was stored in the nervous system and tissue, until they let their guard down," he says. "A lot of individuals haven't fully dealt with their trauma — they come in willing to do everything and anything to improve quality of life and alleviate discomfort." As is fairly common news nowadays, he sees a lot of nerve pain issues, developing from all different sources, which he treats as entry points into healing.

Through practices like massage therapy, acupuncture, soft tissue manipulation, physical therapy and adaptive yoga, individuals can not only discover relief from the body ruts of chronic pain and other physical issues, but also from the psycho-social-spiritual issues that might be compounding — or compounded by — the ruts.

Many of us may not immediately make a connection between bodywork and our ability to cultivate a personal approach to sexuality or an intimate relationship. But if something physical is getting in the way of our ability to open



Photo by HDC Photo/Hillas Del Caribe

FLIP THE SWITCH

Body ruts often switch off our brains to the possibilities that exist for us at any time, at any point in our journey. Beating the body rut requires that we take some sort of step to re-engage intimately with our bodies.

While some of us may be at the point of engaging in person again — either through bodywork, dating or socializing — there are many other ways to “flip the switch” and reinvigorate our sexual/sensual headspace in a safe way, prior to engaging in person. These methods also allow for setting boundaries and establishing a space over which we have control and power. Essentially, engaging with yourself before you move on to involving someone else.

The internet is a fabulous place to start, as long as you employ some common sense and caution when engaging. You can choose how far down the rabbit hole you want to go.

Erotic writing: The brain is one of the most powerful sexual organs, and words and images are incredibly effective in eliciting your inner sexual being and making you feel interested again. The internet holds a treasure trove of creative writing from talented literary artists willing to share their art, which also come from a sex-positive perspective, for the benefit of our enjoyment and pleasure. A good place to start is Kinkly.com, which includes a page of sex



Photo by Bear Gutierrez

“The nether regions are my playground. I can’t pound you through a wall, but I can give you Bambi legs!”

— Stewart Tucker Lundy

blogs to explore, complete with ratings, reviews and titles.

Websites: EnhancetheUK.org has a variety of resources to explore, including information about sex and disability. Hot Octopuss.com is an identity-inclusive site

ourselves to intimacy, an investment in body-based modalities is a good way to cultivate a healthy relationship with your own body. Often, we may not even realize that a healthy intimate relationship with our own body may be lacking.

To be absolutely clear, bodywork is not — *not* — a sexual experience or practice. However, it creates a safe space to start engaging with our personal physicality, vulnerability and trust ... which are major components of human sexuality and relationships.

For many of us with long-term medical conditions, we often have no choice but to open ourselves and be vulnerable in situations that are not based in personal joy and fulfillment — such as the doctor’s office or emergency room. Creating

with options for toys, readings, and general sex-positive info with an “accessible sex” section. The-BodyIsNotAnApology.com is a self-described radical site with all sorts of content that cultivates self-love and body empowerment. It includes articles on sexuality, disability and other body-positive angles, with many pieces written by individuals with disabilities.

Influencers and social media: There are many folks whose social media presence conveys confidence and charisma, directly focusing on sexuality or not, including Abby Sams, Eddie Ndopu, Rebekah Taussig, Ruby Allegra, Alex

Dacy, Andrew Gurza, Sam Bosworth, Imani Barbarin, Dr. Eric Sprankle, Keah Brown and Crippling Up Sex with Eva. Also the #DisabledPeopleAreHot hashtag brings up a wide diversity of folks with disabilities with that extra little zing of human attraction.

Chatting: If you want to start engaging, there are many chat rooms available to experiment and let your brain go wild with fantasies. Just make sure you set your own boundaries (what are you open to discussing, whether you want to use a fake name and e-mail, etc.) and don’t be afraid to be assertive. Do not take people up on moving out of the chat room to other forums (Snapchat, e-mail or text) unless you are comfortable with it. Definitely be extremely wary of offers to meet in person!

an alternative space where we can surrender *by choice* reminds us that we have that power. We deserve a space where our bodies can be explored and enjoyed through human to human contact ... not just medicalized and treated.

“We are all tactile beings, we all thrive on touch,” says Siciliano. “How we choose to express that can be incredibly scary, or beautiful, amazing and liberating for a lot of people in a lot of ways.”

Beyond bodywork, getting out of a body rut demands an investment in your body and yourself, and a belief that you’re worthy of the attention. “Now I wear dresses all the time,” says Ramirez. “Getting older and more mature, I don’t care anymore. Regardless of how you look, you’re still beautiful, you still



matter, you're still valuable." She regularly makes time for things that make her feel good physically, including manicures and pedicures. "Especially the pedi because it's hard for me to do it for myself. Physically, it's nice to get it done, taking care of yourself and doing something nice for yourself."

For Yates, it has been important to develop a comfortable relationship with herself. "I know that I can manage perfectly fine and

have a brilliant time on my own. I can happily go to a restaurant and sit at a table for one without a care in the world," she says. "There's something about enjoying your own company and being totally self-sufficient that makes sharing special moments with someone you love even sweeter."

Lundy emphasizes the incredible power that comes from investing in yourself and developing robust confidence that doesn't originate with anyone else. "For me it's always been a mindset," he says. "I know the reality of me sitting in this chair, what I look like, my thighs, blah blah blah. But as long as I can put on a blazer and someone rolls up on me and says 'hey, you're looking good, what's up, how you doin,' I know I still got it."

Lundy emphasizes that reframing your personal perspec-

"I know that I can manage perfectly fine and have a brilliant time on my own."

—Emily Yates

tive can counter the effects of a body rut. "If I'm in a sexual rut, I think to myself, I know what I can do to a woman in a way no other guys do," he says. "The nether regions are my playground. To me, giving pleasure is a way to exercise control or power — I can't pound you through a wall, but I can give you Bambi legs!" Most of all, he doesn't allow his confidence to waver. "I know my reality. If you beat up

the reality, then you get into the 'woe is me' category. The reality of my body that I inhabit is not bad. As long as I think of myself in the present as being normal and sexy, I'm good."

THE IMPORTANCE OF SUPPORT

Taking care of your body is an optimal way to start working out of a body rut but seeking additional support outside yourself is often crucial.

After Yates's experience with her breakup, she utilized the support of friends and family who helped her reestablish her confidence and set healthy boundaries without lowering expectations. "In this modern world of Instagram 'likes' and Tinder swiping, I think it's really easy after a breakup to accept

a situation that you wouldn't usually accept," she says. "Most of us are fully aware, even at the time, that we are allowing unhealthy boundaries and are worth much more than that, but it's a tough cycle to break when your self-worth isn't tip-top at a time of heartbreak."

