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I swore I wasn’t going to write about straws. I’ve read so many opinion pieces and news articles about the various bans popping up all over the west coast that I’ve even lost the desire to make jokes about how much they suck or how their supporters are relying on a straw man argument.

Following the story has been nothing short of surreal. In Washington, D.C., the government is dismantling our healthcare system and stripping away the protections we, people with disabilities, rely on. Two weeks ago, the woman President Trump appointed to oversee community living for the Department of Health and Human Services publicly said she favored “segregation” of people with disabilities.

Let that sink in.

The person who is supposed to be working to better integrate people with disabilities said she wants to separate us from our communities.

And we’re fighting about straws?

Drawing a parallel between the straw bans and institutionalizing people with disabilities might seem heavy-handed, but the two policies share more than a fundamental disregard for our community. They are both evidence of how many of our legislators have seemingly forgotten, or abandoned, common sense.

If more legislators still had their common sense, a bill like the Disability Integration Act wouldn’t be languishing in the halls of Congress. First introduced in 2015, the bill would ensure that people with disabilities have the right to live and receive the services they need at home, instead of in a nursing facility or institution. It makes sense from a financial perspective. It makes sense from a humanitarian perspective. It makes common sense. But apparently, that’s just not enough anymore.

How else can you begin to explain the straw bans?

Reading about all the municipalities that have set down this road, the one thing that becomes clear is that none of them took the time to think about how a ban would affect our community. It’s obvious in every backtracking statement, press release and after-the-fact “clarification.” They saw an easy eco-victory and they pounced.

And at the most basic level, I get it. I want to save the environment. I like turtles. Hell, I don’t know anyone who relies on plastic straws that wouldn’t be perfectly happy to give them up tomorrow if there was an equally functional, more eco-friendly product available. But there isn’t.

We put a man on the moon, you’d think we could build a next-gen straw. It’s encouraging to see creative projects like The Final Straw, a Kickstarter initiative that raised almost $2 million, try to devise such a solution, but until there is something that works just as well for everyone, it’s time for the ban proponents to slow their roll.

So far, very little damage has been done, and you could even argue that the public discussion that has come out of the flawed policy has been a positive. I’ve seen more people trying reusable straws for suitable drinks and fewer restaurants handing out plastic straws willy-nilly like garnishes.

These are good things. Let’s just not put straws before people with disabilities and move forward with a little common sense.
ALEX GHENIS

Alex Ghenis is an active C5-6 quad living in Berkeley, California. He started his disability writing as “Axel Grande,” the dating and relationships columnist for *Life in Action* magazine, and has contributed to *Life in Action* and *New Mobility* for nearly 10 years. Outside of magazine writing, Alex works on disability policy and education around climate justice, disaster readiness and economic empowerment. He is a proud Cal Bears fan and loves spending free time at ball games or relaxing by the San Francisco Bay.

DAWN BOWERY

Dawn Bowery is a photographer from Britain now living in the Laurel Canyon neighborhood of Los Angeles. She enjoyed a long and successful career as a visual effects artist for film and television in London and LA before becoming a professional photographer in 2010. Dawn’s fine art is in private collections around the world. Her portrait coffee table book *California Dreaming: Real Life Stories of Brits in LA* features stunning portraits of an eclectic mix of celebrities, athletes and more. Find her online at Dawnboweryphotography.com.

JOANNE SMITH

As a certified nutritionist who focuses on providing personalized nutrition programs centered on therapeutic lifestyle changes, Joanne Smith specializes in providing services to individuals with disabilities, such as spinal cord and brain injuries, multiple sclerosis and cerebral palsy. She co-authored *Eat Well, Live Well with Spinal Cord Injury & Other Neurological Conditions*, and has hosted and produced two national television programs focused on telling in-depth stories about Canadians with disabilities: the Gemini Award-winning CBC show *Moving On* and *Accessibility in Action*.

*Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org*
More Than an Editor
I, too, worked with Tim for 13 years. I wasn’t asked to add my sentiments, but I must add my tribute as well [“Thanks, Tim,” July 2018]. When I began writing in 2003 for New Mobility, his editing steered me and helped improve my voice. I was always apt to add “inspirational” one too many times to my articles, which he quickly assured me wasn’t in NM’s voice. If only I could’ve met you while we worked together. You are a legend.

Tiffiny Carlson
Newmobility.com

Glad You Made It
Congratulations, Tim, on rejoining the world of the up-sitters! [“Complete Healing: Reclaiming Lost Ground,” June 14 Blog, Newmobility.com.] My longest post-flap “bed vacation” lasted just six weeks, and coincided perfectly with Lent, which I found ironic and humorous that year. Your six-month stint ... I can barely imagine. So glad you made it through and could share this rich experience in words, added to the years of others you have enriched us with. Cheers!

Tom Vander Molen
Newmobility.com

A New SCI Group
We should start a new sub-group of SCI people called “Flap Surgery Survivors.” The war stories would be awesome [“Complete Healing: Reclaiming Lost Ground”]. It might even help deal with the associated PTSD that only us “veterans” would understand, while giving special thanks and recognition to spouses and caregivers. I have a saying I tell everyone who will listen ... “My ass rules the world.”

It other words, the health of my posterior takes precedence over everything else in my life, much to my chagrin.

Pete Smith
Newmobility.com

Callahan is Smiling
Callahan was a great friend of mine. He was so pumped when his great friend Robin Williams purchased the rights to his life story [“Movie Review: Don’t Worry, He Won’t Get Far on Foot,” July 17 Blog, Newmobility.com]. Callahan was always hoping this movie would be made ... hope there is Netflix in Heaven ... and a way for John to get there to see it!

Beth Barclay Livingston
Newmobility.com

Not Sold on Motives
Re. “Aerie Steps Up Inclusive Advertising with Wheelchair-Using Underwear Model,” July 30 News, Newmobility.com: This is probably a result of a lawsuit. It’s next to impossible to get in some of their stores, let alone navigate around them.

Navin Johnson
Newmobility.com

Things are Changing
I’m voting that there are companies out there that are trying to do the right thing versus the lawsuit angle [“Aerie Steps Up Inclusive Advertising with Wheelchair-Using Underwear Model,” July 30 News, Newmobility.com]. My kids are teens — they are growing up differently than we did. Diversity isn’t something you strive for with them, it’s just the way life is. They see these three [models] as “classmates,” not checkboxes on a diversity list. It’s actually happening, people!

Those of us who’ve been around the sun a bunch more times are either going to get on board or get left behind.

John Nicholas
Newmobility.com

Yay for Izzy!
Welcome back Izzy! I’m so glad that you are back [“IZ Adaptive Clothing Relaunches and Expands,” July 3 News, Newmobility.com]. Your jeans are incredible, the fit is perfect for someone in a wheelchair. I can’t wait to order!

Lisa J. Maheu-Gauthier
Newmobility.com

Exciting Progress
This is the kind of study that puts a little smile on my face [“Non-Surgical Recovery of Function: Not a Fantasy,” Research Matters, July 2018]. I sit here typing with a stylus strapped to my completely useless hand. Has this kind of study made it up to Canada yet? Thank you for the article.

Brent James
Newmobility.com
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People with disabilities who require straws to drink are pushing back against increasingly draconian, yet well-meaning, bans that seek to cut down on pollution. “At first, I figured it had to be a joke,” says Brook McCall, a high quad who is the grassroots advocacy manager for United Spinal Association, about recent straw bans. “I’m from San Luis Obispo, a small city in California that prides itself on being ahead of the game on some of these issues. We were the first that outlawed smoking back when people laughed about it, and we’ve banned plastic bags and now charge 10 cents for paper. Locals who don’t have disabilities were talking about fines for servers or jail time for those who hand out straws, which sounds ridiculous, as if they’re serving alcohol to a minor. I thought, calm down, it’s a straw, but that buzz in the media is scary for me because I don’t want fearful restaurants to eliminate something I need as a customer.”

Straws are now available in San Luis Obispo restaurants by request-only, and another California city, Santa Barbara, is considering a fine of $1,000 and up to six months jail time for servers who provide restaurant patrons with plastic, single-use straws. Seattle has a ban, as do a sprinkling of Florida cities such as Fort Myers and Miami Beach. New York City is considering a ban.

Restaurants are joining in, most famously Starbucks, which narrowly escaped the optics of disabled patrons protesting the restriction of single-use plastic straws by releasing an unclear statement that straws will be available, but not specifying what material they’ll be made of. Activists insist straws must be plastic and flexible, so Starbucks may not be out of hot water quite yet.

Why Fix What Works?
Especially since good replacements do not yet exist, straw bans are an example of an accessibility accommodation that works beautifully but is now in danger of being taken away.

To be universally usable, straws must be flexible so they can bend to where a person’s mouth is. Paper and other compostables may disintegrate or melt when used with hot liquids like coffee or soup. Metal or glass straws may cause injuries if a person with a disability like cerebral palsy bites down too hard. Reusable straws may be hard to keep clean throughout a long day of being out-and-about, and bringing your own back-up straws — while something everyone who needs them does or should do anyway — means if you run out or forget to stock up, you are out of luck.

As Disability Visibility Project’s Alice Wong, who has spinal muscular atrophy, notes in her essay, “The Last Straw” [Eater.com], “Plastic straws are ubiquitous, whether we like it or not. Once you have something that provides access, it is difficult and harmful to take it away from a marginalized community that depends on it. I live in a world that was never built for me, and every little bit of access is treasured and hard-won. Bans on plastic straws are regressive, not progressive.”

Seattle’s ban, notably, exempts people with disabilities who require straws. But if that ban is successful, it would become increasingly hard to find an establishment that keeps some on hand in case a customer who needs one wanders in. Some activists, joking-not-joking, muse they can see the day when single-use plastic straws are only available with a doctor’s prescription and for a high price out of a medical catalog.

Meanwhile, today, some who ask for drinks with straws in a locality where that is still legal report they are being eco-shamed. “I live in Portland now, where people pride themselves on being forward thinking. When I’ve asked for a straw, though, I’ve been chastised and told management doesn’t really want to pass them out. I have to point out that I actually need the straw to drink,” says McCall. “They’re trying to be as environmentally friendly as possible but forgetting about people’s needs and customer service. Recently I requested a straw and was told, ‘We’ll give you this one, but in the future, you could limit your usage.’ Seriously, I’m a C4 quad buying an overpriced drink in a place with four milk alternatives. I’m not the one who deserves a lecture on social consciousness. Not allowing me a straw is like serving a plate of pasta without a fork. It doesn’t make sense.”

Straws Aren’t Even the Biggest Problem
Perhaps if banning plastic straws would significantly cut down on our planet’s undeniable waste problem, these bans and public chidings would be easier to take. But there are undeniably other items that
Recently I requested a straw and was told, ‘We’ll give you this one, but in the future you could limit your usage.’ Seriously, I’m a C4 quad buying an overpriced drink in a place with four milk alternatives. I’m not the one who deserves a lecture on social consciousness.”

could be banned first that would have a greater impact and not infringe upon the rights of people who use straws for their disabilities to take a drink.

In the Ideas.Ted.com article “What Plastic Item Would You Love to Ban?” 15 ocean experts who are also TED speakers named microfibers like those found in yoga pants; straps used in shipping; grocery and other plastic bags; all single-use items associated in take-out and restaurant dining (of which straws are only a part); microbeads found in products like exfoliants and Styrofoam; and all petroleum-based plastics.

"This means inventing bioplastics and other materials that don’t persist for decades or degrade into harmful substances," said TED Talker David Gruber about that last point ["Glow in the Dark Sharks, and Other Stunning Sea Creatures"]. "I’ve seen plastics of all kinds polluting the most remote waters and beaches in the world. We need a ‘Manhattan Project’ for plastics: an initiative that drives people to invent similar materials that aren’t harmful to life in the ocean. If we’re smart enough as a species to put a lander on Mars, why can’t we invent good replacements for plastic?"

Which underlines a main problem with straw bans. Since no good replacement for plastics is on the table, these bans, while feel-good to many who care about the environment, can’t accomplish the long-term change their proponents hope they will.

