



NEW MOBILITY



THE MEMBERSHIP PUBLICATION
OF UNITED SPINAL ASSOCIATION

THE TRAVEL ISSUE

**Traveling with
a Caregiver**

**Exploring the
California Coast**

Vacation Nutrition



**DRONE PHOTOGRAPHER
JAIMEN HUDSON**

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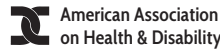
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JAIMEN HUDSON'S EYES IN THE SKY

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BULLY PULPIT

By Ian Ruder



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HANDLE HARD BETTER

Sitting in my hotel room after the opening day of this year’s Los Angeles Abilities Expo, I kept coming back to something I told an attendee while I was manning United Spinal Association’s booth that day.

A newly paralyzed young man and his partner had stopped by to find out about SCI resources. I gave them my best spiel on New Mobility and United Spinal and answered a couple of his partner’s questions. I could tell by the look in his eyes he appreciated the info but was too overwhelmed to fully process everything. And I understood: As much as I love the expo, it’s overwhelming to me too. Imagining what must have been going through his head as someone with a new SCI, I blurted out the comment that had my mind racing later that night.

“It gets better.”

Aside from sounding so cliché even a Hallmark Card creator would reject it, there’s nothing inherently wrong or untrue about what I said. Yet I remembered how shallow those words sounded when others tried to reassure me in the wake of my injury.

I felt like I owed him a better explanation: How does it get better? What is better?

As I thought about what I should have said, a news segment about Duke University women’s basketball coach Kara Lawson came on the TV in my room. The segment focused on a speech she had given to her team that went viral.

Her message was simple: We will be a good team because we will learn to “handle hard better.” She said, “We all wait in life for things to get easier. It will never get easier, but you will handle hard better. ... If you go around waiting for stuff to get easier in life, it’s never gonna happen.”

Lawson was speaking to a group of elite college athletes, but her message had broad appeal and particularly resonated with me as

a disabled person. Living with a disability is like taking a master class in learning to handle hard better.

I get why this may not be the most popular class in the catalog, and we did not choose to sign up for it, but the best advice I can offer is to embrace the opportunity: to master handling hard better.

Working through all of the medical issues that I’ve run into over the last few years, I can’t help but think how these same issues would’ve

“Living with a disability is like taking a master class in learning to handle hard better.”

crushed me two decades earlier. They still suck and are draining and infuriating, but I’ve learned to handle them and get back to living.

Many of the things I’ve gone through have left me with concrete lessons and tactics I’ve been able to apply again. I’ve also learned to accept that sometimes you just have to be happy with getting through something without learning anything. Regardless, each time that I make it out the other side, it builds confidence in my ability to do so.

What I was ineloquently trying to tell the man at the expo wasn’t so much that life gets better — hopefully it does, although no one can guarantee that — but how you handle the hassle that comes with disability does get better. And that’s the key: handling all the bullshit so you can enjoy all the good stuff — so you can live. It won’t get easier, and sometimes it will be oppressively difficult, but as long as you don’t give up, it will get better.



BEHIND THE STORIES

With Ian Ruder



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Spin the Globe is an award-winning travel blog and site for accessible trip planning and disability resources.
spintheglobe.net

Having grown up in Northern California within walking distance of the Pacific Ocean, I hold the Pacific Coast Highway and its stunning terrain near and dear to my heart. As such, I was ready to tear apart **Lilly Longshore's** guide to accessible highlights on the PCH if she messed anything up. But I'm happy to say she nailed it. Covering all the fun things to do along the PCH would take more space than we have, but Longshore has assembled a great introductory itinerary. "I can't wait to go back and see the parts I didn't get to," she says. "There's so much beauty and so much to do, it's all a little overwhelming."



I couldn't help but laugh when I realized that not only had I enlisted **Bob Vogel** for two stories in this issue, but that one covered bowel issues and the other covered bladder matters. Long-time readers will know that Vogel has probably written more about these topics here — including his award-winning Bladder Matters column — than has any other writer on any platform. When it comes to Nos. 1 and 2 and SCI, he is the man. "If you had told me during my skiing career that I'd be thrilled to know and write about this, I don't know if I would have believed it," he says. "But hey, if it helps people, I'm all for it."



It's great to have **Joanne Smith** back in the fold with her guide to managing a vacation diet that helps you maximize your enjoyment and minimize health complications. A certified nutritional practitioner, Smith tackled all our readers' diet and nutrition questions in a column she co-authored for many years. Now she's in her second decade of running Fruitful Elements, her business dedicated to helping people with disabilities eat and live better. She's also fighting to make air travel more accessible as a member of Air Canada's advisory board, and building up quite the television resume as she records accessible-fitness specials for Canadian TV.



Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org

United Spinal's Resource Center provides information on any aspect of living with SCI/D. Contact: 800/962-9629; unitedspinal.org/ask-us; 120-34 Queens Blvd, Suite 320, Kew Gardens, NY 11415.



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SHARE

“This was a reminder of a familiar journey that has blossomed into an exciting, fun and full-of-love life!”

MARCH-APRIL 2024

Making Peace with My SCI

I love this article. As a quadriplegic for 38 years, it was a reminder of a familiar journey that has blossomed into an exciting, fun and full-of-love life! I really enjoy your writing, Cassandra!