She ended up meeting a new partner — "the kindest man I've ever known" — and now works as a "non-expert sexpert" with Enhance the UK. The user-led organization engages in a variety of disability advocacies including Love Lounge, a Q&A forum that encourages disabled people and their loved ones to write in with any questions surrounding love, sex, dating and relationships.

Through her work with Love Lounge, she engages with many people who are struggling through body ruts that often have less to do with themselves, and more to do with the issues and frustrations of engaging with the outer world. "People often get in touch with us when they are experiencing a body rut through a lack of confidence or heightened vulnerability," she says, "be this through not knowing whether to show their impairment in online dating photos, or cringing at the thought of having to have the 'pain and positioning' chat once again with a new sexual partner."

Often it's related to shifts that disrupt personal routines, and consequently impact trust and confidence. "I think we're all more likely to experience body ruts when we experience change, whether that's the end of a relationship, when braving the dating scene after a move to a new city or, indeed, if we become disabled and the way our bodies move and work changes."

For Ramirez, getting out of the rut came with finding the right dating mechanism. "I started together with my friends. I signed up for Coffee Meets Bagel — it connected you with friends of friends. It wasn't swiping, it was about answering questions, getting connected with someone based on your similarities, not just a photo." There she met Pat, a teacher, who had never dated someone with a disability.

Ramirez was very honest from the beginning about all of her circumstances. "Definitely communication is so important — talking about your fears — from the beginning, getting it all out there," she says. "It helped with my anxiety, saying 'this is what you can expect.' You're giving a person a chance to understand what your life is like and if they want to be part of it." The couple married in December after about two and a half years together.

Lundy has found that having strong friendships with females has helped him to understand more about what they are looking for and what matters to them. "It's so important to get out there and engage with people in general," he says. "I never knew when a woman was trying to be with me. For a long time

I didn't try because I didn't want to misread it."

Learning to be patient, listen, and talk showed him that he could develop great chemistry with potential partners. "My brother would say, 'I'm gonna talk the panties off her!' It's always a possibility, but you have to do it in a tactful way. Us guys in wheelchairs, we can't be that aggressive," says Lundy. "Eventually the right woman will come along, but you have to be patient." Having friends who can provide insight can help build confidence in forging potentially intimate relationships.

Now married for eight years, Lundy and his wife, Marci, work together to actively cultivate confidence. While Marci can be his cheerleader at times, it's mostly in reminding him

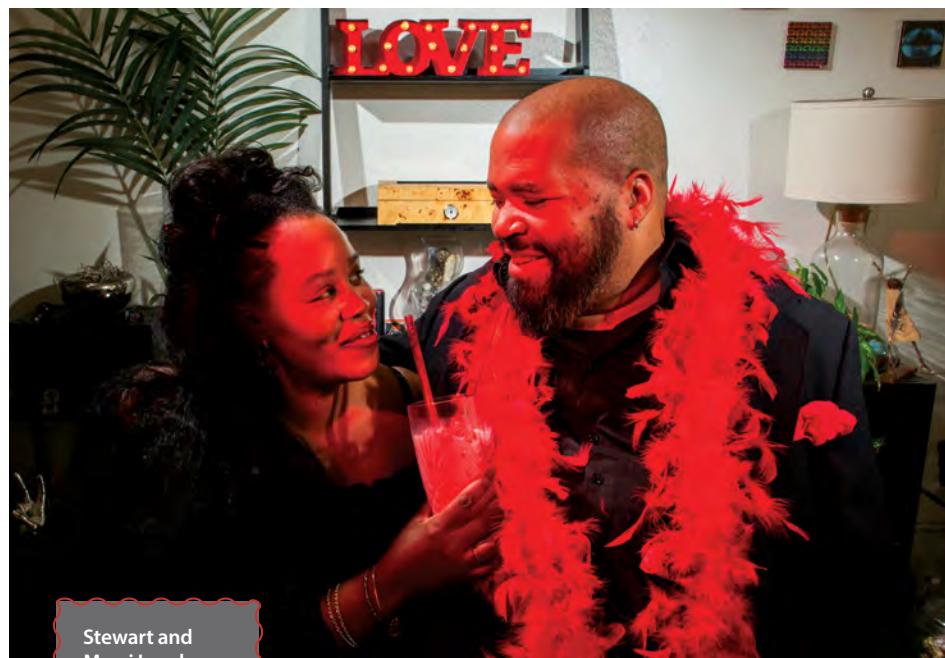


Photo by Bear Gutierrez

Stewart and Marci Lundy work together to actively cultivate confidence, and it shows, says Stewart. "We've met people who say, 'Damn, you make us want to screw because you're so sexy!'"

to maintain his confidence, even when in a rut. "When people say you're lucky to have such a beautiful wife, I say, 'Dammit she's lucky! We're both lucky!' It's not just a sweet lady taking care of a guy in a wheelchair," says Lundy. "We're two sexy people. We've met people who say, 'Damn, you make us want to screw because you're so sexy!'"

In the end, the people around you can be helpful in reminding you to stay true to yourself, even when you're in a body rut. "You've had so many years of being you, you're probably really good at it," says Lundy. "Don't change that midstream."



Body ruts will happen, but they shouldn't relegate anyone to a life that is devoid of body love, sexuality and relationships. Putting trust and value back into your body after a difficult experience — perhaps even one where you feel some measure of body betrayal — is difficult. As Yates reminds us, "It's OK to be at odds, angry or upset with your body, but don't forget all the magic that's in it too."

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HOW TO KEEP the FLAME BURNING

BY EMILY ANN HUPÉ



In October 2012, my husband and I were celebrating our anniversary with a romantic dinner from our local Italian restaurant. As we ate, Stephen stopped talking to look at me. Our eyes met, and we said nothing and everything in those few moments of silence. After 24 years of marriage, our eyes spoke more than any words we could choose.

Suddenly, a bright light and the noise of a door opening interrupted the moment. It was 7:30 p.m. The nurse walked in and yanked us back into reality. Being in the hospital on a special day wasn't new for us, and we were doing our best to celebrate our marriage despite me being sick again.

In 2004, during the delivery of our youngest son, a rare epidural complication caused a lesion at my T11-12 vertebrae, and my new life began. The first five years were the most difficult. By 2009, our marriage was in real trouble.

Chasing a cure, managing my constant medical complications, raising our family and running a business all came to a head that August. We were facing bankruptcy, and the reality that there was no miracle cure for me overwhelmed us both. We had become ghosts of our former selves, floating through whatever fresh hell came at us from day to day.