Another TED Talker, Chris Jordan ["Turning Powerful Stats Into Art"], said it like this: "I see the whole public conversation around plastic straws as a shot of morphine into our collective veins to avoid facing what actually matters." He goes on to list an alarming number of polluting items, from pleasure boats to highways, and notes how overfishing is decimating ocean creatures. "So, my proposed ban is: this conversation. Let’s quit pretending that plastic straws even make the list of the top 1,000 problems we should be discussing, and perhaps we can begin to summon the courage to take a deeper look at our culture — and ourselves," he concludes.

These ocean experts highlight environmentally sound reasons why the disability activists pushing back on straw bans deserve our community’s full and complete support. Banning plastic straws probably won’t save a single whale, but will lead to the discomfort and possible dehydration of people we interact with every day. Yes, the earth needs to be saved. But solutions that feel good for some, yet water down the freedom of others, are not solutions. They’re distractions.

— Josie Byzek

United Spinal Association produces more than 30 brochures and pamphlets on subjects like Disability Etiquette, Fire Safety for Wheelchair Users at Work and Home and Understanding the ADA. You can download them for FREE or order printed copies on our website at www.unitedspinal.org
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CHAPTER NEWS

ENDURANCE SWIMMER TRENT THEROUX RAISES $100,000 FOR BOSTON CHAPTER

On August 11, triathlete and open-water swimmer Trent Theroux attempted to swim the 21-mile span of the English Channel as a fundraiser to benefit Rise Above Paralysis, the Greater Boston Chapter of United Spinal Association. The swim titled Back to Britain was his third fundraiser, following Back to Block and Back to Newport.

Unfortunately, high waves and choppy conditions forced Theroux to abandon his effort after completing 11 miles in just over three hours, but he had already raised tens of thousands of dollars for the organization.

The channel swim is considered one of the hardest endurance tests in the world. “It’s quite the endeavor,” says Doug Frey, the president of the board for the Greater Boston Chapter. “Ten times as many people have climbed Mount Everest as have swum the English Channel.”

Theroux came to endurance swimming after sustaining a spinal cord injury when he was hit by a boat while out kayaking near his Rhode Island home in 2002. His injury was incomplete, and following a lengthy recovery, Theroux regained most of his pre-accident function. During his rehabilitation, he made a list of physical goals, from lifting his children to competing in an Ironman to completing an unprecedented ocean swim.

Theroux’s accident opened his eyes to both the debilitating cost of medical equipment necessary after a spinal cord injury, as well as the important work being done by Rise Above Paralysis. He chose to use a pair of open water swims — one using only the backstroke — as fundraisers to benefit the spinal cord injury community.

Frey estimates that Theroux has raised more than $100,000 for the organization. Proceeds for two swims were earmarked for durable medical equipment and the third for vehicle modifications. The funds have allowed the chapter to give grants of up to $2,500 to help individuals with qualifying needs.

“Trent initiated this campaign and he has done virtually all of the fundraising himself,” says Frey. “He is a world class athlete and a caring, giving person. It is phenomenal for him to offer to do this for us! We, as a chapter, cannot thank Trent enough for his generosity and commitment to the SCI community.”

FROM UNITED SPINAL

Trent Theroux
For more information on how you can support United Spinal and become a corporate member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
THE PROS OF PROBIOTICS

At any given time, we have trillions of microbes living in our intestines. These are essential to our well-being and survival. Among many other purposes, everyone needs them for proper digestion, bowel function and immune health, and they are even more critical for individuals with conditions such as cerebral palsy, multiple sclerosis and spinal cord injuries, who are at high risk for compromised digestive and/or immune function. Dr. Nigel Plummer estimates that healthy bacteria, or probiotics, make up 50 percent of our fecal matter, produce 2-4 liters of gas per day and constitute 2-3 pounds of our total body weight. The more good bacteria we have in our guts, the better our physical and mental health. Without these healthy bacteria, we would become ill and, estimates say, die within five years of birth.

Initially we acquire probiotics from the birth canal and our mothers’ breast milk, then as we age, through the consumption of fermented foods. Before the invention of the ice box and refrigerator, fermentation was used for centuries by different cultures around the world to not only preserve food, but also support peoples’ health. Fermentation occurs when food is exposed to microbes that consume carbohydrates (sugar) as a fuel source and give off alcohol and acid as a byproduct. These byproducts create an uninhabitable environment for harmful bacteria, thus preventing food fromrotting and ultimately extending its shelf-life.

The gastrointestinal tract is one of the largest immune systems in the body, and maintaining its integrity is critical for immune function. For example, probiotics enhance the normal function of the intestinal mucosa, which in turn decreases intestinal permeability and symptoms of irritable bowel syndrome, as well as decreasing allergic reactions and inflammation, the latter of which wreaks havoc in the body and brain. Probiotics also protect us as they produce substances such as lactic acid and hydrogen peroxide, which stop harmful bacteria from growing in the body, therefore reducing the risk for individuals with neurological conditions who have a tendency to develop chronic bladder and/or respiratory infections.

Furthermore, probiotics help facilitate a wide variety of biochemical processes that impact hormonal, cognitive and central nervous system function. That means these tiny microorganisms have the enormous capacity to affect conditions such as traumatic brain injury, stroke, Alzheimer’s disease, depression, spinal cord injury, Parkinson’s disease and multiple sclerosis.

One of the best ways to support gut health and reap all these health benefits is to eat fermented foods that are loaded with good bacteria. To help enhance your microbiome and in turn support your gut, immune, neural, hormonal and overall health, I highly recommend you consume fermented foods such as yogurt, cheese, sour dough bread, sauerkraut, kimchi, miso, kefir and kombucha several times a week and take a daily probiotic supplement.

When choosing between probiotic supplements, look for a minimum of 15 billion active microorganisms and try to find ones that contain multi-strains (at least five) including lactobacillus acidophilus and bifidobacterium. It’s best to store probiotics in the fridge. Keeping them at eye level is a great reminder to take them every day. Take them at bedtime when your stomach acid tends to be lower so more of the microorganisms will pass into the intestines where they are most effective. If you are taking antibiotics, you can also take probiotics, just ensure they are consumed at least two hours apart.
I have never considered myself to be a disruptive person. The word makes me think of an unruly child in a classroom (I was always too scared to misbehave in school) or someone causing a scene in public (I try my best not to call more attention to myself).

One day a few years ago I was called disruptive. I smiled and welcomed the adjective as one I wanted to add to my identity. Every so often, I think of the word and examine what I am doing to live up to it.

It has become clear to me that we people with disabilities are disruptive by just being. Simply navigating the world in our different and beautiful bodies, and our mobility devices, we are challenging physical barriers and societal attitudes. I get stares while doing everyday things, I get sighs when I request accommodations, I get told NO until I fight to get a YES.

The world was not made for us, but I know I belong in it. It seems every day my civil rights as a woman, person of color and person with a disability are being threatened. So, if my existence is disruptive, then I will make the disruption count and the exhaustion of educating the ignorant worth it.

I can decide to just be, or I can do more — by writing something, creating art, marching in a protest, visiting with my legislators or starting a conversation with a stranger. I can make the disruption count by sharing my story with others and listening to theirs. Pull up a chair. Sit. Tell me YOUR story.

Maybe one day I will not be seen as disruptive but as a person right where she is supposed to be.
GEAR HACKS
By Seth McBride

YARD WORK ADAPTATIONS
If spring is gardening time, fall is yard care time. Like gardening, there’s something soothing about putzing around the yard — gathering leaves, mowing, weeding, cutting back all the growth from a long, hot summer — simple, repetitive tasks outside lend nicely to reflection and stress relief. But, while gardens can be set up with accessibility in mind [“Roll Out There and Garden,” March 2018], making an entire yard accessible, especially if you have any property, isn’t feasible for most. It would take a fortune and some serious earth moving equipment. When you can’t (or don’t want to) make the world accessible, adapting equipment is your best bet. This month, I talked with a couple of wheelers about how they get outside to maintain their personal patch of earth.

Like a Surf Board for Your Yard
Arwen Bird, a para from Beaverton, Oregon, has an interesting way of managing all her weeding and planting needs. She lies down on an elevated platform on wheels to push and pull herself all over her yard, and it works great for any tasks that are low to the ground. “I’ve actually been able to get to places in my yard that I was unable to get to in my wheelchair,” she says.

The idea came about when Bird was dealing with an extended recovery from a pressure sore on her ischial tuberosity a few years ago. She started to dream up ways to garden without sitting, and eventually decided that being able to move around while lying on her stomach would be ideal. Instead of fabricating something from scratch, she saw a modified yard cart as the perfect solution. Yard carts are basically heavy-duty wagons with large casters that are available at most garden and home improvement stores. “It’s already a platform with wheels, and I knew I needed to start there,” she says. She looked online and found a Gorilla Cart for $119 (available at Lowe’s and other retailers).

The Gorilla Cart was perfect because she could easily remove the sides, leaving a flat platform to lie on. Steering isn’t an issue because the front wheels already swivel, so Bird can just pull and push herself in whatever direction she needs to go. To pad the platform, she used a simple outdoor seat cushion, and used the straps that it already had to tie the pad down to the cart.

So was it effective? “Yes, absolutely,” Bird says. “It was as effective as I was hoping, immediately. I was able to go tend to the yard, and after being so confined for nine months [of recovery from the pressure sore], having the cart really restored a sense of agency for me.”

The cart worked so well that Bird has continued using it ever since. The only modification she’s had to make to her original design was to wire some closed cell foam to the sides of the cart under the top cushion to make a cradle for her legs. That way she can swim all over the yard without her legs falling in the dirt.

Go Slow and Make Sure to Reward Yourself
Rob Pollock is a C6 quad who does a lot of yard work. He owns three rural acres near the Lewis River in Washington State, where he lives with his wife and twin toddlers. The setting is idyllic, but living on acreage requires a lot of upkeep during the sunny months. “Mowing, weeding, pruning, watering. Over and over,” says Pollock.

For mowing, Pollock uses a Craftsman riding lawn mower with a hydrostatic transmission that eliminates the need to shift. Instead of a foot pedal, he chose a model that has a lever throttle — one similar to a boat throttle — mounted on the right fender. Even with weak hands,
Pollock can easily operate the lever. The only modification he made was to replace the standard seat with the seat from an old power chair, which he purchased for $30 from a local used wheelchair store. The wheelchair seat has a higher backrest, giving him more stability, and comes with armrests that are especially useful in reducing fatigue from getting bounced around over his ample yard.

Getting the new seat attached wasn’t too difficult. “I had to hack saw off a bit of tubing from the seat,” he says. “Every mower is a bit different. The underside of the new seat is wood, so I just used lag bolts to screw it in place. Eventually the wood will get weak from being in the elements, so I’ll need to do something different.”

While Pollock normally uses a manual chair, for the rest of his yard work he has an off-road power chair that he’s been using and abusing for the past 15 years. The power allows him to hold onto his tools and still get over rough ground.

“For watering, I use a fire hose style nozzle, so I don’t need to squeeze,” he says. He uses a sharp hoe to keep weeds in check. Still, it’s a pain, so Pollock plants ground cover plants where he can to let nature keep unruly growth in check as much as possible. Otherwise, Pollock uses a set of Ryobi 40V electric power tools — extension chainsaw, weed eater, rototiller and hedge trimmer — to do everything else he needs. “Better than a gas motor in my face,” he says.

Pollock’s best advice for yard care, though? “I go really slow,” he says, “and I make sure to reward myself with plenty of beer.”

Besides bolting on a used power wheelchair seat, Rob Pollock says his rider mower didn’t need any adaptations.
VOC REHAB WIN: I pursued Voc Rehab and I jumped through all the hoops they asked me to jump through, and they got me a standing wheelchair.

CAN’T LIVE WITHOUT: My friend who also uses a chair has a jet ski davit crane and we use it to pick ourselves up in our wheelchairs and it swings us over onto his fishing boat.

STAND-UP GUY

Scott Liesch

Scott Liesch crisscrosses the nation representing The Standing Company, trumpeting the many benefits of standing wheelchairs. He sees himself as more than a sales rep: “I want to get chair users up on their feet again.”