Kary Wright

Newmobility.com

8 Steps to Improving Your Emotional Health After Disability

This is a phenomenal post! I'm a dietitian but if anyone asks me what is the most important thing for SCI survivors, I'd say mental health before all else.

paralysis.nutrition

Instagram

This is a life-changing post for any individual facing and dealing with a disability and all that it involves. Me being the first one. I've had a spinal cord injury 12 years, and I'm still learning and sometimes struggling to get through my everyday life as a disabled person.

maria_gmen

Instagram

How to Get the Most Out of Your Medical Checkup

I wish that people in the medical field would read this and educate themselves.

Mary Ann Sciacca

Facebook

I don't bother with annuals anymore. Croakers just go through the motions, don't even look up from the computer screen. Just fill the freakin' Rx and see ya next year.

Billy Lee Sharkey

Facebook

I haven't been weighed in 10 years because no one has a wheelchair scale or bed scale. Not even the therapy offices or a rehabilitation facility.

tbenz078

Instagram

Independence Through Art

I like anything like this that you can do independently, and it is the same thing with finding new assistive technology to do things. You need to keep trying things until you find something that works for you.

Larry Pagel

Facebook

Quad Snow Plowing

I commend your ability to transfer and operate the machine. I'm also a quad with an ATV. I had a backrest welded to the rear rack. I transfer throwing my leg over the seat first and then sliding up a transfer board. I swapped the hand brakes left to right and right to left and mounted them in front and above of the handlebars. This allows me to push for braking. Loosen or disconnect the foot brake, so it isn't a factor.

Morgan

Newmobility.com

Love this! I'm a para and tried shoveling in my wheelchair and got stuck. I gave up. This is inspiring.

akualezlihope

Instagram

How to Choose the Best Cushion for You

Seth, you left out the obvious: While you can test drive a car or try on clothes before you buy, you can't try



out wheelchair cushions first. How can someone decide which expensive cushion is right for them by “thinking it over” without actually experiencing what it feels like to sit in one for a couple days first?

chrissheridan333

Instagram

Seth McBride responds: I agree! Some wheelchair users with access to a top-notch seating clinic may have the opportunity to trial different types of cushions. But for the rest of us, it's ludicrous that there aren't good options for extended test drives with products we're going to be sitting on for 12-plus hours a day. For now, the best options I've found are to talk with professionals and peers, consult web resources, get pressure mapped and make as informed a decision as you can. Sometimes it will go great, and sometimes not — one of the many reasons that keeping tabs on your body after getting a new cushion is important.

Great article, Seth. As we used to say: not every cushion is for every butt. Every cushion type will suit a certain category of users. Comfort is the most important thing in my opinion. If you get prescribed a cushion that does not make you comfy, you will throw it out of your chair. This means there needs to be a balance between comfort, protection and functionality.

Monica

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Medicare Now Covers Exoskeletons

Thanks to a rule implemented earlier this year, Medicare now reimburses for two different brands of personal exoskeletons, allowing more wheelchair users access to this



Washington

formerly out-of-reach technology.

Ekso Bionics' Indego Personal and ReWalk's Personal 6.0 Exoskeleton are currently the only exoskeletons approved by the Food and Drug Administration for home use. A lot of media coverage has focused on exoskeletons' potential for everyday mobility, but because of cost and limited functionality, the devices have mainly been used in clinical settings. Still, there is evidence that regular use of an exoskeleton can improve some secondary complications of paralysis, including circulation problems, pain, reduced bowel and bladder function, and reduced range of motion.

LaTasha Washington, a 51-year-old T8 paraplegic from Detroit, is one of the first to have an exoskeleton covered by Medicare. "I was interested in trying the exoskeleton for the opportunity to exercise, walk and hopefully improve my bowel program," says Washington. "My first time in the device, I was really nervous, but once I got into a rhythm, it was great."

For more info on costs and eligibility, go to newmobility.com/medicare-to-cover-personal-exoskeletons.

complications of paralysis, including circulation problems, pain, reduced bowel and bladder function, and reduced range of motion.



LapStacker Relaunches Carrying System

For a wheelchair user, dropping stuff off your lap is part of the game, but a device from New Zealand inventor Mike Brown aims to change that. The LapStacker is a retractable strap system that allows you to easily secure things on your lap.

Once the device is installed, you pull out the webbing loops mounted on either side of your chair, stretching them over the items on your lap and clipping the buckles together. Finger loops and a magnetic buckle make it easy to operate for people with limited hand function. When not in use, the straps retract out of your way at your sides.

LapStacker originally launched via Kickstarter in 2019. The original run made Brown rethink the design to make it easier to install on a wide variety of wheelchairs. Brown says the resulting LapStacker Flex is lighter weight and mounts on most manual wheelchairs in five minutes. A power wheelchair version is also available.

LapStacker Flex ships worldwide and retails for \$119. For more info, go to adaptdefy.com/products/lapstacker-flex, and look for an upcoming review on newmobility.com.