"I just don't know what to do, Em. I can't do this anymore," Stephen barely whispered one day as we sat in the car at a stoplight. I looked over at him, and I honestly felt nothing. I was completely numb. It had happened; Stephen wanted out, and I wanted it for him. He wanted to move out, but the problem was, we were broke, and I was unable to live on my own while I recovered from spinal implant surgery. Staying together was our only option.

When I was first injured, the doctors and our friends told us we would thrive in

our new life, and maybe even help other couples once I had adjusted. Throughout those first five years, we would hear how inspiring we were despite the many setbacks in my recovery. We didn't feel like we were inspiring or thriving. Honestly, we were barely surviving. We weren't having sex, and most days, we only talked about kids and medical issues. I couldn't remember the last night we'd spent alone together outside of the hospital.

I knew something had to change, so I went about finding small ways to connect despite the chaos of the medical issues I was experiencing. I gave up the idea of thriving post-injury, and I began what I called "surthriving." We had to keep surviving as well as making our relationship a priority.

'SURTHRIVING' 101

We started with small things like coffee and breakfast in the mornings. Stiff and awkward in the predawn light, we sat and tried to remember who we were when we fell in love. Later, we planned small outings and made sure to steer the conversation toward anything other than my injury and the wreckage left in its wake. We crept around resentments, fears and lost dreams.

Slowly, we began to find each other again. Stephen and I had not been intimate for a long time, and it was mainly my fault. I refused to give up on getting back to "normal," and paralyzed me was never in the mood. Sex was hard, and starting slow was the key. When we were together physically, intercourse was not the goal. We needed to start over at the beginning, as though we had just met. I had lost who I was, and I couldn't start again where we had been. Together, finding the new me proved



The author, Emily, and her husband, Stephen.

very exciting. Everything became brand new again and slowly, over time, we began to know each other again.

Marriage and long-term relationships are difficult under the best of circumstances. The U.S. divorce rate is currently around 40%. For those in relationships at the time of injury, statistics predict an increased risk of separating in the first three years. Recovery, and the strain it puts on couples, make keeping romance alive challenging. Rehabilitation and recovery goals focus on the person who has been injured, leaving their partner feeling more like a caregiver and cheerleader. Being a caregiver is taxing and depleting. It can lead to tension and even the end of a relationship.

One of the dirty little secrets about life as the partner of an SCI/D survivor is that resentment is inevitable, especially in the early months and years. You know the injury is not your partner's fault, and they need your love. But a significant detour from the life you expected can be a hard thing to accept. In my case, what would people say if Stephen left me? What kind of soulless dirtbag leaves his paralyzed wife and seven children?

Tiny cracks between couples begin to build, and unspoken needs go unanswered. These building blocks for resentments can grow unchecked. When people return home following rehabilitation, they need to take time to reinvent their current relationships and find new ways to be intimate. For couples that meet their partners post-injury, communication is key to building long-lasting commitments.

JEFF & ARIANE

When Jeff Mitchell met Ariane Newhall at a concert over three years ago, there was an instant connection. Mitchell, an investment specialist and a C6-7 quad since 1994, says he first noticed Newhall's eyes and beauty. "She had such a sweet nature," he says. "I felt comfortable with her right away." The attraction was mutual for Newhall, a medical assistant. "He had such nice looks, and I liked the way he looked at me," she recalls.

Despite living two and a half hours apart, the two Californians began texting and calling each other daily. After a few weeks, they met for a first date. Both shared a love of music, good food, wine and staying active. Soon, they began seeing each other every weekend.

"It was exciting when I met Ariane, and it still is today," Mitchell says. "Ariane takes time to plan special things for us to do together. I'm more spontaneous, which works to keep our time together feeling new and exciting." They keep connected with frequent text messages, funny memes, photos and telephone calls throughout the day. She will text him a few days before the weekend to let him know she's excited to see

Jeff and Ariane shared an immediate attraction, and they make a habit of fanning the flames.



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him. She may pick up something sexy to wear that she knows Mitchell will like. Newhall says, "Jeff will light candles, play romantic music, and we share a bottle of wine cuddling and kissing." Discovering new restaurants and music is a steady source of creative dates for the couple. Adding to the excitement of their weekends together, Mitchell and Newhall share a deep connection and intimacy earned by working through difficult times as a team.

Over the past year, Mitchell has been fighting a complicated UTI, which makes it difficult for the duo to be as active as they would like. Newhall helps with Mitchell's additional medical needs as well as keeping him upbeat and focused on his recovery. "I'm sure to let Jeff feel my love and commitment to him during times of sickness," says Newhall.

Mitchell, in turn, focuses on patience and planning events for when he is well again. "It helps us to know what we are currently going through is temporary," he says. "We have things planned for the future, and it motivates me." Newhall agrees: "Part of keeping the romance is being able to work through situations with the understanding that our love is the most important thing to protect." Mitchell adds, "We

keep the flame alive because we share the same level of chemistry we had when we met. The rest just comes naturally."

That doesn't mean things always come easily. "When Jeff is sick, there is more work, and it can be harder," says Newhall. "We love each other and know the little things don't matter, our love does, and we focus more on the good times." Mitchell is excited about the good times to come. "Something must be working right," he says. "This spring, I'm selling my house and moving in with Ariane."

JOANNE & PAUL

Unlike Mitchell and Newhall, Joanne and Paul Wilde were 15 years into their marriage when Joanne sustained a spinal cord injury at T11-12. Joanne met Paul in 1999 when they worked for the same company in the United Kingdom. "I noticed Paul's thick, long blond hair and blue eyes," Joanne tells me. "He was tall, slim, and his confidence was so attractive." Paul found Joanne's good looks, charming personality and sense of humor intriguing. "We laughed a lot, especially at each other, and we loved being together," says Joanne. After dating, then traveling for a year, the couple decided to move to the U.S., settling in Largo, Florida.

They married in 2002 and welcomed their son, Zak, in 2005. Between work, travel, and being parents, Joanne and Paul were enjoying the simple things in life. The couple focused on ro-

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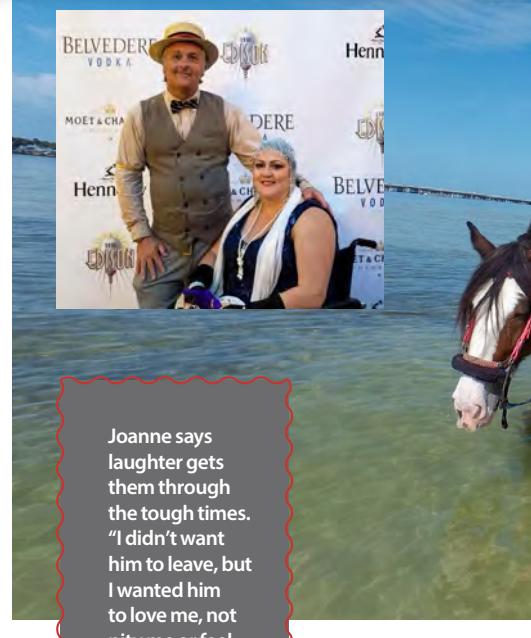
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mance despite being parents to a young son, planning regular romantic dates and making time for weekends away together. They also enjoyed taking cruises and going on family road trips. During one of these trips to North Carolina in January 2014, Joanne sustained a fracture at T11-12 while sledding with Zak.