The Salesman Travels

For Scott Liesch, an L1 para, this year’s three-day-long Roll on Capitol Hill was essentially a stop on a much longer work trip — the longest since the sales rep has been with The Standing Company. “But it was good because I also traveled with my girlfriend, so we added some personal stuff with business, so that was nice, too,” says Liesch, 53, whose home base is Forked River, New Jersey.

The trip, including ROCH, was structured around personally delivering one of his company’s signature standing wheelchairs to a client in Florida. Liesch likes to tie as many appointments to a drop-off as possible. After leaving Washington, D.C., he met with clients in Raleigh, North Carolina; Columbia, South Carolina; and Macon, Georgia; delivered the chair, and then squeezed in presentations in Tampa and Orlando, before stopping off in Tallahassee and at Shepherd Center in Atlanta. “It’s a lot of good stuff,” he says.

On long trips like this, Liesch drives sitting on a ROHO cushion and hopes hotels are as accessible as they say they are during the reservation process. If a hotel doesn’t deliver on what it promised, Liesch has learned a little discomfort today may earn him a free stay next time.

Recently he booked a Holiday Inn Express because it had a pool lift, but it was broken when he arrived. “There were a couple of other things they messed up on, like the air conditioner was messed up, so I complained about it,” he says. “They lowered my nightly rates and gave me a whole bunch of reward points. All these chains, they all have their own little reward systems. You get so many points and you get free stays.”

Before the 2001 dirt bike accident that caused his injury, Liesch was a truck driver who loaded up, delivered and assembled on-site trailers to construction sites. “It wasn’t something where you just get in the truck and drive from one loading dock to another,” he says. “This was a labor-intensive type truck driving,” and not something he could still do with an SCI.

For a few years he focused on recovery, working out at an
expensive post-rehab gym for as long as he could. “I soon realized that I would be broke before I would be walking,” he says. “And so, I always told people, I’d rather be broke and walking than have a lot of money and use a wheelchair. But I certainly don’t want to be broke and in a wheelchair. So, I gave up the therapy and I did some of my own therapy for a while after that.”

A pressure sore on his left butt cheek laid him up in bed for three years. During that time, he remembered once seeing a young woman using a standing chair and thought a chair like that might help keep his skin from further breakdowns. He Googled standing chairs, which led to where he is today — a rep for the chair he most prefers.

He couldn’t be happier with this outcome. “I love my job. It’s plain and simple,” he says. “I love the company. We’re a small company, it’s personalized. They trust me. I’m my own boss, I make my own schedule, I develop my own contacts and leads and everything. It’s really great.”

LIFE CHANGER
Birth of a Salesman

“When I found out The Standing Company didn’t have any reps on the East Coast, I thought to myself, ‘Geez, I wonder if I could do this job?’ But then I thought, ‘How can I do this being in a wheelchair?’ So, I kind of just dismissed it and I referred the job to a friend of mine who was in sales, but he turned it down.

I spoke with the company at the Abilities Expo, and told them I was considering applying, but just figured I couldn’t do this. That’s when the vice president of the company said, ‘You know, we’ve got other chair users that are sales reps for us. They figure out ways to do whatever they need to do.’ And I said, ‘Let’s say I had to go into a facility, and bring a demo chair in.’ He said, ‘You ask a security guard. They’re usually more than happy to help you out, or something like that. You’ll figure out a way. And when you go to somebody’s home, usually somebody else is always there, a family member or a friend, something like that, or you make sure somebody’s there to help you bring your other chair in the house.’

Scott Liesch stands with Barbara Delia, her husband, Sam, and their grandchildren.

ALL WORK AND SOME PLAY: I usually tie in some pleasure in my travels, whether it’s visiting family or friends or just going anywhere I want. If I want to see something, I just go there.

WHY I JOINED UNITED SPINAL ASSOCIATION: Because of United Spinal’s support group directory, I get to meet a lot of great people. It’s always really, really nice to be around peers, because no nondisabled person knows exactly what we’re going through.
My wife, Kelly, drives away down the dirt road that winds along the wooded slopes of Mount Hood. When the taillights disappear, I’m left in the dark — just me, a sleeping bag, pad, a small bag of kit and my handcycle. My tent and wheelchair I’ve left at home, some 50 miles away. It’s been a long time since I’ve spent a night under open skies, and longer still since I’d been so far away from my wheelchair.

The thought makes me a little nervous. But the air is fresh, the night silent save for the faint rustling of branches in the breeze, and directly in front of me the moon peeks through the forest canopy. I click on my headlamp, crack a can of wine — yes, in Oregon at least, this is a thing — and open up my book, *A Short Walk in the Hindu Kush*. Who cares if I don’t have a wheelchair? This is my happy place.

My life, pre and post disability, has not been short on adventuring. I like testing my limits, being outside and trying to get from point A to B under my own power. And even though the word may conjure thoughts of large expeditions and far off lands, adventure, at its essence, is far simpler than that.

In his best-selling book, *Microadventures: Local Discoveries for Great Escapes*, the British author and adventurer Alastair Humphreys describes adventure as, “A state of mind, a spirit of trying something new and leaving your comfort zone. Adventure is stretching yourself mentally, physically or culturally. It is about doing something you do not normally do, pushing yourself hard and doing it to the best of your ability. You do not need to be an elite athlete, expertly trained, or rich to have an adventure.”

Humphreys developed the idea of microadventures, for which he was recognized as *National Geographic’s* Adventurer of the Year in 2012, as a way to break down the barriers — whether monetary, time, fitness or experience — to adventure. He spent a year in his home country only doing adventures that left from his front door and could be completed in, at most, a long weekend.

The concept is especially appealing for the disability community because it shows that adventure is relative — your level of function, personal finances and how much free time you have don’t really matter. What matters is that you break out of your normal routine, whatever your
“normal” is, push yourself a little, and find a little fun and maybe even some extra confidence in the process.

My idea of a microadventure is to spend a night wild camping and then ride home in the morning. It’s also to sleep a random night in the backyard, or to pack up and do our normal morning coffee routine in a park close to home. Sound silly? Probably, but that’s the point. Having silly little adventures forces you to overcome obstacles and unexpected detours. That they’re contrived doesn’t really matter, the process still builds self-assurance and resourcefulness, and the change in routine often brings small, unexpected joys.

Below are a few ideas for microadventuring, based on where you might do them — in the city, wilderness or wherever. Try one. If you have fun, that’s the point. Try another. If you’re exhausted at the end, that’s also the point. If it’s terrible, blame me. At least you’ll have a story to tell.

Urban

It’s a warm night and I’m in a button-up shirt, racing my handcycle down city streets, trying to keep up with Kelly as she toys with me from ahead, “Ten seconds left on the light, you better make it!”

If tent camping has gotten tame, maybe try a night under the stars.

I make it through the light, arms a little tingly and breathing harder than I should, but a smile on my face. We’re moving at speed, and dinner awaits. Kelly and I have ridden our bikes across a large expanse of the earth, but lately, with a 16-month-old son, it can be difficult to even get out to dinner on our own. So, as we have a babysitter for the night, we decided to combine date-night with a microadventure. We both put on some grown-up clothes, I got on my handcycle and

The Gear Box

Making it easy to get away

I keep a camping box in the basement of the house that has most everything needed for a night of car camping. On a more minimalist adventure, I simply pull out the box, grab what I need, and put it in bags. On my night without my wheelchair, I kept my gear super minimal, knowing I would be riding every ounce of weight home with me. That pack list included:

- Sleeping bag: Down mummy-style for warmth and packability
- Sleeping pad: Ultra-lightweight air mattress
- 4-liter water bladder with drinking tube
- Warm clothes: A synthetic beanie, wool sweatshirt and thin down jacket
- Riding clothes: A tank top and a thin long-sleeve for the morning riding
- Food: Calorie-heavy and long-lasting snacks
- Duffel bag: To stuff everything into in the morning
- Sun block
- Headlamp

All of this gear, minus the clothes, food and duffel bag, typically resides in the camp box at home, with these additions:

- Tent: Most modern camping tents clip onto their poles, making them way easier to setup. If you need to be able to setup from a wheelchair on your own, make sure to get one with a low head height.
- Stove and fuel: A Primus two-burner for car camping and an MSR Pocket Rocket for bike touring and back packing.
- Cookware and dishes: Two each of pots, plates, small bowls, mugs, forks, spoons and butter knives. One small spatula and one sharp cutting knife.
- Pack towels: three microfiber towels of varying sizes.
- Water bladders
- Coffee makers: A simple plastic French press.
- Sun Block, Bug Dope, Dr. Bronner’s biodegradable soap
- Headlamps
- Matches
- Utility knife: A ton of options, we use a Leatherman
- First-aid kit
Kelly bungeed the frame of my wheelchair to her rear bike rack and off we went.

The ride isn't difficult — only three miles each way, but a welcome break from the typical nightly routine of cleaning up and trying to be in bed in time to get eight hours of sleep. We park our bikes on the curb in front of the restaurant, Kelly unhooks my chair and removes the rear wheels from my handcycle to use while we're dining. My shirt isn't even dirty. We sit at the outside bar and sip glasses of wine as we wait for a table.

This isn't my typical idea of “adventure,” but it's out of the ordinary and a fun, easily accessible challenge that we can do in the city. Wilderness doesn't hold a monopoly on adventure. Here are a few more ideas for city slickers.

The Random Map Point
Unless you're already a keen cyclist, this one works better for city dwellers. The idea is as simple as it gets: Grab a map (you control the maximum scope of this adventure by how big of an area the map you use covers), close your eyes, wave your hand around and then jab a finger or knuckle down. Wherever it lands is your destination. Now roll there in your wheelchair, ride there on your handcycle or whatever, just get there by some conveyance that leaves you exposed to the elements and doesn't move faster than cycling speed. You’ll be amazed at how many unexpected discoveries you’ll make along the way. Need something to eat or drink along the way? Stop somewhere you've never been, without looking at any online reviews. I'm 95 percent certain it won't be worse than Applebees.

The Multi-Course Meal
Drinks, appetizers, main course, dessert. You probably know places that do one of these components better than the others, so why not make an expedition out of dinner and do each component at a different place? Foodies do this all the time, so the adventure part is pushing — or taking public transit, really anything that puts you out in a position to interact with the world — between stops.

Wilderness
I pick Kelly up from work on a random Tuesday night. I've packed the car with our camp box and an extra set of work clothes. I haven't told her we're going camping, but when she opens the car door to put her work bag in, I see a quizzical smile come over her face. “Um, what’s happening here?” she asks.

We drive to the woods, slowly leaving more and more commuters behind, until it's just us, the dog, a few fellow campers at a Forest Service site, the trees and a babbling stream. We sit and breathe in the mountain air. When the sun slips behind the hillside, we heat Frito pie on the camp stove. Not long after, we fold the car seats flat, unfold our foam mattresses and tuck in for the night.

In the morning, we make coffee, cold fingers wrapped around warm mugs, and then pack up. An hour later, Kelly is at work and I'm ready for another day, both of us unwound to a degree that is rare for a Wednesday.

From a workday camp trip to waking up before the sun, getting outside into a little patch of wild doesn't have to be a big process. Here are a couple ways to make it happen.

The 5-9 Camp Trip
Worried about going camping for a weekend because you don't know how you'll manage a bowel program in the woods? Don't like the idea of being away from running water and electricity for multiple days? Go for a single night. Apart from any disability concerns, finding time for adventure can be difficult, especially if you're in the thick of adulting. That’s where the concept of 5-9, or the time in between two work days, comes in handy. It’s not difficult to find a weekend free, you just have to use it. There are few places in the country that don't have some form of camp spot within an hour to an hour and a half’s drive. If you have a camp box ready [see sidebar], pick a day that works, and you can be gone before you think of a reason not to.

The Sunrise
This requires waking up really early. I'm not a morning person and understand the pain but, even so, anything is manageable for a single day. Pick a favorite scenic spot with a view to the east and set your alarm. If your morning routine takes a while, do whatever you can the night before. Check Google for the sunrise time, and get up at whatever time is needed to get out the door and to the spot before the sun peeks over the horizon. Then, sit there and watch the
sunrise. One early morning for half an hour of peace and beauty? I’ll take that trade.