READ



SOUTH AFRICAN DISABILITY-RIGHTS ADVOCATE EDDIE NDOPU TAKES READERS THROUGH A WORLD OF CONTRADICTIONS IN HIS NEW MEMOIR, **SIPPING DOM PÉRIGNON THROUGH A STRAW: REIMAGINING SUCCESS AS A DISABLED ACHIEVER**. IN HIS PROFESSIONAL LIFE, NDOPU, A POWER WHEELCHAIR USER WITH A MASTER'S IN PUBLIC POLICY FROM OXFORD UNIVERSITY, HOBBOS WITH WORLD LEADERS AT THE UNITED NATIONS AND THE WORLD ECONOMIC FORUM. BUT IN HIS PERSONAL LIFE, HE EXPERIENCES THE SAME SYSTEMIC INACCESSIBILITY AND CASUAL DISCRIMINATION THE REST OF US DO. BOTH FUNNY AND FIERY, NDOPU'S BOOK SHOWS THAT NO MATTER HOW SUCCESSFUL YOU ARE AS A DISABLED PERSON, ABLEISM STILL BITES. FIND **SIPPING DOM PÉRIGNON THROUGH A STRAW** WHEREVER YOU GET YOUR BOOKS.

Health Information Survey Needs Your Input

Finding quality, disability-specific health information isn't easy. The North American Spinal Cord Injury Consortium is trying to find ways to fill this information gap, but first they need to hear from you. They want to find out where you look for health information, what topics are most important to you, and what subjects you have the hardest time finding quality info about.

Go to surveymonkey.com/r/SCINeedsInfoSurvey to fill out the survey. Anyone who completes it can sign up for the chance to win a gift card.

WATCH

FILMMAKER PAULA WHETU JONES CHRONICLES HER POST-PARALYSIS EXPERIENCE IN **SPINAL DESTINATION**, A NEW DRAMA/COMEDY SHOW ON NEW ZEALAND'S SKY GO NETWORK. RIGHT NOW YOU'LL NEED A VIRTUAL PRIVATE NETWORK TO STREAM IT, BUT KEEP AN EYE OUT FOR A U.S. RELEASE. skygo.co.nz/show/mac_sh_136130.



Wheelchair User Finishes Off-Road Racing's Toughest Test

Since it started in the late 1970s, the Dakar Rally has been one of off-road racing's most infamous and challenging competitions. This year wheelchair user Albert Llovera completed the 5,000-kilometer course as the lead driver for the Ford Trucks Spain team.

Llovera is no stranger to high stakes racing. The Andorran was the youngest person ever to compete in a Winter Olympics, in alpine ski racing at the 1984 Games when he was 17 years old. A year later he broke his back in a crash while competing. After the accident he took up motorsports, eventually racing on the World Rally Championships circuit in 2010 and 2011.

But Dakar is a different beast. It spans 14 days and features some of the toughest driving in the world, as drivers compete on motorbikes, four-wheeled quad racers, cars, buggies and trucks. Llovera has raced for years in the truck division. He gets up into the almost 9-ton behemoths with a harness-and-pulley system, and drives with ring-style hand controls mounted on the steering wheel. This year his team battled the race's usual hardships, including sand traps, mechanical issues and navigational errors — and came away with a 17th-place finish.

Follow Llovera's many adventures on Instagram [@albertllovera](https://www.instagram.com/albertllovera).

By Shannon Kelly

United Spinal Partners With Abilities Expo

United Spinal has been appointed to spearhead the on-site programming for the Abilities Expo. The Abilities Expo is the premiere live national exhibition showcasing products, resources and services for the disability community, staged in seven

cities across the nation.

United Spinal will be responsible for organizing and leading the expo's workshop series, covering topics like accessible travel, home design, financial planning, assistive technology, fundraising and

more. It will also plan an array of inclusive events, including adaptive sports, dance, and service dog demonstrations. The workshops and events are packed with information and are a popular attraction for many with disabilities.

"We look forward to continuing the Abilities Expo's long tradition of providing diverse workshops and presentations to meet the needs of its hundreds of thousands of attendees with disabilities, their friends and families, and service providers," says Vincenzo Piscopo, CEO of United Spinal.

Join United Spinal at an upcoming Abilities Expo near you:

- New York, May 3-5, 2024
- Chicago, June 21-23, 2024
- Houston, Aug. 2-4, 2024
- Phoenix, Sept. 6-8, 2024
- Ft. Lauderdale, Oct. 18-20, 2024
- Dallas, Dec. 6-8, 2024
- Los Angeles, March 26-28, 2025



NEW MOBILITY Editor-in-Chief Ian Ruder (right) with an Expo attendee.



Jones

New PlayStation Controller Benefits from United Spinal Member Input

PlayStation launched the Access controller for the PS5 console, designed to help people with disabilities play games longer and more comfortably (see review, page 42).

Paul Amadeus Lane, a United Spinal Tech Access Initiative member and quadriplegic, is one of a handful of disabled gamers who consulted on the design. He has been assisting Sony with accessibility since 2017 and has consulted on the Access controller since 2021, providing feedback on the design and software.

"What really excites me about this technology is the fact that it would get more people the ability to game at a very high level," Lane says. "I'm also excited to work with children, older adults and therapists on how to implement gaming as a part of the therapy program." He also stressed to the team the importance of avoiding a "disability tax" by ensuring that it is not more expensive than a mainstream controller just because it is accessible. He is confident the controller will elevate other disabled gamers. "It really helped me to have a full gaming experience," he says.