Paul says he never felt like leaving the marriage following Joanne's injury. "In the beginning, it was harder, but you

work through it, and now it's just normal for us," he says. Still, Joanne admits the thought of Paul staying in the marriage out of obligation has crossed her mind. "Paul is aware of these feelings, and he knows I would hate to have him stay for that reason ... I didn't want him to leave, but I wanted him to love me, not pity me or feel an obligation to care for me."

Joanne lets Paul know how much it means to her that he manages everything



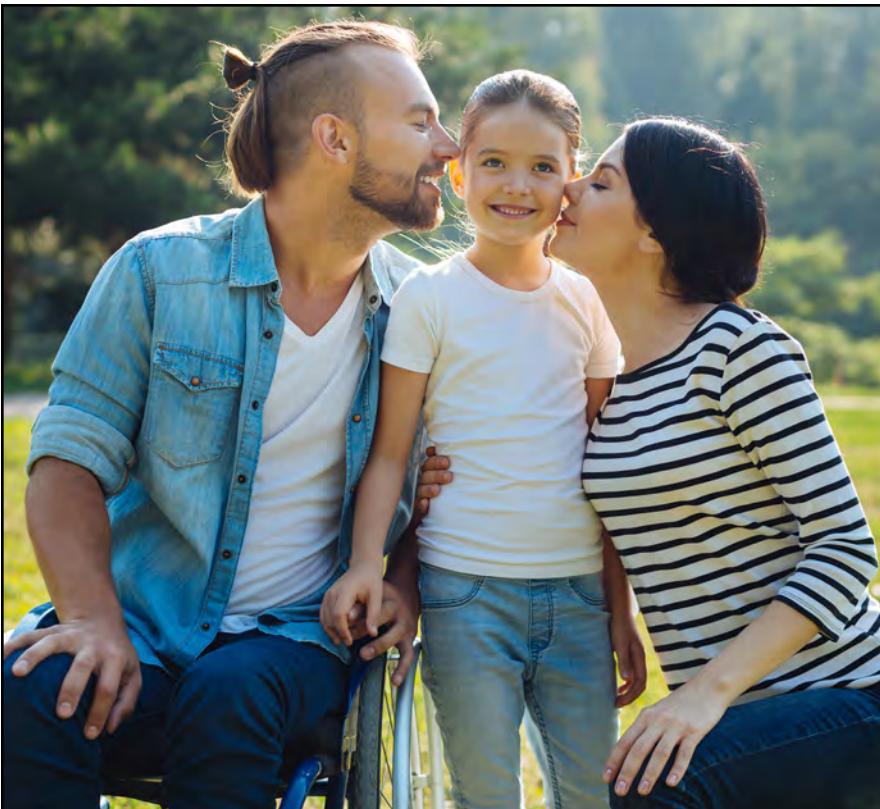
Joanne says laughter gets them through the tough times. "I didn't want him to leave, but I wanted him to love me, not pity me or feel an obligation to care for me."

and keeps the family on track.

"Paul is my rock, although at times he tries to do too much," she says. "I try to remind him that I need some independence." Paul admires Joanne's strength and determination and feels supported by his wife of 20 years. "I always let Paul know how much I appreciate everything he does for us. I remind him he is an excellent husband and father," adds Joanne. Likewise, Paul reassures Joanne of his love for her with frequent text messages, little gifts and flowers. "I don't just love Joanne," he says. "I am *in* love with her."

Paul and Joanne keep their love exciting by shopping for sexy underwear together and booking nights at a local hotel to reconnect. They also text sexy messages to one another during the day. Sometimes Paul will surprise her with her favorite take out.

Although happy with the couple's intimate times, Joanne struggles with her confidence and libido. Confidence was an issue pre-injury, and she tries to remember to focus on what makes her feel attractive when they're together. "I wish I could be more comfortable with sex. I've never had a lot of self-confidence," she says. "I wish I had a stronger libido and that Paul would slow down and listen." Paul is happy with their sex life, although he would like to be intimate more often. "We keep working at it, and that's all that matters. We are close physically, and I like that," Paul adds.



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To learn more about how to open an ABLE account, visit ablenrc.org/get-started.



“I don’t just love Joanne. I am *in* love with her.”

When medical complications sideline romance, the couple adjusts. “We tackle it together and keep smiling,” says Paul. He helps by scheduling appointments, picking up extra chores and keeping Joanne focused on the positive parts of life. Another way the couple helps to maintain passion during these times is to have quiet date nights at home.

“From the time of my accident, we have been open and honest with each other. We also find that laughter is the *best* medicine,” says Joanne. The hardest part for Paul is seeing Joanne in pain and feeling helpless to fix it. “Even though Joanne is the one with the injury, we deal with it together,” he says. “There is nothing we can’t do together. When she’s down, I feel it is my job to keep going and make her happy.”

IT CAN GET BETTER

Stephen and I have come a long way since those early mornings spent drinking coffee and breathing to life our worst feelings. We now find time for nights away in the desert and going away for the weekend with friends. Two years ago, we began to journal weekly. If there is something we need to talk about or want to do, it gets written down. The journal ensures we take time to plan dates and keep communication open. Once a month, we plan an afternoon to go over the journal

and make any adjustments. It’s working for now, and I think our marriage is better than before my injury.

As long as both partners share a deep commitment to each other, are able to communicate and are willing to explore the new reality after SCI/D, there is no reason that love and romance can’t be even more intimate and fresh than it was prior to injury.

This past September, Stephen and I

took a trip to Northern California with some friends. One evening, after dinner, I overheard him talking to a friend about our marriage of 26 years. “How did you do it?” our friend asked, “I mean, you guys have been through so much?” Stephen answered, “I looked at Emily one day and I realized I couldn’t live without her, and I had to figure it out. … We rebuilt ‘us’ from nothing, and now she’s my everything.”