**Wherever**

It’s a typical workday morning. Ewan let us sleep in until 6:15 today, so we’re feeling lucky. We start the normal routine — getting a pot of stovetop espresso boiling for Kelly and me, and a bottle of milk warming for Ewan. Except when our preferred fuels are ready, instead of going into the living room, we load up the wagon and head to the bluffs.

A few blocks from our house, there’s a small green space, a bowl cut into the hillside overlooking Portland’s industrial port and the Willamette River. People take their dogs there to run around, but at 6:45 in the morning, we are the only people. I hold Ewan and we watch a bird play in the breeze so Kelly can drink a few sips of coffee. When he gets fidgety, Kelly walks Ewan around and Kona gets the urge to do some fast running for no apparent reason. Even with a boxer tearing through the grass, this is as quiet as our neighborhood gets.

There’s a cool breeze blowing through overcast skies and I sip from my steaming to-go mug. Sure, this puts the micro in microadventure, but some extra fresh air is never a bad idea.

**The Bike Tour**

Like the idea of bike touring but worried about your fitness and carrying a whole bunch of gear? Conscript a nondisabled friend (or a para with enormous arms) to throw your wheelchair in a bike trailer and ride to lunch. If that goes well, do the same thing, but book a room at a place that’s on the far edge of what sounds like a reasonable day’s ride. Some food, water, catheters, meds and a change of clothes are about all you need. You’ll end both days exhausted and can eat whatever you damn well please with no guilt.

**The Picnic**

Feeling old-timey? It’s dumb that picnics are no longer a custom. On a nice day, there are few things better than eating a good meal outside. Breakfast, lunch or dinner — you don’t even need a basket. You can get an insulated reusable grocery bag for $10 or less that will keep any perishables plenty cold until you’re ready to eat them. Find a nearby park, the top of a mountain, even a marina dock, whatever seems right and is easily accessible, and bring a bag of delicious. Maybe somebody will see you, decide it looks like a good idea and all of a sudden, picnics are back.

These ideas are obviously not intended to be a compendium of all possible options, just a few ideas to get the juices flowing. We would love to hear your ideas. If you go out and try a microadventure, we want to know about it. Tag New Mobility on social media, email smcbride@unitedspinal.org or write me an old-fashioned letter to United Spinal Association, 120-34 Queens Blvd, Suite 320, Kew Gardens, New York 11415. Let’s continue the conversation. And remember, there’s always time for adventure.
In their attempts to land roles, actors often say they were born to play a part, but when Santina Muha read the description of “Debbie” in the script for the John Callahan biopic *Don’t Worry, He Won’t Get Far on Foot*, her reaction was even more visceral. “The description was this aggressively cheerful brunette girl who can prove that there’s life after spinal cord injury, and I was like, ‘Holy shit, that’s me,’” she says.

Muha got the gig, and months later, after filming with award-winning director Gus Van Sant and an all-star cast, Muha lived out one of her childhood dreams, rolling down the red carpet at the Hollywood premiere of her first big movie. “It was everything I have been wanting,” she says. “Literally a dream come true.”

Even with the seemingly perfect fit between role and actor, Muha’s success in landing the part was testament to the hard work she has put in building her name as an actor and comedian, and the latest of many signs that it is starting to pay off. When she is not performing in or hosting shows for the Los Angeles theater run by the famed comedy group Upright Citizens Brigade, Muha is filming episodes for the third season of Netflix’s revival of the ’70s classic TV show *One Day At a Time*, reprising her role as “Beth” from season two. She also has a number of smaller projects winding down, including a role as a non-wheelchair user in a mockumentary called *Spinners: Izzy Lyon*.

That’s the kind of packed schedule Muha envisioned for herself when she decided to take the plunge and move to Los Angeles five years ago. Living the life is proving as rewarding as she had hoped. “My goal when I moved out here was to start getting called in for work,” she says. “Now, this is my life every day. I’m not waitressing. I’m not hostessing. I’m not delivering weed. I’m not driving for Lyft. I’m not doing any of that. I’m just focused on creating. And luckily, I’m able to do that.”

**AN ENTERTAINER EMERGES**

Muha grew up as part of a large extended Italian family in New Jersey. Among her earliest memories are watching *The Golden Girls* with her Italian grandmother. Muha’s grandmother could barely speak English, but they both cracked up in response to Bea Arthur’s expressions. “Whenever I made a joke, said something funny or did something funny, it broke the tension,” she recalls. “It added levity. And then it wasn’t sad anymore. That’s something that got ingrained in me from childhood, that if I could make people laugh, I could make the situation less sad … I want to make people happy. And I want to make people laugh.”

Los Angeles offered Muha more opportunities to do just that, and after feeling uncertain following her first visit,
on her second visit she put down roots. “I came out here on a Friday, I signed up for classes at the Upright Citizens Brigade theater and I started class on a Monday,” she says. “Once I started those classes, that was it. I never lived back home again. Never.”

Muha loved UCB, and was getting connected and making friends when a medical emergency landed her in the hospital for three months. Her worries about how she’d cope thousands of miles from her family disappeared when she was inundated with visitors from UCB and her new Southern California friend group.

“It blew my mind,” she says. “It made me feel loved, which I think is really important whether you have a disability or not, whether you’re trying to be an actor or not, but especially in this field. To feel loved is so important because it’s the foundation. It was after that hospital stay that my career really started to pick up, and I think it has to do with the energy that I was able to harness from everybody.”

MORE THAN A WHEELCHAIR
Prior to her hospital stay, Muha had made an appearance on Comedy Bang! Bang!, an IFC television show based on a popular podcast. Soon after Muha got out of the hospital, the show invited her back as a recurring character. “That was really cool because the first time they hired me it was about the wheelchair, but then they were like, ‘Oh, that’s a funny girl. Let’s get her back.’ And that made me feel really accomplished.”

Establishing herself as an actor and not just “a wheelchair” is one of the tricky realities Muha navigates. When she started to hone her standup routine, she avoided wheelchair jokes out of fear of being pigeonholed. “I thought if I did too much wheelchair stuff, it would become my only thing. But now, I’m realizing I need to do it because it’s funny and there’s a — there’s a hole in the world that needs to be filled.”

Muha’s new approach is evident in her standup and it helped her craft her one woman show, That Girl in the Wheelchair. Beth Appel, UCB’s artistic director, has been impressed by Muha’s evolution.

“I’ve seen her perform a ton, and I’ve seen her get huge laughs from comedy that’s completely unrelated to her using a wheelchair,” says Appel. “And I’ve seen her use the wheelchair to make certain moments in shows even funnier than they would be otherwise. She definitely uses it to her advantage comedically when she can, but that’s not the only comedic value that she has.”

Just as she works to balance the “wheelchair stuff,” Muha is equally aware of the responsibility that comes with increased visibility. Looking back on her childhood following her injury, Muha remembers not having wheelchair-using role models to look to. “I couldn’t go to Spencer’s and find any posters [of wheelchair users] to put on my walls,” she says. “There was nobody. Nothing. I really wanted there to be someone, but even more than that, I wanted to be that person.”

“I still want to be that person,” she says. “I realize I’m not getting any younger, so the clock is ticking if I want to be a poster on anybody’s wall, but I’m working on it.”

In January Muha and fellow improviser Fiona Landers rallied a throng of UCB friends and local celebrities to raise over $2,000 for United Spinal Association with a one-night-only event titled “Don’t Just Stand There.” In addition to raising money, Muha wants to raise awareness of some of the obstacles facing wheelchair users.

Headlined by former Sopranos star Jamie-Lynn Sigler, who has multiple sclerosis and served as a monologist, all the event’s entertainers had to take the stage and perform using a wheelchair. “Within 15 minutes of being in the wheelchair they were like, ‘Oh my god, I never realized this theater is accessible, but the other UCB one still needs a ramp,’ and ‘How do you come out of the curtain?’” says Muha. “So just in that short amount of time it really had an impact.”

Muha thinks the approach has wider potential. “My ultimate goal is to have a platform where I can have politicians and celebrities live a day in the life of people with various physical disabilities so that we can start to incorporate the accessibility and the adaptations that we need in everyday life,” she says.

Photos by Dawn Bowery Photography

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An ascending star in both Democratic politics and disability rights circles, Ola Ojewumi stands, or sits (as a power chair user), at the intersection of several identity groups as an advocate for all who are oppressed. She is best known in and around the Washington, D.C., area, where she gained valuable formative experience interning, first with the House of Representatives while still in high school, then with the Democratic National Committee, the Obama White House and Speaker Nancy Pelosi. In addition to advocacy and activism, she founded two nonprofits and has served on the boards of numerous others. In 2017, she received the AAPD Paul G. Hearne Emerging Leader Award.

At 27, she has already established herself as an effective analyst, speaker, writer and advocate for a number of important issues, especially health care, accomplishing what many would consider a lifetime of worthy achievements. But when I mention this to her, she waves it off, saying, “I’m a novice, really. I have so much to learn.”

One thing Ojewumi knows is discrimination, and she knows it from multiple angles. As a power wheelchair user with an obvious disability, a dual organ transplant recipient and cancer survivor, she experiences the kind of everyday discrimination that many New Mobility readers know too well. But as someone who can also stand and walk small distances, she often is the target of invisible-disability bias as well. As an African American, she represents another minority that must wrestle with more than its share of confining stereotypes, and as someone whose parents came to the United States from Nigeria and whose name speaks to her roots, she is often mistaken as an immigrant or non-English speaker. She sees herself not only as an American, but also as someone who is part of a multinational community. But mostly, she is a strong woman who seems destined to make a difference.

**EARLY LIFE**

Ojewumi says she was nondisabled for most of her childhood, but she didn’t move as fast as others. “My parents thought I had asthma,” she says. “Then one day at summer camp when I was in the sixth grade, I passed out, couldn’t keep up with the other kids. My mom drove forever to come get me and take me to a pediatrician, who diagnosed me with a heart condition. Then I had to have both heart and kidney transplants. After that it was wild.”

By wild, as if dual transplants as a pre-adolescent isn’t wild enough, she means that from that moment forward, her eyes were opened to all the identity markers that tend to skew the way we are seen and treated by others, whether we welcome them or not, especially in high school. “I hated high school,” she says, but not for the ‘usual’ reasons. “Don’t get me wrong, I was born and raised in Beltsville [Maryland], one of the richest black communities in the country, but in high school I saw how a zero tolerance attitude toward black girls was the norm that led to many being pushed out of school. If you were not in class by the time the bell rang, you were automatically punished. I ended up getting detention for being caught between classes and would get deductions for being late. I was told, ‘you had a heart transplant, but you should be over it now.’ They knew that fact but still punished me — as if they knew what it was like to be me.”

She points out that educational research shows that black girls are seen as troublemakers who are treated more harshly than white girls for the same infraction. “Labels lead to dropping out, where making money becomes more of a priority than getting an education.”

In her case, race, gender and her hidden disability worked against her (she became a wheelchair user after high school). But she’s quick to add that some of her schoolmates, many of whom come from less affluent neighboring towns, had it tougher. “My school, High Point High School, was also known as Knife Point or Gun Point. These kids went through hell in their own personal lives. Last year a mother was killed in front of her own child.”

**FINDING HER VOICE**

Her own experience plus empathy for oppressed people led her to actively seek ways to help others early in life.
graduated from the University of Maryland, College Park with a bachelor’s in government and politics and was active in the UMD Public Leadership Program. While in college she founded the Sacred Hearts Children’s Transplant Foundation, collaborating with local politicians to provide hundreds of teddy bears to children in hospitals across the United States. On the cusp of graduating, she founded another nonprofit, Project ASCEND, which awards college scholarships to at-risk teens and provides grants that help youth groups advance public service projects not only in the United States, but also in West Africa and Guatemala.

In April, on Tax Day, she braved very cold temperatures in her power chair to speak at an outdoor rally in Washington, D.C., protesting the Trump administration’s tax bill. Passed by Congress, the new tax law gave wealthy Americans the lion’s share of reduced taxes while slashing the Obama administration’s Affordable Care Act and putting Medicaid recipients and people with disabilities in danger. President Trump also issued an executive order that bypasses Congress and endangers the lives of Americans with costly pre-existing conditions, meaning anyone with a serious disability.