The device retails for \$89.99 and can be operated from any 360° orientation, used on flat surfaces, or be attached to an AMPS pattern mount. The swappable button and stick caps can configure the Access controller's console layout to suit a player's range of mobility. The adjustable stick-length allows you to lengthen or shorten the control stick's extension arm, then lock it down at the ideal distance from the controller.

Learn more about United Spinal's commitment to accessible technology at unitedspinal.org/tech-access-initiative.

Meet New Member Cierra Jones

T9 para, Age 31 from Acworth, Georgia
Painting, pottery, rock climbing and bird watching
Currently training to be a United Spinal Peer Mentor

Why did you join United Spinal?

I was at the Life Rolls On event in Atlanta last year and really liked how United Spinal made their presence known to the community. I was newly injured at the time and United Spinal's warmth was very welcoming.

What is the one product you couldn't live without?

My padded exercise mats. It's freeing to spend time outside of my chair stretching, lightly exercising or watching a movie.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be?

The main thing is awareness and consideration for wheelchair users in public spaces. We could use more parking spaces and bathroom stalls because there never seem to be enough. That would go a long way with overall inclusivity. Airline travel should be a lot easier and a lot less risky than it is, as well.

Disability Etiquette Guide Gets an Update

United Spinal Association has revamped its popular *Disability Etiquette Guide* with an updated look and more social and cultural insights on interacting with people with disabilities. Eastern Paralyzed Veterans of America, which became United Spinal Association, published the first *Disability Etiquette Guide* shortly after the 1990 passage of the Americans with Disabilities Act. The new update has 21st-century sensibilities in mind, but the basics are still the same: People with disabilities are people first. We deserve dignity and respect, as do all people everywhere.

The topics include:

- Terminology tips.
- Physical disabilities.
- Sensory disabilities.
- Web and print access.
- Service and support animals.
- Neurodivergence.
- People with intellectual disabilities.
- People of short stature.

The goal of this guide is to make interacting with members of the disability community more comfortable for the non-disabled community, leading to increased understanding and improved accessibility. It is a great resource for businesses, schools, organizations, staff trainings and disability awareness programs. Download the guide for free at unitedspinal.org/disability-etiquette.



May Is Mental Health Awareness Month

United Spinal member Laurie Crosby shares her personal account of surviving post-spinal cord injury PTSD.

Like many of us, my SCI came into my life with a bang — a car accident, to be exact.

My first encounter with a therapist post-SCI was in the intensive care unit when I was hopped up on a large amount of morphine. I remember her asking me how I dealt with stress in my life. I told her that I saw joy as a cloud, and whenever I felt down, I could just reach out and pull a little piece of joy off that cloud for myself. Yeah, those drugs were strong.

The next time we saw each other, I was no longer on the morphine drip. I was coming back into my body and into my new normal of being paralyzed, the harsh edges of trauma no longer cushioned by chemistry.

[After meeting with several therapists] I spent the next few years white-knuckling my way through life without professional help, stumbling from one day to the next while barely keeping my head above water.

I didn't yet know that I was suffering from PTSD. I wasn't having flashbacks of my car accident or waking up from nightmares about it. I was, however, experiencing many lesser-known symptoms of PTSD that included emotional numbing, being easily startled, outbursts of aggression and feeling constantly on guard.

I began seeing a therapist who specialized in trauma therapy. I learned that what I experience is complex post-traumatic stress disorder. C-PTSD occurs when a person is exposed to long-term trauma, while PTSD involves a single traumatic event.

I started eye movement desensitization and reprocessing therapy, a targeted technique for treating PTSD. When we sleep, we enter stages of rapid eye movement, which is when we dream. During these stages, the brain processes memories. However, when we go through trauma, traumatic memories can get "stuck" in a certain part of the brain and are unable to be properly processed by our REM sleep. EMDR therapy uses back-and-forth eye movements that mimic how the eyes move during REM sleep to help "unstuck" those memories, so that they can be properly stored and processed.

Through EMDR I stopped ruminating over the early, grief-filled years of my SCI, became more emotionally vulnerable and less angry overall. I don't always get it right, and every now and then a storm rolls in, but that's OK. Even in the gathering of storm clouds, there is sometimes great beauty.

Find in-person or virtual support at unitedspinal.org/peer-support-groups.



DAY IN
THE LIFE



DR. JEFF HEINZ, D.D.S.

Dr. Jeff Heinz says he needs only one word to describe his life: grateful. Gratitude was the theme of a speech he gave recently at a prestigious orthodontic conference, where he talked about becoming a T9 paraplegic in a motorcross accident while in dental school in 2011, and how it didn't stop him from becoming the only orthodontist in the world to use a wheelchair.

Heinz, 36, returned to dental school only months after inpatient rehabilitation. "It was really hard," he says, "but at that point I knew I had only two choices, one of which I could never live with, and another that would be a treacherous road but could ultimately let me regain the 'normal' that I longed for so badly."

Being back in school was therapeutic for Heinz. "I didn't have time to feel bad for myself or to dwell on the past — I barely had

time to breathe some days!" he says. "I quickly found that I needed to be more prepared than my classmates, whether that meant studying more for exams or never forgetting something from the clinic dispensary, so I didn't have to make multiple trips back for equipment. I didn't have time for inefficiencies."

After a year of practicing general dentistry, he went back to school to specialize in orthodontics. "I love the transformations and seeing how giving someone a big, beautiful smile makes them light up like a Christmas tree," he says.