MM

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YOU CAN FIGHT CITY HALL

A Squeaky Wheel Guide to Local Advocacy

BY STEVE WRIGHT

“You can't fight City Hall” is one of the oldest sayings around, often based on a boulevard of broken things such as long-neglected potholes in crosswalks, uprooted sidewalks and other barriers to wheelchair mobility.

Local government might seem like an impenetrable maze, but you don't have to fight City Hall. You can work in a collaborative, non-combative way to get local officials on your side. Call this the Squeaky Wheel Guide — a roadmap to getting your city to remove barriers and promote progressive legislation for people with disabilities.

EDUCATE Yourself

Knowledge is power, and it's easier than ever to power up. Most local governments have a place on their websites where you can type in your address and find out who represents you. While visiting your municipality's website, check out how the city is organized — is it run by a strong mayor or a city manager? Who are the key department heads?

A municipal government's transition and barrier

Justice required public entities that employ more than 50 people to have an ADA coordinator, an ADA policy and a grievance policy. While too few cities have full-time coordinators plus appropriate staff, most at least identify an employee acting in that capacity.

“Unlike any other civil rights laws, the ADA not only requires that an entity not treat people differently because of their disability,” says Matthew W. Dietz. “It also requires these entities to affirmatively modify their premises or policies and procedures to ensure that the person with a disability has an equal opportunity to get the same benefit as a nondisabled person.” Dietz is a founding member and litigation director of Disability Independence Group, a Miami-based nonprofit that promotes recruitment, education and employment of people with disabilities.

“When a complaint or request for accommodation is received, then it will go to a person who hopefully has knowledge of the ADA,” says Dietz. “If the person with a disability disagrees with the finding, then they will have a procedure to go through.”

Although Karen Tamley is now the president and CEO of Access Living, until recently she was the commissioner of the Mayor's Office for People with Disabilities in Chicago. She says it pays to know how to interface with your local government.

“Know what's available to you. Many cities have 311, a line you can call to state your issue. You get a case number so you can track it,” says Tamley, a wheelchair user. Many cities have a smart phone app that you can use to capture your issue in pictures and send it in to be addressed.

It's easy to document things with a camera phone. Take a picture and caption it to precisely explain the issue you are addressing. This will help city inspectors and repair workers to pinpoint the location and impress elected and appointed officials that you meet with.

CONNECT and Get Involved

Once you've done your basic research, it's time to hit the ground rolling: meet your representatives, get on committees, get involved. Tamley says nothing beats con-

Photo by Daniel X O'Neil



Karen Tamley suggests being a persistent advocate, but also building a rapport with officials who may help.

removal plans spell out its goals for accessibility. These documents are public record — meaning you have a right to see and review them. When the Americans with Disabilities Act was enacted, the Department of

necting personally with the elected representative for your part of the city. "They know your neighborhood, so they know who to contact," she says. "We work with aldermen all the time — their staff contacts the proper city office and works to solve a problem that their constituent is having."

Call your representative or councilperson's office and make an appointment. Don't be surprised if after a brief meet-and-greet with the elected official, you are handed off to a staff member. This is not a bad thing. That staffer is the one who will contact city employees

on your behalf. Also, they know what part of the city budget can be used to fix your problem or fund your initiative. Constituent services is their job — they will keep the pressure on the city manager or department head to ensure your issue progresses toward resolution.

Tamley strongly encourages interested advocates to find time to attend public hearings and town halls. Be persistent, but polite. Build up a rapport.

"I'm amazed at how many people don't show up to a city budget meeting or a transit authority board meeting," she says. "You have a captive audience and you have all the staff that can resolve your problem or support your policy initiative right there — be a part of it."

If you want to take your involvement to the next level, getting on a board or committee can lead to even more dramatic results. The more active you become with local government, the more influence you will have over creating positive change.

"People don't understand disability basics. A board or committee can educate city officials by having outside professionals come in and give presentations," says Alex Ghenis, a policy and research specialist at the World Institute on Disability. "If more people engage, it helps amplify the disability voice."

Some progressive cities, such as Seattle, strive to have a person with a disability on every board. If your city has never had a wheelchair user on any boards, it probably has never thought in terms of universal design, inclusive mobility and the budgeting to make those things happen.

Ghenis, a quad, has served on a city board that is

influencing changes in the building code to increase accessibility, such as requiring wide doorways, units with roll-in showers and two elevators instead of one in the basic requirements for new housing.

"Sitting on an advisory board is more effective, in a lot of ways, than doing protests. It can be proactive instead of reactive," he says. "Getting involved can be the key to drafting good policies. Because you are appointed to the board by a commissioner or mayor, you have more access to staff — to get things done."

SEND the Right Message to the Right Person

Craft a complaint that gets results. Accuracy, brevity and conciseness matters. Yes, maybe there are thousands of curb ramps that need repair in your city — but address the high impact ones first. State what your issue is and what result you're seeking. If you are vague, unclear and angry, you will not be setting the stage for allowing officials to help you. State that you will be checking back on progress toward resolving your issue. Resist the temptation to copy every city official under the sun. Doing that is likely to get you dismissed as a crack pot.

Kim Harrison has learned the value of a narrow and focused ask in her years advocating for disability rights in Georgia. Harrison, who has transverse myelitis, focused her energy on broken, obstructed sidewalks and curb ramps. She built a coalition that held a "Roll a Mile in our Wheels" event.

"We got rental wheelchairs and got city officials to go a mile on both sides of a street. They were embarrassed by the conditions," she says. "They were scared because they were so close to traffic without any buffer or protection for pedestrians. They saw how little it took for a wheel to get stuck in a sidewalk crack or a bumpy/poorly constructed curb cut."

Harrison is quick to point out that while this built awareness, it did *not* give the officials the true experience of navigating endless barriers while using a wheelchair for mobility. "We said if you get stuck, you can get up and move around — we can't. One guy got so tired of getting stuck that he got out and started pushing his wheelchair. 'Get back in,' we said, 'we don't have that option and you need to experience this.'"

Local and state transportation officials are holding a meeting in early 2020 to follow up with a plan, budget and timeline for fixing sidewalks.

Like Harrison, Arizona advocate Gina Schuh has found success by tailoring her approach and whom she targets. "A few years ago, I was so sick of access aisle abuse, I asked the legislators in Arizona to make it illegal to park in an access aisle whether you have a permit or not," she says. "I hosted an event for people to meet with their legislators. The law was approved and we worked with cities to amend their parking and traffic codes to



Kim Harrison honed her advocacy skills at United Spinal's Roll On Capitol Hill.

comply. Getting involved is how we get change."

Later, she worked with the Phoenix Police Department to address disability parking abuse.