Ojewumi is not afraid to speak her mind. As someone who embraced the Obama White House and was nurtured by Democratic Party leaders, she doesn’t hesitate to single out what she sees as an attack on her mentors. “I don’t think President Trump really cares about health insurance. He cares about erasing the legacy of Obama. This is about ego. We are expected to accept millions dying so he can undo what Obama did.”

But Ojewumi is anything but a defeatist. She is a fighter with a bright future. “Yes, I am sick of it all, but I know it will be different in 20 years.”

Those of us with disabilities need a strong voice like hers, and fortunately for us, she already has an impressive start as a well-connected, dynamic leader. As she urged at the Tax Day rally in April, “People with disabilities, people in wheelchairs, our rights matter. Make sure your movements are inclusive of everyone, from every background. We can really change the world together.”

BY CINDY OTIS

Cody Unser is used to the wide eyes and surprised silences she gets when she tells medical students about the time she involuntarily urinated on her partner while they were having sex. It is one of the personal stories Unser, 31, shares as a paralyzed woman when she presents to medical students and professionals about the sexual and reproductive health needs of people with disabilities.

Unser’s work with the medical community started the same way all her advocacy work has since she became paralyzed at age 12 — she saw a problem and decided to use her voice to try to fix it. Unser, whose spinal cord was damaged at C7 by transverse myelitis, has lived and worked all over the country, and no matter where she went, she discovered the same inadequate access to obstetrics and gynecological care. Doctors were woefully unprepared to accommodate her or to answer her questions. With a little research, Unser discovered most medical schools do not have a set curriculum focused on treating people with disabilities.

Since 2016, Unser has traveled all over the country to talk about the sexual and reproductive health needs of people with disabilities to help the medical community be better prepared. Among the places she has presented are the American Congress of Obstetricians and
Gynecologists Annual Clinical and Scientific Meeting, the Council on Resident Education in Obstetrics and Gynecology, the Department of Obstetrics and Gynecology at the University of New Mexico and Oklahoma State University.

"Women with disabilities want to have loving and fulfilling sex lives and to also have families," Unser says. "But there are physical challenges and attitudinal barriers that prevent individuals from receiving proper care."

Most medical offices do not have accessible exam tables for wheelchair users, for example, and doctors often make unfounded assumptions about their disabled patients.

Unser recalls one of the times she had to be lifted onto an exam table at an OB-GYN office. "The doctor came in, and I explained everything about my paralysis. Even after my long explanation, I started spasming and he patted me on the head saying, "There, there. Don't be nervous." Once he did that," she says, "I felt defeated and left the clinic feeling that he didn't listen to anything I had just said. Why should I care about my sexual health if he didn't?"

Incidents like that fuel Unser's educational efforts. "I don't want other girls and young women with disabilities to feel defeated and that they don't matter when they go to an OB-GYN," she says.

During her presentations, Unser spends a lot of time talking with students about the differences between treating nondisabled and disabled women, as well as the range of disabilities. "A woman with a spinal cord injury may have different medical needs and desires than a woman with spina bifida. I tell them they need to be sensitive to these differences," she says. "Many people think that having a disability means that you are not sexually active." Having misplaced assumptions can lead to discriminatory statements and inadequate medical care, according to Unser.

NEW FRONT, OLD PASSION

Before working with the OB-GYN community, Unser worked with Johns Hopkins University to study transverse myelitis and multiple sclerosis and was also part of the embryonic stem cell research movement to bridge the gap between medical researchers and politicians. Her work in disability advocacy in the medical community led to a master's degree in public health at the George Washington University Milken Institute School of Public Health this year.

But Unser's advocacy work began long before. After she was paralyzed from TM in 1999, she created the Cody Unser First Step Foundation. The foundation focuses on raising awareness of TM, advocacy and creating quality of life programs for people with disabilities.

One of the foundation's biggest and longest running initiatives is its adaptive scuba diving training program called Cody's Great Scuba Adventure. Unser, who is scuba certified herself, says diving is "pure freedom from the gravity I feel in my wheelchair every day." Diving was something she always wanted to do before she became paralyzed. Once she felt the freedom of the water after she was paralyzed, she wanted other people with disabilities to have the same opportunity ["Cody Unser, Beauty in Deep," March 2010].

CGSA offers adaptive scuba events all over the country and partners with several disability groups and organizations to get people with disabilities certified in diving, including wounded veterans. Unser's involvement in a study of the neurological and psychological effects of scuba diving on paralyzed veterans led to her induction into the Women Diver's Hall of Fame as the first woman with a disability. Most recently, CGSA started a program at Kennedy Krieger Institute's International Spinal Cord Injury Center to train physical and occupational therapists in adaptive diving so that they can teach their clients.

Unser knows she has a long road ahead of her in her advocacy work. On the medical front, her goal is for any woman with any disability to be able to go into any OB-GYN clinic in the country and access the services without physical or attitudinal barriers. She believes the long-term solution to ensuring proper OB-GYN care will come from having a permanent curriculum on disability issues that can be developed and taught at every medical school and OB-GYN residency program.

Unser also encourages women with disabilities to be vocal about their medical needs. "You have to be your own advocate. No one else is going to know exactly everything that is going on with your body."

After almost 20 years of learning and fighting, Unser is a confident and forceful advocate, undaunted by the scope of the tasks she has set out to conquer. She can see a future where any woman can walk or roll into her OB-GYN’s office and get equal access to the care she needs. "I'm only one person," she says, "but I am determined to make sure it happens."
While lots of people with disabilities talk or joke about a near-future where they can rely on robot caregivers, Kavita Krishnaswamy is working to make that near-future a reality. Krishnaswamy, who has spinal muscular atrophy, is pursuing her doctorate in assistive robotics from the University of Maryland, Baltimore County. Driven by her personal experience with disability and a passion for learning and innovating, Krishnaswamy dedicates her research to projects that increase independence and quality of life for people with disabilities.

Among the many prototypes Krishnaswamy and colleagues have built or proposed are robotic arms that help with repositioning, specialized air mattresses and a motorized commode chair. “She had the idea for an inflatable mattress with independently controllable segments/bladders to help relieve pain from staying in the same position for too long,” says her doctoral advisor, Tim Oates, a professor of computer science and electrical engineering at UMBC. “She developed a software prototype of the accessible control interface, convinced a team of mechanical engineers in their capstone course to build a prototype, and leveraged that into an internal UMBC grant to explore commercialization. I’ve never seen a student so adept at driving from concept to product while galvanizing support from a variety of sources. … Kavita’s drive and ability to get things done are astonishing.”

It is possible that none of these visions would have seen the light of day if Krishnaswamy hadn’t seen a video of a surgeon operating remotely in another country. “It caught my attention,” she says. “If someone can do a remote surgery, then there can be remote caregivers. Even people with disabilities should be able to use an interface to help another person remotely.” This realization inspired her to explore robotics and how the field could alleviate some of the need for caregivers and create more independence for people like her.

Krishnaswamy requires personal care assistants for a large part of her day. Between her mother, who serves as her primary caregiver, and two women who have worked with her for a combined 16 years, she feels lucky to have reliable help. At the same time, she knows first-hand how difficult it can be to find competent caregivers who stay for a long time. “Sometimes I’ve used CARE.com or word of mouth, but I shouldn’t be constantly stressed to figure out who is going to help me for the day,” she says. “I want to lose my stress in that area. I want a good robot that can safely help people with severe physical disabilities and then that wouldn’t be a problem and I would worry less.”

Further complicating Krishnaswamy’s pursuits is her limited mobility. “Because of my physical circumstances, I can’t travel,” she says. “I’m limited to my home. I had been taking classes using Skype or Google Hangouts, but I wasn’t able to network and form research collaborations.” Introducing her ideas to advisors was challenging until she found an enthusiastic and supportive advisor in Oates. Krishnaswamy began to use Beam, a rolling robot that allows users to interactively videoconference with a remote location, to have a telepresence in the classroom and collaborate with classmates from home. She has also been able to use Beam to attend and present at conferences.

FINDING HER VOICE

Krishnaswamy is currently the only woman on a team of six men working on a research collaboration in Switzerland. “I feel like I’m different, but I also feel I am capable of sharing my ideas and skills with them,” she says. “Sometimes I feel intimidated, other times capable. They are a great example because they have never made me feel inferior. I’ve been treated respectfully and they value my intelligence and skills.”

Other situations have not been as welcoming. “Sometimes I was the only woman in class,” she says. “It can be uncomfortable. They don’t know how smart I am. On top of that, add the disability! They don’t seem to understand I have the same amount of intelligence and I am capable. Sometimes, even if professors treat me fairly, the way they speak to me sends a different message. I can tell they don’t have high expectations for me. It’s male-dominated and nondisabled, so I had to work three times as hard to prove I
am capable.” Krishnaswamy credits some of her leadership skills to her female mentors, Professors Janet Rutledge and Renetta Garrison Tull from UMBC, and Professor Patricia Ordóñez at the University of Puerto Rico.

Recently, Krishnaswamy found herself on the other side of the mentor relationship, mentoring a nondisabled man at the University of Washington. When they first met, the student was not planning on continuing his education, but after talking with Krishnaswamy, he changed his plans. Today, he is a graduate student in computer science at Yale University. “I feel proud that I could be a mentor to someone the complete opposite of myself and I can also be a mentor for students with disabilities,” she says.

So what’s next? Krishnaswamy has been selected to participate in this year’s Heidelberg Laureate Forum in Germany, which connects top student engineers and scientists from universities around the globe with the world’s leading scientific researchers. Only 200 people receive the prestigious invite. She has also been invited to participate in the Disability:IN Rising Leadership Academy.

Her long-term goal is to become a faculty researcher. With her work in the field of robotics, we might soon see a transformation in independence and quality of life for people with disabilities. She hopes that society is more aware of people with disabilities and wants to change the perception of what people can or cannot do. Whether she is doing that through her research or by simply being the female force that she is, keep an eye out for her progress and achievements.

For more on her research, visit csee.umbc.edu/~kavit.

WOMEN TO WATCH

ROSE HOLLERMANN: ATHLETE

NAME: Rose Hollermann
DISABILITY: Spinal cord injury
HOME BASE: Elysian, Minnesota
PASSION: Winning championships
FOLLOW: www.teamusa.org/para-wheelchair-basketball/athletes/
Rose-Hollermann
QUICK FACT: As a sophomore at the University of Texas, Arlington, Hollermann won the National Wheelchair Basketball Association Collegiate Player of the Year Award, and led the UTA Lady Movin’ Mavs to their first national championship.

BY SETH MCBRIDE

It’s 2012, with six seconds remaining in the Paralympic semifinal for women’s wheelchair basketball, and Team USA has cut a 10-point deficit to Australia to one. Following two missed Aussie free throws, Rose Hollermann, the youngest player ever selected to a USA women’s wheelchair basketball Paralympic team, rolls to the basket, catches a tough pass and centers herself for a shot. As her front end rides up on her defender’s wheels, she shoots.

The ball bounces off the back rim and falls to the side where her teammate rebounds the ball and quickly sinks a putback layup. But the whistle blows.

Inexplicably, the referee has called a shot clock violation even though the ball clearly hit the rim. There is no review, no consultation with a replay center in New Jersey. Australia is awarded possession and they inbound to seal the win.

“That was a heartbreaking moment for me within my career,” Hollermann says. “It’s probably the toughest loss I’ve ever had. But it was also a really good thing for me to go through, because it motivated me, and it pushed me.”

AN EARLY START

At 5 years old, Hollermann was in a car accident with her mother and three brothers in which she sustained a T11-12 incomplete SCI. By 6, she was starting sports programs at the Courage Kenny Rehabilitation Institute near Minneapolis, Minnesota. “My mom really wanted me to be active and involved in things,” she says. “And she believed that I wouldn’t be able to really find what I loved if I didn’t try all the different sports. So I tried everything.”