Today, he is also grateful for the beautiful life he is building with his wife, Katie, and their 2-year-old son, Jack, while juggling his own bustling private practices in West Michigan. Here's a look at how he spends his day.

5 a.m. I get up early so I can work out. I have a home gym where I do cardio and strength-training. After showering and getting ready, I'll grab a protein shake and some fruit before heading out. Tuesdays are my favorite because I go into the office a little later, so I'm able to make breakfast for Jack and hang out with him for a while.

7:30 a.m. I arrive at the office. I started Heinz Orthodontics in 2020 in Rockford, Michigan. I opened a startup in the middle of the pandemic, but it was the right opportunity at the right time. And in 2021, I purchased a second location, an established practice, in Grand Rapids. I split time between both locations.

I have a team of 15 people. Our day starts with a team huddle where we talk about special cases that might be coming in that day, or any announcements or reminders we need to communicate. At the end of each huddle, we link arms in a circle, and we go around and say one thing we are grateful for that day.

10:30 a.m. Patients are lined up in a row of chairs, having brackets and wires replaced, getting impressions or being fitted for an aligner. I try to empower my team with as much knowledge as possible. Replicating my knowledge in each team member means the less I need to be everywhere. However, on super busy days you might still find me in sterilization cleaning up, or taking phone calls. And,

of course, there is always a lot of charting and computer work to be done between patients.

I haven't had to make too many accommodations inside my clinics, other than purchasing some new chairs that I could maneuver my wheelchair underneath and finding drills that could be operated with hand pressure versus foot pressure.

12 p.m. I head out to visit a local dental office to introduce myself and the services my practice offers. These "lunch and learns" are a great way for me to connect to the community and establish relationships with other providers. I'm a people person, so meeting people is fun.

Even though I am the only orthodontist in a wheelchair, I have never really had problems finding a job or being accepted when I was working for others all those years ago. People have always been more interested in my personality and skillset.

2 p.m. My wife is a physician assistant at a nearby dermatology practice and works two days a week. On the days she is off, Jack is a frequent visitor to the office. He really likes sitting on my lap as I wheel around. He'll go into the exam room with me when I'm doing new patient consultations. He is a real charmer and great salesman!

3:30 p.m. Reviewing before-and-after photos is probably one of the favorite parts of my job. Just seeing the difference we can make in their [lives], their

confidence and oral health is amazing. Getting your braces off is a big milestone we like to celebrate in the office. Everyone in the office claps and the patient gets to ring a gong.

5 p.m. By this time, we have seen anywhere from 65 to 80 patients today, and it's time to head home. I make it a point to leave by 5 p.m. so I can spend some time with Jack before he goes to bed. Coming into the house and hearing him scream "Dadda" never gets old. Jack has a really cool playroom in our basement with a blow-up bounce house and an obstacle course, so we go down there to play a lot. I love getting on the floor and rolling around with him. If it's nice outside, one of his favorite things to do is to go for a ride in my track chair around the yard.

7 p.m. Once we get Jack in bed, my wife and I start dinner. If we're really on top of our game, we'll do some meal-prepping on Sundays so we have ready-to-go meals for lunches and dinners; otherwise we split dinner-making duties. After dinner we'll catch up on the day's events, maybe watch a couple shows on TV or invite the neighbors over to hang out.

10 p.m. Time to go to bed and get ready for the next day, but not before I brush, floss and put in my retainers. Yes, I absolutely practice what I preach!

Follow Dr. Heinz at [@heinzorthodontics](#) on Instagram and Facebook, and [@dr.hotwheelz](#) on TikTok.



GEAR HACKS

By Kary Wright

MAKING A SHORT-TERM RENTAL-ACCESSIBLE

This year I was fortunate enough to escape part of the Canadian winter. Being a quadriplegic, there are a lot of things to consider before making the temporary move to another place. My list of needs in a potential destination is long: minimum 30-inch-wide doors with no sill, no stairs, a comfortable bed I can get into that won't cause me to sweat or develop pressure sores, a bathroom — with a shower — that can accommodate my commode, a fenced-in backyard for our two dogs and, if possible, an RV pad for our friends to stay on-site. Finding a property that checks every box is very difficult, but with some ingenuity and a few tinkers and hacks, it's totally doable. Here's how we did it.

A Home Away from Home

I'm grateful and fortunate that my darling wife, Terry, has a black belt in property research. My attention span is about as long as ... wait, what's that shiny thing ... you get the idea. I looked at three properties and decided we really didn't need a winter getaway.

"Found one!" she said.

"Found what?" I said.

"A Vrbo at Lake Havasu!" she said.

I love Arizona's Lake Havasu. There's a lot of accessible fishing piers, nice parks and trails, and good weather. Terry back-and-forthed several emails with the owner and soon was satisfied that we could make the house work for us. I was all in.

Our friend Super Dave came along on the trip to help out and share the driving. We pulled out from home in Alberta, Canada, at 8 a.m., and, with Terry and Dave trading off at the wheel, arrived at Lake Havasu the next day at noon. I had my headrest on my chair and leaned back to nap when needed, but stayed awake to enjoy the scenery as much as possible. We pulled a 10-foot utility trailer full of immense quantities of gotta-haves behind our Toyota minivan. When we arrived, we got right at it, making the place wheelchair accessible without doing any permanent damage.