"We did a video to train police on why they must issue citations," she says, noting that many cops are reluctant to ticket. "We launched a whole campaign about the problems that people with disabilities face."

Schuh's experiences reinforce that city employees often have not had a personal experience with disability, so they are ignorant of needs and uncomfortable asking about them.

STAY COOL. Keep Fighting.

Stay gentle, firm, professional and positive in your communications. If you truly are getting stonewalled, consider going to the media. Have documentation of your problem and all your communications with your city. Social media is another way to get your message out. Tweet at the city, its officials and your council member. Make a factual, not an emotional, Facebook post. Share photos of the barrier in your way on Instagram. Do a blog post on why cities *must* be inclusive and how ignoring an accessibility issue is discriminatory.

"Pick your battles. It will have a higher impact," says Bonnie Lewkowicz, the manager of Access Northern California, a nonprofit that advocates for access to nature and outdoor recreation. She recommends a cool-headed, focused approach. "I could write 20 letters a day, but I'm not going to. I'm going to focus on parks and outdoor entities and do trainings and awareness so staff can better serve their patrons with disabilities."

Lewkowicz says her style is to be direct and not overly confrontational, even when a progressive city is building projects that are negatively impacting access.

"The bike coalition is very strong," she says of her hometown, Berkeley. "A lot of street redesigns have been improving the situation for cyclists but at the same time taking away access for people with disabilities."

Previously, cars and vans parked next to the curb, where a ramp-equipped van could safely deploy onto the sidewalk. To protect cyclists from traffic, the new design moves the parking spaces away from the curb and paints a bike lane between the sidewalk and on-street parking. This means that a van ramp deploys perilously into the pathway of fast-mov-



Bonnie Lewkowicz's style is to be direct but not overly confrontational.

TIPS FROM A PRO

United Spinal Association's Accessibility Services program provides consulting services devoted to making the built environment accessible to people with disabilities. Vice President Dominic Marinelli has worked as a certified accessibility specialist for over 30 years and knows a thing or two about how to effect change.

"A great example of working directly with City Hall is to establish a relationship with the local code enforcement office," he says. "While building officials and inspectors are not responsible for enforcing the barrier removal requirements of the Americans with Disabilities Act Accessibility Guidelines — for buildings designed for first occupancy after Jan. 26, 1993 — they are required to enforce the accessibility requirements of the local building code and existing building code."

Since the early 2000s, building codes throughout the country have mirrored the accessibility requirements of the ADA for both newly constructed and existing buildings, Marinelli explains.

New construction regs require that buildings provide accessible parking and paths from that parking to accessible entrances. Interior building features must include corridors and doors that provide adequate clear width, lowered counters, tables with knee space, drinking fountains with lowered spouts and bathrooms with accessible fixtures.

Existing buildings are required to dedicate 20% of alteration costs to providing an accessible path of travel to renovated spaces within the building. If an existing building changes use, such as a historic warehouse being converted to apartments, the

building must comply with new construction requirements.

Unfortunately, many architects, planners and city officials are either not aware of ADA compliance rules for adaptive re-use, or they are lax in enforcing them. That's why it's important to forge and maintain good contacts — so previously inaccessible buildings become accessible via renovation.

"Many people with disabilities develop a relationship with their Department of Buildings to ensure that accessibility is emphasized in new and existing projects and to discuss ongoing projects," Marinelli advises.



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ing bicycles. Also, because the ramp is at street level instead of curb level, wheelchair users have no way of directly accessing the sidewalk and must roll many car lengths — hoping there are no obstructions — to make it to an intersection where the curb ramps are.

Lewkowicz says a few wheelchair users drove around, showing bike coalition members how the design impeded lift-equipped vans. She is still searching for common ground and working to get the city's bike-pedestrian point person to create a design solution.

Tamley points to a similar battle in her city to show that persistence can pay off. In Chicago, Tamley says the input of the disability community ensured the city heavily regulated micromobility (dockless rental bikes and scooters) in a pilot program. While many cities have suffered from discarded scooters dangerously blocking sidewalks, curb ramps, crosswalks, bus stops and more, Chicago minimized the impact to wheelchair users and pedestrians by tightening rules on locations of use and corralling the devices.

FINISH Strong

You can fight City Hall, but not with fighting words. No matter how long your issue has been neglected, nor how much your frustration has built up, you will not influence decision makers by shaming, scolding or cursing them.

RESOURCES

- Find the Center for Independent Living in your area: ilru.org/projects/cil-net/cil-center-and-association-directory
- The US DOJ website on ADA Titles II (state and local government) and III (public accommodations, aka private businesses): ADA.gov
- Accessibility Services, a program of United Spinal Association, assists property owners and designers as they navigate the myriad accessibility requirements that apply to a facility at the state and federal levels: accessibility-services.com/about-accessibility-services.

When your accessibility issue is resolved, don't forget to praise all those involved with addressing your issue. Formal, written thank you notes may be rare as VCRs these days, but that doesn't mean you can't take a few moments to send an email thanking all those involved. A brief email of praise to a city manager, department head or city commissioner goes a long way.

"We write a generic follow-up letter before we have a meeting, so it is

ready to go right after the event. We say, 'Here's our number, reach out to us any time.' It's important to show that we appreciate their taking the time to get informed about our issue," says Harrison.

A concise, positive, embracing note can break that harmful myth that people with disabilities are only complainers. And the next time you have an issue, your key city contacts will think of you as an active citizen with valuable insights into universal design. **MM**

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PRODUCTS

By Michael Franz

IDENTIFYING THE GAME CHANGERS SO YOU DON'T HAVE TO

Early on after my injury, I faced a dilemma. My main caregiver was about to go on maternity leave, and her replacement had shaky hands. That mattered because at the time I had grown used to shaving with a traditional razor, and I still needed help shaving.

I realized that I had to choose between risking daily injuries to my face or finding a way to shave independently. I searched high and low for a suitable electric razor and sought advice on the pre-Facebook spinal cord injury internet groups. After much trial and error, I figured out how to attach a plastic hook to an electric razor and shave without assistance. I was proud of myself, as it was the first time I'd found a combination of products that improved my quality of life.

Over the course of the nearly two decades that I have been injured, I have encountered countless medical devices, gadgets and tools that were supposed to make my life with a spinal cord injury better. Some of these products have worked very well, while others have failed to live up to their lofty aspirations. With so many products out there, it can be difficult to sort through everything to determine which are worth trying out.

Not to mention, everything has a price, and nobody wants to waste



Dining With Dignity flatware mimics the natural grip of a fork, spoon or knife.

for an adaptive handle for my toothbrush and as much as hundreds of dollars to play Xbox independently.