Wheelchair basketball, track and field, sled hockey and swimming were favorites of a youth spent in motion. Hollermann first got in a basketball chair when she was 7. At that age, “It’s more of a fun thing. And it’s little chairs, little wheels, all the cute little things,” she says. “But we had a prep team … that’s where I got the foundation for my fundamentals defensively and offensively, learning how to play big-wheel defense and those critical things.”
Of growing up with a disability, Hollerman says, “I don’t remember what it was like to be walking around and all that stuff. So it’s just my norm, which makes it more positive. … In terms of sports, it gives me an advantage, because I’ve been playing and using a wheelchair my whole entire life.”

And Hollermann has certainly exploited that advantage to its maximum benefit. She had already been playing wheelchair basketball for eight years when, at the age of 15, she was invited to her first national team selection camp. She had few ambitions of making the team, but was excited to see what the top level of the sport looked like. As to what struck her the most, she says, “I’m a very competitive person, so just seeing that competitive fire in all the girls, and how committed they are, and seeing a group of teammates that were so passionate about the sport.”

**GROWING UP, QUICKLY**

Hollermann did make the team. But she knew she wasn’t experienced enough to warrant playing meaningful minutes at that level, so she spent the summer of 2011 traveling to colleges and camps to play as much high-level basketball as possible. “That was a great experience for me as an individual,” she says. “I learned how to do laundry. I learned how to cook. I learned how to do all those things.”

It was an early initiation into the world awaiting her after high school when she joined up with Team USA. There, instead of being surrounded by equally immature undergrads, she found herself immersed in a group of strong role models. “I had 11 girls and women that I could look up to. And they were all very respectable, intelligent, hard working, great athletes who were on very good paths in life and took me under their wings and tried to mentor me and teach me.”

Her education was quick. By 2012, Hollermann had already emerged as a role player for the U.S. squad, a 16-year-old that her coaches and teammates trusted enough to play 10-20 minutes a game on the biggest stage in the sport.

**LEARNING FROM LOSS**

The 2012 Paralympics were a bittersweet experience, but Hollermann did what all great athletes do, and used it as fuel to improve her focus and commitment. The biggest hurdles in her continued development, she says, were mental. “The hardest thing was just decision-making, being able to do stuff fast but within control and then being able to make reads and decisions off of it,” she says. “I think it was frustrating at times, because I had the physical ability to do it, I just didn’t have the mental maturity … and I had to learn it.”

Her national team experience eased her transition to college ball. As a sophomore at the University of Texas, Arlington, during the 2015-16 season, she won the National Wheelchair Basketball Association Collegiate Player of the Year Award, on the way to leading the UTA Lady Movin’ Mavs to their first national championship. Her stat line from the championship game — 35 points, nine rebounds and seven assists — sealed her bid for tournament MVP.

Following the national championship, Hollermann immediately went back to work with the national team, which had been having an up and down run since London. But this USA team had the right combination of experience, talent and cohesion. “We just came together. We understood what each other needed. We understood how to communicate through every situation, and we just bound together … and everyone just clicked at the right time,” she says.

Led by players such as Becca Murray, Desiree Miller and Hollermann, who had all been part of the London heartbreak, USA went on a tear at the 2016 Paralympics, outscoring their opponents in the group stage by more than a 2-1 margin and winning the knockout rounds by double digits. A decisive win over Germany capped off the team’s dream run. The final seconds are ingrained in Hollerman’s memory. “There’s three, two, and all the girls starting to cry already on the court, and the buzzer sounds. And the bench storming,” she reflects. “That was great.”

**THE NEXT CHAPTER**

So what do you do after you win a gold medal? If you’re Hollermann, a lot. Now 22, she’s a year away from graduating with a dual degree in elementary education and German from the University of Texas, Arlington. She wants to play professional basketball in Europe, where there’s a coed league in which she could potentially make a living doing what she loves. She wants to go to graduate school, but she’s not yet certain what for. Tokyo 2020 already shines on the horizon.

With 10 of 12 players leaving after Rio, Hollermann has gone from mentee to mentor. The same fire and motivation is still there, but it’s turned more outward now, toward teaching and setting an example for those who don’t yet know what it means to be a champion.
The Environmental Impact of Wheel Life
As a wheelchair user, it can be easy to feel guilty about the waste and impact generated by the large quantity of medical supplies we often need. But there are ways to reduce our impact through smart shopping and conscientious use of our supplies. Eco-conscious wheelers have partners in this fight, as medical supply companies are working to lower their environmental footprint and to reduce waste by donating unsold supplies to nonprofits. Here’s a look at how we can reuse, reduce and recycle to minimize our environmental impact.

Reuse
Sarah Thomas has spina bifida and, like many wheelers, relies on catheters to use the bathroom. Whether latex, silicone or plastic, in order to ensure sterility, every catheter is intended for one use. Once used and thrown away, the catheter joins the rest of the nation’s trash in landfills. On average, Thomas uses about six catheters a day. Multiply that by 30 days in a month, and she would be going through 180 catheters per month — or over 2,000 per year.

Except, she doesn’t use 2,000 per year. Not even close.

“I reuse my single-use catheters, sterilize them myself, and use them over and over until they start to look grungy,” says Thomas. “It probably enables them to be reused hundreds of times. I boil them vigorously in a sauce pan for 20 minutes because my urologist told me this is the standard time to sterilize anything.” The whole process takes time but saves her from wasting those supplies: “I pour out the water in the pan, let it cool, wash my hands thoroughly, splash rubbing alcohol on my hands and gently pry about 20 catheters into a brand-new Ziploc snack bag.” Of course, they don’t last forever, so she opens a new set every couple of weeks — but that’s still almost a 93 percent reduction. When you consider how much less waste that is, there’s no doubt Thomas is making a difference.

Nils Jorgenson, a C5-7 quad, grew up in a family that prioritized reducing, reusing and recycling long before it became a catch phrase. “With my mother, anything that was reusable, she would reuse it,” says Jorgenson. “I grew up in that culture.” Jorgensen carried on his family’s habits when he became an adult, especially when it came to his medical care. He has set up his medical routine to use as few gloves as possible while still protecting himself and his personal attendants. He reuses disposable items if they aren’t dirty. And he keeps sup-
plies clean so they will stay functional as long as possible.

He applies the same approach to his durable medical equipment. He has kept his Bounder power chair running for 12 years thanks to spare parts he found online. Conserving supplies and making them last is a way of life that’s worked well for decades, and one he plans to continue in the future. “It takes planning and organization,” says Jorgenson, “but it can be done.”

Gregor Wolbring, associate professor of community rehabilitation and disability studies at the University of Calgary, stresses that wheelers should not beat themselves up over the increased profile of their environmental impact as long as they are aware and working towards a more sustainable lifestyle. “Disabled people are part of society, they are citizens and have obligations [around conservation],” Wolbring says. As far as living sustainably goes, “Disabled people should do as much as anyone else. Then it will become a habit that also goes to medical supplies as well.”

Reduce

Wolbring believes that company choices should be prioritized above consumer actions when it comes to the environment. “I think it [sustainability] should be done much more on the producer level,” he says. “There should be a system that makes this as pain-free as possible for consumers.”

For example, Coloplast, one of the largest producers of urinary and ostomy supplies worldwide, has committed to minimizing its environmental impact during production, shipping and disposal of its products. A recent improvement in Coloplast’s SpeediCath reduced the amount of aluminum in its packaging by 50 percent compared to previous products, dropping total use by the equivalent of 150 soft drink cans per user per year. Thanks to an increased focus on efficiency, Coloplast reduced its carbon footprint by 7 percent between 2010-2014 despite 12 percent growth in production. Hollister, another catheter and ostomy manufacturer, has taken actions ranging from increasing its recycling rate to reducing the energy and water use at its manufacturing facilities. A representative says that “as a manufacturing operation, Hollister is very conscious of its place in the community and its obligation to protect the environment in which it operates.”

Cure Medical, a leading manufacturer of prescription intermittent catheters and closed systems, is working to make a difference by reducing packaging, providing pre-lubricated catheters, and eliminating certain chemicals such as DEHP, which can harm consumers as well as the environment. Lisa Wells, vice president of marketing at Cure Medical, explains the company’s thinking: “We feel the conscious decision to avoid scary chemicals and to offer reduced packaging options is a reflection of our commitment to serving our customers and community in an ethical, responsible way.” This includes practicing smart inventory management that takes product expiration dates into account. “Cure Medical does donate any excess inventory to a charitable organization, Globus Relief, to avoid throwing away product unnecessarily,” says Wells. “Globus Relief works to improve the delivery of healthcare worldwide by gathering, processing and distributing surplus medical and health supplies to charities in the U.S. and abroad.”

By practicing sustainability, medical supply companies make it easier for wheelers to live environmentally-friendly lives. Now that companies such as Coloplast, Hollister and Cure are acting more sustainably, wheelers have an opportunity to applaud them and push other companies to take similar steps. Part of that is communication and advocacy — and part of it is just “voting with our wallets.” The more that consumers support companies that act sustainably, the more likely other companies are to take the same path.

Recycle

On the flip side of conserving can be the equally vexing problem of what to do with unneeded supplies. Even with the best of plans, a closet full of leg bags, ostomy supplies, or bed pads can be hard to avoid. Doctors prescribe how many of any given supply you need, then insurance pays for and ships a set amount for a given period. For someone who uses disposable catheters, that might be the equivalent of five per day, and somebody with a suprapubic might receive enough to change their cath and bags twice per month. Even if you only end up using four catheters per day, or only switch out an indwelling cath once every...
three weeks instead of once every two, extra supplies add up quickly.

Calling the supplier and asking them to hold off on the next shipment might seem like a simple solution, but there is always the question looming: What will insurance think? Will they send fewer goods in the future, even if our routines change so we need the original amount? It’s an anxiety-causing conundrum, which leads us back to the same cycle — you use less than you get, the piles build up and you clean house after a while with a bunch of latex and plastic going straight to the landfill.

The best way to address this problem is to establish and maintain a good, personal relationship with all the members of your medical team: insurer, doctor and provider. With trust and a deeper understanding of your medical situation, doctors are likely to be more comfortable changing prescribed quantities, raising your chances for a hassle-free encounter with insurance.

Another great option is to simply donate medical supplies that haven’t yet expired, either to a nonprofit or a community program. Many nonprofits have recently sprouted up to deal with the massive medical waste in the U.S. hospital system, where unused supplies get thrown away when a patient leaves the room, or only a few goods are used out of a pack. Partners for World Health was founded by Elizabeth McLellan, a nurse who saw the need after visiting hospitals abroad and seeing how many didn’t have enough supplies.

She started Partners for World Health in 2007, and in one year she collected 11,000 pounds of single-use supplies, biomedical goods and durable medical equipment from hospitals and nursing homes. Partners in World Health obtained nonprofit status in 2009 and now has six warehouses across the Northeast, with McLellan expecting nearly 1 million pounds of donated goods in 2018 alone.

The majority of resources donated to Partners for World Health come from hospitals and nursing homes, but the organization also accepts donations from individuals — single-use supplies as long as they are not expired and durable medical equipment if it is in good condition. “Everyone is grateful that there’s an organization that takes the supplies because they don’t want it to end up in landfills,” says McLellan. Donating is simple, and just takes getting in touch and paying for shipping. “Anyone’s who’s interested in donating can call us and tell us what they have, or go to our website (partnersforworldhealth.org) and see what we need.” Of course, running six warehouses, shipping supplies and sending medical missions abroad costs money, so financial support is always appreciated.

There are plenty of other opportunities to pass off unused supplies at the local, national and international levels. Some other nonprofits that accept medical goods include the Global Surgical and Medical Support Group, and Project C.U.R.E.

As director of United Spinal’s Resource Center, Bill Fertig has fielded hundreds of calls from people looking to donate extra supplies, and he encourages callers to connect locally, either with local United Spinal chapters, support groups or centers for independent living. “Many of the 400-plus centers for independent living may have loan closets for single-use and durable medical equipment so check with one in your area,” he suggests. Online communities such as Care Cure Forums sometimes have members in need — for example, individuals with limited health insurance — who may be looking for affordable goods from others with disabilities. Even if one person has to cover shipping, it’s worth it, considering the price of disposable goods. “You can probably put in a box supplies that comprise $1,000 of retail costs,” Fertig notes, “and ship it across the country for less than a hundred bucks.” And even more, it will be putting them to good use instead of going straight to the garbage dump.