The first step was getting into the house. The front and back doors were plenty wide but had lips that needed ramps. In anticipation of steps, we'd brought several pieces of plywood and a 10-foot aluminum ramp. Now we were in. The priority then was setting up the bedroom. The bedroom doorway looked narrow and required a tight 90-degree turn. Terry suggested removing the door. Problem solved.

The queen-size bed looked fine — maybe a tad crowded with our Great Dane dogpiling in, but it would work. To make sure I'd be comfortable, we brought a ROHO mattress overlay. But when we placed it down, we didn't like that my side of the bed was 3 inches higher than Terry's. We purchased a queen-size memory foam and cut out a hole to fit the ROHO, making both sides of the bed an equal height. I like to sleep in a reclined position, so we brought a memory-foam bed-

wedge-pillow set. It lets me relax as I'm used to, and I was as comfy as in our recliner-bed at home. To transfer me to bed, we brought along an Arjo EasyTrack Free Standing portable rail system. It's easy to carry and set up and we found it online for a good price. Dave and Terry had it ready in minutes.

Next up was the bathroom. My commode chair fit fine, but the shower looked tough to manage. The existing enclosure had an 8-inch lip and there wasn't a lot of room for a ramp. Fortunately, our friends Joe and Sue showed up to camp on-site.

Joe happens to be great at carpentry and fabrication, knows my needs, and was happy to problem-solve the tub/shower. "I'll build an insert so your commode wheels don't drop down into the shower pan," said Joe. "It'd be hard to get you back out."

Joe took a few measurements, committed them to memory and jumped in his truck to head to the lumber yard for the needed materials. A while later he returned, unloaded some wood and strolled over to his motorhome. As he started opening storage compartments and pulling out woodworking tools, I was enthralled. I'm not sure how much storage a motorhome has, but Joe takes this number, multiplies it by two and somehow fits it all in.



Kary with the black belt in property research herself, Terry.



The Wrights loaded up their trailer with all the necessities including the Arjo EasyTrack Free Standing portable rail system (above).

Soon you could hear saws sawing, drills drilling and hammers hammering. Then all was quiet; the masterpiece was unveiled. Joe had built a plywood top above the shower pan that my commode chair could roll onto. He'd drilled the plywood full of holes to let the water run through. He carried the insert to the shower and, voila, it fit the shower pan perfectly — of course.

The only thing keeping me from a refreshing shower was an 8-inch rise from the floor to the lip of the shower enclosure. Terry measured, and it looked like a 6-foot ramp would fit in the bathroom. We'd noticed on our mandatory trip to Harbor Freight, the handyman's toy store, that they had folding aluminum ramps. There were various lengths, all wide enough for my commode. I wanted the longest one possible, since pulling a couple of hundred pounds of lard up a steep ramp on little caster-wheels isn't easy. We purchased a 6-foot ramp and headed back to the house. It fit perfectly and wasn't too steep to pull me into the shower.

The last room to tackle was the kitchen. To get close to the kitchen table and have a place to set a laptop, we brought a wooden tray, also fabricated by Joe, and used plastic clamps to temporarily fasten it to the table.

The whole setup worked perfectly. We now had accessible entryways front and back, and a surprisingly comfortable accessible bathroom and bedroom. In a few hours Dave, Terry and Joe transformed a regular inaccessible house into a temporary, fully accessible one.

Wright's friend Joe created a shower insert from scratch; his wife places a ramp over the 8-inch lip of the shower.





ROADMAPS

By Rebekah Taussig and Hannah Soyer

THE FEAR OF EXCLUSION

Dear Rebekah and Hannah,

When I was in middle school my entire group of friends started eating lunch at a table that my wheelchair couldn't get up to. A part of me saw this for what it was — them successfully excluding me — while another part of me refused to believe they could be that cruel and were just eating at a different table because ... what? They liked the view better?

Anyway, fast forward 20 years or so and I have the greatest group of friends I could ask for. Really. The notion of what happened to me in middle school would enrage them. And I know that, and I know that they care deeply for me, but I'm still terrified that someday they'll do something similar — slowly leave me behind, weed me out of their friend group. I don't want this to happen. How can I make sure this doesn't happen?

Sincerely,

Let's Not Repeat History

Dear Let's Not Repeat History,

Is there anything more human than that panic-in-the-gut fear of being left behind, excluded, abandoned? I think it's written in our DNA to do everything in our power to avoid that very feeling. And as disabled people, I think this might be written even deeper into our bodies.