Fortunately, independence can often be achieved for very

their hard-earned money on something that is not going to work. As a columnist for NEW MOBILITY, my goal is to write about products that anybody with a spinal cord injury can use. I want to find the newest, coolest and most functional products on the market. I will do the dirty work so that everybody who reads this column won't have to.

When I look for a new product, I am interested in a variety of qualities. The most important thing to me is how something will contribute to my independence. As a quadriplegic who requires assistance with many things on a daily basis, I try to identify tasks that I would like to be able to do on my own, or at least be a more active participant in. When it comes to my independence, I would pay almost any price. I have spent as little as \$5

little cost. One line of products that has made a huge difference in my life are the utensils from Dining with Dignity (diningwithdignity.com). Dining with Dignity offers utensils with metal rings that you put your fingers through to mimic the natural grip of a fork, spoon or knife. As someone who struggled with using a U-Cuff to eat, the Dining with Dignity utensils were a total game changer. Dining with Dignity's products start around \$20 each and are well worth the investment.

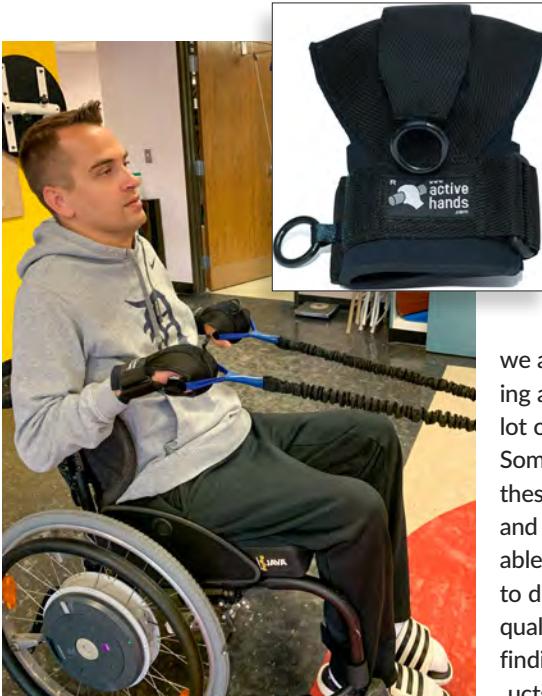
Another vital characteristic of any product I use is how it will affect my health and well-being. Like most everybody with a spinal cord injury, my biggest fear is skin breakdown and the complications that come with it. The integrity of my skin was a constant

source of anxiety, as I developed my first pressure sore while in the ICU immediately after my accident and dealt with them recurring every few years.

After many pressure maps, cushion trials and one flap surgery ("Where to Turn When Wounds Won't Heal," October 2018), a physical therapist recommended the Java cushion made by Ride Designs (ridedesigns.com). Since switching to the Java, my skin has never had even the slightest of irritations. The Java cushion is designed to completely eliminate the pressure in areas prone to breaking down like the tailbone and ischia. This is achieved by cutting out the area under the bony prominences and redistributing weight to the thighs, hips and upper buttocks. By removing the area under the ischia, the Java cushion has the added benefit of reducing heat and moisture buildup that can compromise skin integrity.

Finding products that can help achieve a variety of goals makes purchasing decisions easier. The General Purpose Gripping Aids from Active Hands (activehands.com) are a great

example of a single product solving many problems. Personally, I have used the Gripping Aids for weightlifting, cooking and adaptive sports. Coincidentally,



Workouts are easier with Active Hands.

the Gripping Aids also promote independence and health by allowing users to utilize many things that would be difficult to use with impaired hand function. Cooking healthy foods and exercising are perhaps the two biggest keys to staying healthy while living with a spinal cord injury.

I hope that through this column I will be able to share my experiences with as many products as possible and help improve the lives of the readers of *New Mobility*. As we all know, SCI life can be frustrating and challenging, and it requires a lot of improvisation and adaptation. Sometimes all it takes to overcome these challenges is something new and innovative. With so much available on the internet, it can be difficult to discover reliable information and quality products. I look forward to finding and reviewing the best products for all of us in the months and years to come.

POWER ACCESS

A photograph of a woman in a wheelchair using an automatic door opener. She is smiling and pushing a button on a wall-mounted device. The background shows a modern interior with a large window and some plants.

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IN THE MEDIA

By Teal Sherer

COST OF LIVING: 'THIS IS OUR HAMLET'

I lift my legs into the bathtub and wrap my arms around two stagehands who help me into the warm water. I take a deep breath and think about the upcoming scene. Ani, played by me, recently became a quadriplegic and is being bathed by Eddie, her soon to be ex-husband. Their relationship is complex and heated. As he washes her body, they open up and are vulnerable with each other. Ani shares that even though she "can't feel much of anything there," she still has sexual desires. Relationships, sexuality and disability are rarely explored in entertainment, and it's empowering to say those lines. As the music cue starts, I revolve onto the stage.

Cost of Living, written by Martyna Majok, premiered at the Williamstown Theatre Festival in 2016, had an off-off-Broadway production in 2017, won a Pulitzer Prize in 2018 and is currently being produced throughout the world. In addition to Eddie and Ani, the play follows John, a wealthy graduate student with cerebral palsy, and his new caregiver, Jess. Because Majok's script



Katy Sullivan and Wendell Pierce in *Cost of Living*, 2016 Williamstown Theatre Festival.

Photo by Daniel Rader

reads, "Please cast disabled actors in the roles of John and Ani," these characters are being played by actors with disabilities.

Katy Sullivan originated the role of Ani and has played it 170 times in four separate productions. "When I first read the play, I knew nothing about Martyna, but thought, 'This person has either needed care or been a caregiver. It was too accurate,'" says Sullivan, who is a bilateral above-knee amputee. "Come to find out, she was a caregiver."

Sullivan, who received critical acclaim and numerous award nominations for her portrayal of Ani, has appeared on television shows like *Last Man Standing* and *NCIS: New Orleans*, mostly playing veterans. "Being a woman who is a performer with a disability, so little of what we get to do includes sexuality," says Sullivan. "Having the opportunity to explore a relationship, a marriage in this way ... I mean, 'groundbreaking' is not even the word to use. It's literally worldview changing."

While society teaches us to turn away, not stare and not ask questions when we see a person with a disability, *Cost of Living* insists that audiences look — that they see our bodies and hear our stories. Not only is Ani bathed on stage, but John is showered. Jess takes off John's clothes, transfers him onto a bench, bathes him, dries him, transfers him to his power chair and dresses him. The action feels organic and routine as John and Jess chitchat, enjoying



Photo by Geoffrey Wade

Tobias Forrest delivers an authentic performance of a disabled man.