A Smaller Wheelprint

Let’s face it, living with a disability requires us to use the medical system. Living with zero medical waste is not a realistic option for most of us and, even if we’d like to, we can’t just move into a forest commune disconnected from society. Jorgensen provides some good perspective, comparing his earlier years and current life. He used to live an especially low-impact lifestyle, but now needing regular wound care, he uses bandages daily. “It’s hard with a disability to survive [without waste],” he reflects. “Some people are good at one area of conservation, but you can give yourself a break about another side.”

Still, every little bit counts — and if we all make the effort, it can add up to a lot.

Resources

Global Surgical and Medical Support Group, www.gsmsg.org; 202/854-0071

Globus Relief, globusrelief.org; 801/977-0444

National Council on Independent Living (to find your local Center for Independent Living), www.ncil.org, 202/207-0334

United Spinal Association (to find your local chapter), unitedspinal.org/united-spinal-association-chapters; 718/803-3782
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Any unhappy couples stay together for the sake of their children, and it can be especially hard to leave a marriage when you have a disability. I put up with an emotionally abusive relationship for years for the sake of my children, enduring being manipulated into believing I was worthless as a wife, a mother and a person.

Two years after finally filing for divorce, I’m a single mom with multiple sclerosis and I’m the happiest I’ve ever been, and more importantly, my self-esteem and my relationship with my two sons are stronger than ever. But it was a long and painful road to get here.

Ignored Warning Signs

Before I met Michael, I wasn’t interested in getting married or having children. My relationship with him changed all of that. I was diagnosed with MS right after we got married and just the fact that he didn’t bolt made me love him more.

The emotional abuse started while we were still dating, and I didn’t see it at the time. There were many red flags — the anger, the cruel words, the shaming — but I was so in love and wanted to be with him so badly that I ignored them all. I’m a people pleaser and don’t like to rock the boat, so if he got upset with me, I always conceded and just kept any complaints to myself. I wanted to make him happy, but even before our children were born, I was having trouble meeting his standards.

Motherhood started out well for me. Michael and I parented as a team, and we had a great system in place for our first son. He was an easy baby, and although I had an MS relapse after his birth, I recovered in a month or so and was still able to walk. I went to playgroups, story time at the library and met other mothers. I felt very comfortable as a mom and fortunately didn’t have too many physical limitations. Looking back, I think the three of us were as happy as we could have expected.
If the dishes in the sink didn’t get washed right away, I was OK with that and knew I would get to them soon. If the house wasn’t perfect, I knew it wasn’t a reflection of my competence as a wife or mother.

However, I found some relief when Michael was gone, and I wasn’t quite sure what to make of it. Even though I was on my own with a toddler and an infant, I was able to establish a routine that worked well. I had a great nanny and intermittent help from Michael’s mom and my own. I started to figure out that things were calmer for me because I wasn’t always being second guessed or criticized for little things. If I didn’t fold the laundry right away, I knew it would get done the next morning. If the dishes in the sink didn’t get washed right away, I was OK with that and knew I would get to them soon. If the house wasn’t perfect, I knew it wasn’t a reflection of my competence as a wife or mother.

Unfortunately, that comfort and confidence started to deteriorate after Michael returned. He was so excited to reconnect with our children, and I was thrilled to be a family again. But as the months passed, I started to feel like a fourth wheel. Michael lost any interest in spending time with me outside of family outings. He felt that any time I dedicated to my work was time being taken away from the boys. I stopped sharing my professional successes and accomplishments with him. If I took any time for myself to relax or relieve some stress, he called me selfish.

What made things harder was that I felt like I had really bonded with our kids while he was gone. But as soon as he returned, he was the star of the show and I was back to being in the background, just keeping the household running. I still couldn’t do anything right in his eyes. At one point, I couldn’t help but always feel left out, even when we were all together doing the same thing. I started to wonder if this isolation was intentional on Michael’s part, but felt guilty for thinking that way since he was — and continues to be — such an amazing father.

The fights started getting worse, and so did the emotional abuse. I will never forget sitting on our couch in a puddle of tears and asking Michael if he truly felt I was good enough as a person, wife and mother. He responded that I was good enough, but I could be better.

A few months later, he fell in love with another woman and had an affair. By then, he had done such a good job of convincing me that I was worthless that I begged him to try to work things out and not to leave me, despite how destroyed I felt.

For several months, we attended joint counseling and I began seeing a therapist on my own. It was clear Michael wasn’t interested in ending his relationship with his mistress. Although he attended all the counseling sessions, it was also clear his heart wasn’t in them and he was putting forth little effort to save our marriage. We tried our best to shield the boys from everything that was happening, though we may not know for many years what they saw, heard or understood during this time.

Four months after I discovered the affair, the sessions with my therapist gave me the courage to tell Michael I wanted a divorce. I thought he would be relieved because he seemed to have no interest in keeping me as a wife. Much to my surprise, he was shocked. He started to backtrack, saying he didn’t want a divorce. I kept asking him why he wanted to stay married to me, and he said he didn’t know. Throughout this period, he never told me he loved me and never asked for forgiveness, so I didn’t understand.
Filing for Divorce

I got some clarity when the emotional abuse ramped up to a new high after we met with a mediator and I officially filed for divorce. It wasn’t that Michael didn’t want to get divorced; he didn’t want to be divorced. It was a black stain on the perfect image he projects to others. Being divorced would say to the world that he (at least partially) failed at something. So he did what any good narcissist would do — he blamed me for everything.

Michael reminded me time and again that any suffering our children went through would be my fault since I was the one who filed for divorce. He asked me how I thought I would survive on my own as a woman with MS in a wheelchair, and who would love me or take care of me. I didn’t have an answer for him, but things were so bad that I was prepared to go broke paying for help and never be loved again if that was the price of my freedom from the abuse. He cited my alienation and withholding of love and affection as the reasons he sought comfort from another woman.

We “discussed” custody at a time when I was still under the impression that I was an incapable parent. I assumed the boys would live with me after the divorce. However, Michael made it very clear that if I ever planned on pursuing primary custody, I was going to be in for the fight of my life. Some quick research informed me that courts are often biased against parents with disabilities in child custody hearings, and my physical limitations could be used against me. This, combined with my desire for my kids to have an active childhood, led me to agree the boys would be better off living primarily with their father. To this day, I still deal with feeling like I abandoned them.

I kept seeing my therapist during the mandatory 60-day waiting period after I filed for divorce, and she helped me rebuild my confidence and self-esteem. She helped me understand what Michael had been slowly doing to me over the years through control and emotional manipulation. She also helped me remember who I was before the emotional abuse started, and guided me toward reclaiming who I really was.

Knowing that the divorce would result in not being near my children was the hardest thing I’ve ever had to deal with. I moved across the country after the divorce to be near my family for support. Around the same time, Michael’s work forced him to move to a city only a full day’s drive from my new home. While the transition for the boys wasn’t easy at first, it could have been a lot worse.

An Unexpected Outcome

Fast forward two years, and I’m now wrapping up my second full summer with my boys since the divorce. Under the terms of our custody agreement, they live with Michael during the school year and with me over the summer break.

We alternate holidays, and I can visit them or have them visit me whenever I want.

I run three successful businesses and travel extensively. I’ve also started introducing my children to world travel, and I learn new and amazing things about them every day I’m with them. I have a great circle of friends who have shown me nothing but love and support. I haven’t dated much following the divorce. I’m so busy with other things, and I’m in no rush to get into another relationship.

Michael and I are on very good terms, his family and mine are still close, and all of this is because I chose to forgive him. He never asked for that, but I needed to move on for my sanity and for my children’s happiness. I wanted them to see their parents at peace after years of dysfunction and conflict. Michael recently got remarried, and his new wife is a wonderful person. It’s heartbreaking to know another woman is spending more time with my children than I am, but the boys love her and her son, and they love my boys. I can’t ask for more than that, although I think I will always be concerned for her. I don’t know that Michael can change.

As for me, my relationship with my boys is better and stronger than ever. My confidence as a mother grows every time I see them because I don’t have a shadow of criticism, belittlement and condescension hovering over me.

My confidence as a mother grows every time I see my boys because I don’t have a shadow of criticism, belittlement and condescension hovering over me.
RESOURCE: NURSE ADVICE LINE

Nurses at Craig Hospital in Englewood, Colorado, can help you identify potential SCI/D complications before they become serious health issues. This free service provides a dedicated nurse to answer non-emergency calls about spinal cord injury or brain injury Monday-Friday between 9 a.m. and 6 p.m. Mountain time. To answer questions from callers, resources for over 150 health issues have been compiled in a database from the experience of Craig nursing staff. The nurses answering calls are licensed in all 50 states and Washington, D.C., are certified in rehabilitation nursing or neuroscience nursing. Call 800/247-0257 or 303/789-8508.
INSTRUCTION: ADAPTIVE ROWING

MedStar National Rehabilitation Hospital in Washington, D.C., offers a free rowing program open to any individual with a physical disability. The desire to become competitive is not required; rowing is a good cardiovascular workout for anyone with mobility issues. Each individual is assessed to determine what modifications may be needed to maximize performance, and instruction and coaching are provided by certified coaches.

Rowing is offered year-round, with training on the water April through September, and indoor training November through March. Opportunities for competition both indoor and on the water are available for those interested.

For more info on this and other adaptive fitness programs at MedStar, visit www.medstarnrh.org/our-services/adaptive-sports-fitness.

NEVADA
Renown Rehabilitation Hospital
Reno, NV; 775/982-5000

NEW YORK
Helen Hayes Hospital, West Haverstraw, NY; 845/786-4000
Mount Sinai Medical Center, New York, NY; 212/241-6500
Orange Regional Medical Center, Middletown, NY; 845/333-1000
Rusk Rehabilitation at NYU Langone Medical Center, New York, NY; 212/263-6012
St. Charles Hospital Rehabilitation Center, Port Jefferson, NY; 631/474-6011
Strong Memorial Hospital of the University of Rochester, Rochester, NY; 585/275-2100
Sunyview Rehabilitation Hospital, Schenectady, NY; 518/382-4560

The Burke Rehabilitation Hospital - Spinal Cord Injury Program, White Plains, NY; 914/597-2500

OHIO
Metrohealth Rehabilitation Institute of Ohio, Cleveland, OH; 216/778-3483
Ohio Health Outpatient Neurological Rehabilitation, Columbus, OH; 614/484-9600
Summa Rehabilitation Hospital, Akron, OH; 330/572-7300

OKLAHOMA
Integris Jim Thorpe Rehabilitation Network, Oklahoma City, OK; 405/951-2277

OREGON
Legacy Rehabilitation Institute of Oregon, Portland, OR; 503/413-7151

THE BERKSHIRE HOSPITAL
The Berkshire Hospital, Pittsfield, MA; 413/499-5000

UTAH
University of Utah Health Care Rehabilitation Center, Salt Lake City, UT; 801/585-2800

VIRGINIA
Inova Rehabilitation Center at Inova Mount Vernon Hospital, Alexandria, VA; 703/664-7924

UVA - HealthSouth Rehabilitation Hospital, Charlottesville, VA; 434/924-0211

VCU Spinal Cord Injury Rehabilitation, Richmond, VA; 804/828-0861

WASHINGTON
University of Washington Harborview Medical Center - Northwest Regional Spinal Cord Injury System, Seattle, WA; 206/221-7390

WISCONSIN
The Spinal Cord Injury Center at Froedtert and The Medical College of Wisconsin, Milwaukee, WI; 414/805-3000

UW Health Rehabilitation Hospital, Madison, WI; 608/592-8100

Organizational Members
Center for Neuro Recovery
North Palm Beach, FL; 888/875-7659

Florida Spinal Cord Injury Resource Center, Tampa, FL; 813/844-4711

Miami Physical Therapy Assoc., Inc., Miami, FL; 305/444-0074

NextStep - Kansas City
Overland Park, KS; 913/451-1500

NextStep - Orlando
Sanford, FL; 407/571-9974

Project Walk - Boston
Stratham, NH; 603/583-5119

Project Walk - Houston
Missouri City, TX; 281/410-8348

Project Walk - Mount Laurel
Mt. Laurel, NJ; 856/759-5780

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Interested in becoming a hospital or organizational member?
Please contact Nick LiBassi at 718/803-3782, ext. 7410 or nlibassi@unitedspinal.org
MEGACOLON, BOWEL PROGRAM FREQUENCY

Q: I’m in my 15th year as a C7 quad. I was at a local SCI support group and the discussion turned to “plumbing” and how often to do a bowel program. I mentioned I do my BP every fourth day with a suppository and get good results and rarely have accidents. Another person in our group said they go every fifth day. Somebody said that regularly waiting more than three days is too long and that waiting more than every other day and/or being chronically constipated can lead to something called megacolon. I did a web search on megacolon, and I’m still not exactly sure what it is. What is it? What causes it? Are there any symptoms? How is it treated? Also, how frequently should you do a bowel program?