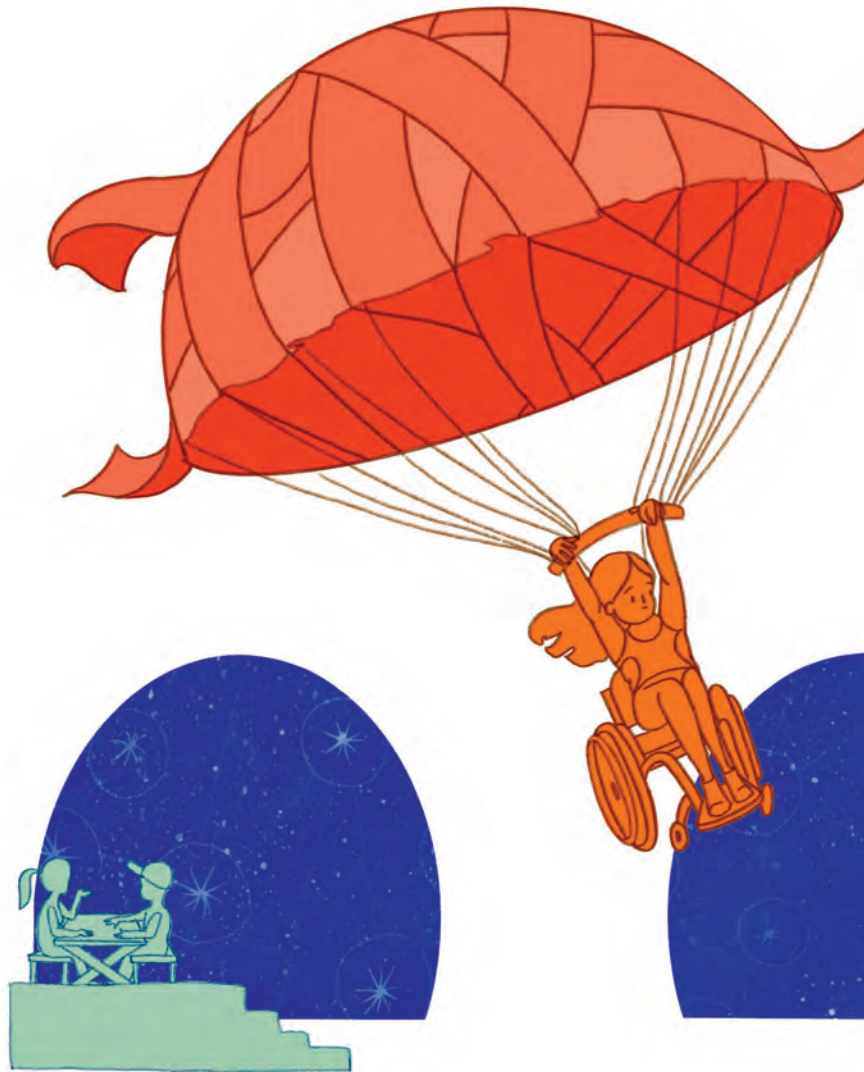
I don't even know how I learned to look for signs that I might be a burden on a friend. I was 8 when I first preemptively cut out a friend from my life before she could cut me out of hers. I worried that going the long way through the lunch line with me was becoming a hassle — that she felt stuck with me on the edges of the inaccessible playground. I know that frantic feeling that can kick up when you sense

someone might be pulling away. I got so good at pulling away first.

And then I fell in love with this man who seemed to have been stitched together out of my dreams. I knew, confidently and quickly, that he was the person I wanted to be with forever. That word — forever — didn't feel scary. Maybe, in part, because I was so sure he felt the same way. Then one night, when he was leaving my house, I threw open my arms and called out to him, loudly and easily, "I love you forever!" He froze in the doorway. Then I froze, staring at his panicked face. And in a matter of moments, this love

that had felt so sturdy became a figment I couldn't grab between two hands. He stumbled over his words. He didn't know how to picture forever with me.

I stopped breathing. My body tingled as every cell in my body blared their loudest alarm: GET OUT. YOU'RE NOT SAFE. END IT. In a matter of moments, we'd decided — let's go on a break. No talking for a week. He left quickly. I cried for days. Eventually, my body settled down enough to take stock. Up to this moment of uncertainty, I felt understood, valued and loved by him. He was kind to me. We made each other laugh. For the first time



ever, I realized that I wanted to be close to this person as long as he wanted to be close to me, regardless of the timeline or guarantees he was able to provide. We stayed together. And counter to all the history that came before, I made the decision to keep my arms open, knowing full well there might be a day when we decide we've reached the end of the road together. Of course, that's the setup with everyone we choose to love. There are so many ways and reasons that people come in and out of our lives. The obvious, terrifying, exhilarating truth we rarely have the guts to face is that there's not a promise in the world that can guarantee we'll never have to say goodbye.

I know the fear in your questions circles around a friend group, and platonic friendships and romantic relationships aren't exactly the same. But the part that felt familiar to me was the grip on the "someday." Will they still be

here next year? Or in five years? I don't know. They don't know.

And letting go of that guarantee can feel exactly like letting yourself fall out of a plane, just hoping your parachute will catch you.

I still hold back and protect my heart a lot. But the time I took a big leap and kept my arms

wide open, despite the risk, I did get this glimpse of something that felt true — we are our own parachutes. Whether or not friends stay or leave or come back, I believe with an aching hope that we will land and grieve and survive.

So, my question to you is: If you knew these friends would only be around temporarily, would you still want them near? If the love they have to offer today feels worth the possibility of grieving their loss one day, then open your arms and soak them up as long as you have them.

Love,
Rebekah

Dear Let's Not Repeat History,

I'm so sorry that a group of people you thought you could rely on ultimately proved you wrong. It would be so easy, and also true, to sum up what happened to you by saying that kids, especially middle schoolers, can be mean. But there's a certain added cruelty when the safety we believed we had with a certain set of relationships is actually not there at all.