“Eddie, giving Ani a bath, tries to determine just how much she can still feel. Most of the investigation happens underwater, beyond our sight. Eventually, though, he lifts her forearm to the rim of the tub and plays it like a piano. The effect on her, as on us, is astonishingly erotic.”

— Jesse Green, *The New York Times*

each other's company. “The shower scene is important because I feel the audience deserves authenticity,” says Tobias Forrest, a quad, who was nominated for an Ovation Award from the LA STAGE Alliance for his portrayal of John in the Los Angeles production. “The shape of my body and the danger of falling are honest. Hopefully my performance challenges and changes the perception of someone who assumes they are watching a nondisabled actor pretending to be disabled.”

Regan Linton, the artistic director of Phamaly, a Denver-based theater company for artists with disabilities, will play Ani in the Round House Theatre’s production of *Cost of Living* in Bethesda, Maryland, in April. She also played Ani when the play was workshopped in 2016 as part of the Ashland New Play Festival.

“When I see a play that has nudity in it, I’m initially a little bit skeptical. Why did you put this in? What’s the purpose? Are you just trying to use it as shock value?” says Linton. “I don’t feel that is what Martyna did. She does a really great job of maintaining respect and value for Ani and John in that stripping down. You don’t usually see that in plays about disability.”

When I interviewed Linton, we talked about the logistics of being a para acting in a bathtub, such as how I got in and out of it and how handles were added inside the tub so I could hold myself up and pull off a dramatic moment (no spoilers!). We also shared our appreciation that the scene isn’t sentimentalized. “I love that it is very matter-of-fact, and to be able to say, ‘I don’t have feeling in the same way but that doesn’t devalue my entire person,’” says Linton.

As I wrap up the Canadian premiere of *Cost of Living* and prepare to start rehearsals for the Seattle production, I think about the other disabled actors who have worked on, and who will get to work on this play. “In some ways, this is going to sound stupid, but this is our Hamlet, at least for now,” says Sullivan. “People haven’t written things with this life perspective so richly thought out.” I don’t think that sounds stupid at all.

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DAILY DILEMMAS

By Sheri Denkensohn-Trott

HOW TO HANDLE 'THE HANDSHAKE'

Q. I am a C4 quadriplegic and cannot move my right wrist or fingers. During waking hours, I wear a splint on my right hand to hold that wrist and lower arm in place, and attached to the splint is a cuff that wraps around my hand to enable me to hold things. My problem occurs when I want to shake hands. In professional and personal encounters, when I put out my right hand, the other person often doesn't touch it and just says hello. This makes me incredibly uncomfortable and self-conscious. Should I say something or just let it go at "hello" and a head nod?

Conquering the handshake situation can be awkward and anxiety-provoking for everyone involved. Shaking hands when you meet someone is an etiquette norm in the United States as well as in many other countries. Much has been written about the nature and nuance of "the shake" and how important it is to make a good first impression. A firm shake commonly indicates confidence, while a weak one means you are tentative. The list goes on, with myriad interpretations of the supposed meaning of each handshake. No wonder getting the gesture right can be so stress-inducing.

When you put out your hand to someone you've just met, the other person will likely do one of three things:

1. Ignore your hand and just say hello.
2. Put out their hand and barely touch yours.
3. Shake your hand.

The third scenario is the most unlikely. Instead, you probably will

experience an uncomfortable moment as hands go down and the individual you've just met moves on to the next person for a "normal" handshake. And once you miss that opportunity to shake hands, it is gone.

However, you can alter the dynamic of this encounter and turn it, discreetly, into a teachable moment. Consider that there's a good chance the person you're meeting also is uncomfortable. They may think that shaking your hand will hurt you or be unsure of how to grab your hand. Or perhaps they haven't had the opportunity to shake the hand of a quadriplegic until now.

When a person approaches you to for a handshake, you can preempt any awkwardness by holding out your arm and saying, "Don't worry, you can shake my hand. It won't hurt." By doing so, you are giving that person permission to move forward. The first handshake may not be great, but at least physical contact will occur. And each time it will get easier, especially when you greet the same person subsequently and they become familiar with your preferences.

In some cases, despite efforts, a handshake may not occur. Trying once again to emphasize that a handshake will not hurt is an option. However, it is up to you to decide how many times you want to try before giving up on the ideal handshake. Although it's not easy, try to take it in stride and realize that the other person's discomfort and lack of understanding are likely responsible for the awkwardness and there's little you can do to prevent it. If the lack of

"You can preempt any awkwardness by holding out your arm and saying, 'Don't worry, you can shake my hand. It won't hurt.'"

a handshake is very important because it involves a close friend or coworker, you may want to pull that person aside and talk about the situation. There may be underlying fears that are worthy of discussion. It is worth a try!

Regardless, there is no reason you should be treated differently because you have difficulty moving your fingers and hand. And the splint and cuff should not be barriers. Although that first handshake may not be the best, know that the awkwardness will likely dissipate over time, and you eventually may find relief when it comes to the tradition of shaking hands.

That said, some people whose arms or hands have been affected by injury might not feel comfortable shaking hands, or they might not be bothered by a hello-and-nod greeting. And some might not find themselves in situations where handshaking is called for. In these cases, people should continue with whichever customs they are comfortable, instead of focusing on the handshake.



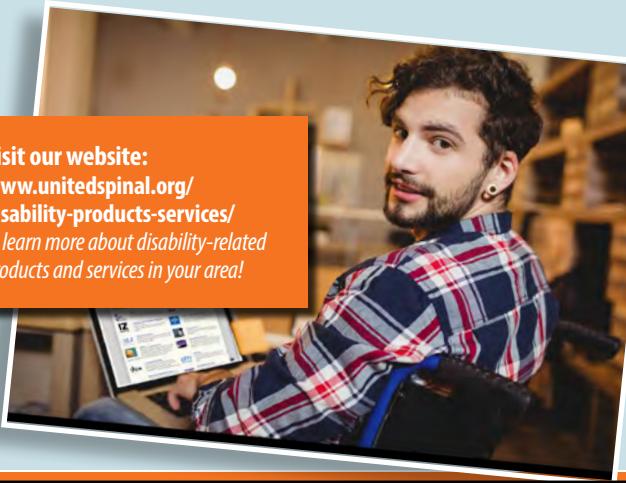
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Can't live without: I try not to use any aids when possible. I rely on my prosthetic leg to get around and occasionally I use a rollator.

What I would change: I would increase awareness about the challenges disabled individuals face every day.

Meet other members or join United Spinal at unitedspinal.org

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1. Chartier-Kastler E et al. 2013

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