— Matt

G reat questions, Matt.

Megacolon is a condition where stool backs up in the colon, stretches the colon muscle, and damages the colon, which loses the ability to return to normal size. Colon enlargement and loss of muscle tone slows stool movement. For someone with SCI, stool usually takes around 48-72 hours to move through the body. Megacolon slows transit time to a week or longer, according to Kathleen Dunn, a retired clinical nurse specialist and rehab case manager.

Spinal cord injury is listed as one of the conditions that can lead to colon enlargement. However, there is very little published about SCI and megacolon. One small study published in a 2000 issue of Spinal Cord looked at 128 individuals with SCI — mean age 57, mean years post-injury 20 — and found that 73 percent of the subjects had mega-colon in at least one section of their colon. Although there is a link between SCI and megacolon, there are ways you can reduce your odds of developing it, starting with regular bowel programs.

“There is some evidence that doing bowel care less than three times a week can, in the long run, make a person more vulnerable to developing megacolon,” says Dunn. Since chronic constipation and/or fecal impaction can lead to megacolon, it makes sense to do a regular bowel program that produces good results. This starts with eating foods that both speed up transit time and discourage hard, lumpy stools that cause constipation and impaction. A key to getting things moving is to reduce consumption of refined flours, rice and cheese, and increase fiber intake. Fiber absorbs water as it travels down the digestive tract and increases the weight and bulk of stool, which helps move things faster.

A Craig Hospital module on bowel care recommends 20-25 grams of fiber per day. The best way to get this is from eating fruit, vegetables and whole grains. Another way to increase fiber is to take an over the counter supplement, like Metamucil, Benefiber or fiber gummies. The Craig module also stresses that when you increase fiber you need to drink plenty of water — one-half to three-quarters of a gallon per day — unless you have fluid restrictions. Dunn adds that it is also helpful to keep a food diary to fine-tune your motility and stool consistency — not too hard, not too soft. Also, remember that with SCI, it takes two to three days from “first bite to toilet bowl.”

Other helpful tips: Regular exercise speeds up transit time, as does being upright in your chair throughout the day. It is also important to avoid routine use of strong, stimulant laxatives. The Spinal Cord study found a correlation between routinely taking four or more laxative doses a month and megacolon.

Symptoms, BP Frequency and More

Distended abdomen is the first physical symptom of megacolon listed in a Medscape link. However, this may be difficult to distinguish from “para or quad gut.” Other symptoms include constipation and unusually long bowel care periods; small amounts of results; and dry, hard stools.

Megacolon can also be asymptomatic. An abdominal X-ray is the first step to diagnosis. If the result shows signs of megacolon, follow-up is done by imaging with a barium contrast fluid. This brings up an important “2-for-1” medical hack: During your annual urology appointment, ask your urologist to look at your kidney-ureter-bladder X-ray with you, because it shows the entire colon and can clarify if you are chronically constipated or backed up.

If the primary treatment of sticking to
a strict high fiber, high fluid diet and regular bowel program does not bring results, surgery may be an option. According to the New England Journal of Medicine, more severe cases of megacolon require surgical intervention in the form of colostomy, colectomy — removal of part or all of the colon — or both.

Dunn says that how often to do a bowel program varies with each person and includes factors ranging from injury level and activity level to diet and fluid intake. Some people need to do a BP as frequently as once or twice a day. This often applies to people with lower motor neuron injuries below T12, since these injuries can damage the spinal reflex arc, cause the colon to lose muscle tone and not respond to digital stimulation or suppositories. Other people do fine with a BP every other day. The Paralyzed Veterans Association’s guide to Neurogenic Bowel Management in Adults with Spinal Cord Injury states that bowel programs should be routinely scheduled at least once every two days over the long term to avoid “chronic colorectal over-distention.”

If you are doing your bowel program less than three times a week, it is a good idea to discuss colon health with your physiatrist and/or your gastroenterologist — even if you are having good results. If you are having BP difficulties such as chronic slow motility or frequent accidents, you should definitely talk with your specialists. A lot of factors can affect bowel programs, including antibiotics and pain medications. There may be alternative medication options that have less effect on transit time.

Last but not least is a discussion of BP options. The basic methods are digital stimulation and manual evacuation. If these methods aren’t producing sufficient results, suppositories may be needed to stimulate increased peristalsis and get stool moving. According to Dunn, “Options include Dulcolax (bisacodyl), which has been around a long time, and works well for many, or The Magic Bullet, a bisacodyl suppository in a water-soluble base rather than a wax base, so it melts faster, has more bio-availability and may work faster.” Dunn’s patients also report good success with Enemeez, a mini-enema of docusate sodium. “I especially like it because it avoids problems with ‘butt snot’ or ‘afterburn’ — a smelly mucus discharge that can show up to one or two hours after bowel care with a regular suppository,” says Dunn. She says she has also had a few patients who used and liked glycerine suppositories, including the Ceo-Two suppository.

Resources
- Craig Hospital: Bowel Care Resources, craighospital.org/resources/topics/bowel-care
- Medscape: Chronic Megacolon, emedicine.medscape.com/article/180955-overview
- PVA’s Neurogenic Bowel Management in Adults with Spinal Cord Injury, pva.org/media/pdf/cpg_neurogenic%20bowel.pdf
Joe hits the throttle, the engine roars and the sound of rushing air envelops us. We quickly accelerate down the short paved runway. Joe pushes forward on the controls, tilting the kite-shaped wing skyward. Soon our wheels lift off the ground and we smoothly climb as he pulls the lever to raise the landing gear.

"Where do you want to go?" Joe asks.

"I'd like to go north up into the canyon. We went there with a pontoon boat and it was so beautiful. I'd like to see it from the air!" I say.

Sounds good, as long as the wind is low, it will be fine in the mountains.

We head north from the airport, gaining altitude, and soon there are mountains creeping by on both sides. You can see the Colorado River, on the border of Arizona and California, off to our left snaking through a rock canyon. The water is crystal clear to the bottom. Amazing. Below us is rugged rock with very little soil or vegetation.

We are flying among the peaks in an open-cockpit, weight-shift ultralight. I'm sitting in the rear seat, securely strapped in, while Joe flies from the front seat. We wear helmets equipped with microphones so that we are in constant communication.

"Can I try flying?" I ask.

"Sure can, grab the controls," he says.

I reach out into the wind and, as well as a quad can, grab the bars.

"OK, I have it. It's hard to reach far enough forward — you guys tied me in well."

"You're flying!" says Joe, letting go of the controls.

I gently shift our weight left, and we bank left. I shift our weight right, and we turn right. This unit is very easy to fly. I think it would be a great aircraft for people with limited arm movement or strength. To climb, you simply add power; to descend, you reduce power. For me, controlling it comfortably would require sitting closer to the controls or having extensions to reach them more easily. I soon get tired of stretching for the bar.

"I'm having to reach a bit far — my arms are tiring out. You take control."

"I have it," says Joe, taking over.

I resume my sightseeing. It is amazing to see the world from above. The mountains and valleys looked beautiful from a boat, but now to see them from the sky is surreal. There is nothing between us and the ground but a few thousand feet of air.

At first it is a little unnerving to not be inside a cockpit, but soon the beauty of seeing the world from above takes over, and it is no longer scary.

"Let's go down over the river," says Joe.

"Sounds good, it is so awesome to see it from up here!"

Flying Low

We come down low over the river in the valley. I can see the beach where we parked the boat to have lunch, and where others hiked in search of a geocache. It's like zooming in with Google Earth.

"Now let's go low over the lake," says Joe.

This kite-shaped ultralight is a great aircraft for people with limited arm mobility.
Joe. I know he wants to show me some touch-and-go maneuvers.

"OK, sounds great to me," I say.

Joe lowers the power, and you can feel us going down. We are on the California side of the lake, lined up on the smooth-as-glass water. As we get down close, Joe adds a little power to reduce our descent. The floats gently kiss the lake. This is the first time I have ever experienced a touch-and-go on water.

Joe adds power and we speed up again and gently lift back into the air. What a blast! Next, he turns the camera rearward and gets some footage of the spray as we skim the water again.

We stay low over the lake, maybe 20 feet high or so, and hug the shoreline. We bank to the right and go into an inlet, then bank left and turn around. Heading back to the lake, I notice some power poles on the hilltops.

"I assume you know where all the power lines and obstacles are," I say.

"Oh yes, been flying this area for years. There are no lines on those poles."

"Can we fly by Lizard Peak?"

"You bet!"

We are soon approaching Lizard Peak. A week earlier, the rest of our group had made a several-hour hike to the top of the mountain. I stayed behind and took pictures of them, met people and was entertained by radio-controlled aircraft doing aerobatics nearby. I wanted to see their trail and the peak.

Looking down and to the right, I can see a trail zig-zagging up the front of the mountain, and the picnic table at the top. About 20 hikers at the peak wave at us. We wave back, Joe cuts the power and circles back, and as we zoom by closer, we wave once again. Then we follow the more gradual trail down the backside of the mountain, leading us to the lake. Banking right, we head toward the airport. What a fantastic day!

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**Frequently Asked Questions**

Where are you flying?
We are flying over and around Lake Havasu, Arizona.

What kind of aircraft are you in?
We are in a weight-shift ultralight that is equipped with amphibious floats so that it can land on water or a runway.

How did you get into the seat of the ultralight?
We have a portable Hoyer lift. It worked out perfectly so that it could be pushed right up to where I could be dropped into the seat. The legs of the Hoyer fit under the floats.

Whose airplane are you flying?
Joe, from Hanging Over Havasu, owns it. He gives instruction and rides. You can take lessons, and he is very open to training people with disabilities.

Were you afraid?
Joe is very conscientious. I felt totally safe with him. You can find him at www.hanginoverhavasu.com.

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We have many clinical research studies for people living with spinal cord injury to participate in, including studies about activity, diet, aging, pain, spasticity, walking, hand function, sleep disruptions, male fertility, and cell therapies. Find more details at www.themiamiproject.org or call 305-243-7108.

To be considered for current and future research studies, you will need to complete a short Intake Form. This can be done online at https://fs.miamiprojectintakeform.org or you can call 305-243-7108 and request an Intake Form be mailed to you.

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Art begets art, especially at the Burning Man festival where Dutch artist Theo Jansen’s Strandbeest — walking mechanisms made of PVC that often resemble giant insects — inspired sculptor Mark Ellis’ own Playa Crawler, which looks like a mutant spider mount. You’ve probably seen one or two videos showing Ellis strolling along in his invention. Or scurrying, or whatever spider chairs do.

While probably not the future of wheelchairs — although, who knows — it might be fun to play Dr. Loveless for a day. Meanwhile, it’s not designed for people with disabilities at all. Ellis just wanted to ride something cooler than his bike around the desert art festival.

Although his sparsely funded project has been languishing on GoFundMe for two years now, a new video of his spider chair by LiveStrong’s Jess Barron is making the rounds. Look for Ellis as @everfalling on Twitter, and find videos at @ThePlayaCrawler on Facebook or GoFundMe.
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