I've had a helper for a little over a year now who, over time, has turned into one of my best friends. Let's call him S. He works a lot of hours, which means we spend a lot of time together. S is 23, which means he's still able to be on his dad's insurance, so our current situation works out. The realization that someday this will likely change — whether because he'll need a job that can offer him health insurance, or for some other reason — terrifies me. It's the fear of losing this iteration of our friendship, but it's also the fear of losing my ideal care scenario: having a helper who's not only attuned to my physical care needs but my emotional health as well. Someone who I feel fully comfortable around in my own home, who I can laugh with and hang out with but is also fine to do their own thing if I need time to myself.

Having someone help you live your life necessitates a certain level of intimacy, I think. This is how I've experienced care since I was 3 years old, when I had my first hired caregiver. She came into my life, I became close to her and then a year or so later, she left. This is the nature of these relationships, right? Since that first hired caregiver, I've had close to 90 helpers, who have all, in some way, shape or form, repeated the story of the very first. Being open to explore how this pattern impacts how I engage in relationships — or, as some might say, my attachment style — has been incredibly healing for me, just as pieces clicked into place when the weight of what I call the Big Leave finally hit me: My mom had to leave the operating room that 8-year-old me was trapped in, leaving me terrified and alone with the truth that I

needed spinal fusion surgery to live.

Which brings me to the phrase you've chosen as your signature, and the contradictory nature of our lives. I read your letter and was struck with the realization that I've assumed endings for nearly all of my relationships. And yet, in so many instances this hasn't been true. I still don't know if my ascribing meaning to that moment in the O.R. is just an attempt at making sense of similar hurts in my life, or if, in fact, the desire to not repeat history is futile because we are all, in some ways, reliving our pasts. But of course, that's not true either, and that seems, perhaps, where you're stuck.

From the sounds of it, your current group of friends will not pull the same

"I've assumed endings for nearly all of my relationships. And yet, in so many instances this hasn't been true."

shit your middle school friends did, which is good. But change in friendships — in any relationship — is inevitable, and it's likely that as all of your lives progress, the shape of your friendships will shift as well. It's possible some will leave. We have no way of knowing. What I do know for sure, though, is that the abandonment and betrayal you felt in middle school will not be the same you might feel in the future if your current group of friends were to betray you, because you are a different person than you were then, and they are different people. It may gut you in the same way, but allow yourself to remember that this is different, that history is not repeating itself, but unfolding anew. I have no way of predicting what will happen with S, because each new relationship I encounter is unmapped — and this is the best way I've found to approach life, at least for now.

Love,
Hannah





COLOSTOMY MAINTENANCE

Things to Know About Your Ostomy

BY BOB VOGEL

A year ago, I underwent a colostomy, a procedure I swore I'd avoid. In my 37 years as a T10 complete para, I'd had a reliable bowel program, but I developed a rectal prolapse that was getting worse and required intervention. After an attempted fix with a surgical mesh sling failed, I agreed with my surgeon that an open loop colostomy would give the prolapse repair time to heal. I took solace knowing the colostomy could be reversed in the future.

Yet, like many with SCIs who get a colostomy, I soon found it to be extremely convenient. I could still enjoy my favorite sports, including scuba diving, and it didn't bother my girlfriend — now my wife — or affect our sex life. Realizing this, I decided against reversal. The colostomy does present its own set of challenges, but with help from my surgeon, ostomy nurse and peers, it's been manageable. Here are tips I've learned about maintaining an ostomy.

The Most Important Thing

No matter how much you know about living with a colostomy, unexpected questions and issues are bound to come up. Having good communication with your colorectal surgeon and ostomy nurse is essential. While some problems may require the surgeon's input, many of the day-to-day issues and maintenance questions can be resolved more quickly, and often with more insight, by an ostomy nurse. Ask your surgeon or primary care physician for a referral to establish a relationship with an ostomy nurse who can provide help without delay in the event of an ostomy problem.

Hernias

After surgery, my ostomy nurse fit me with an Ibnotuiy ostomy support belt (see resources) and suggested that I wear it for at least eight weeks after surgery and consider wear-

ing it indefinitely. Support belts are one of the best ways to avoid developing a post-ostomy peristomal hernia — a bulge around the stoma from a weakness or split in the muscle wall of the stomach. “In general, we tell ostomy patients to wait six to eight weeks before doing any heavy lifting to help avoid hernia, which isn’t really an option for people with SCI who need to transfer. So wearing a hernia support belt is the best prophylactic measure to help prevent hernia,” says Dr. James Taylor, my colorectal surgeon.

Studies suggest approximately 40% of nondisabled people who get a colostomy develop a peristomal hernia, while a 2019 study on colostomy with SCI, published in *Topics in Spinal Cord Injury Rehabilitation*, found rates of peristomal hernia in people with SCI to be 8.3%. For me, the belt helped alleviate post-surgical pain around the stoma and continues to provide a supportive feel.

While surgery is an option to revise problematic or painful ostomy hernias, most doctors recommend seeing if you can live with it or trying a support belt to reduce issues. In the 22 years since John Arnow had a colostomy, he has developed a peristomal hernia that bulges out “about the size of a small egg.” An L1 incomplete para, Arnow, 67, has never worn an ostomy belt, nor has anyone ever suggested wearing one. “[The hernia] never bothers me, and is nothing that I would consider a surgical repair over,” he says, adding that his hernia has remained stable despite his being very active in adaptive cross-country skiing and ocean kayaking.

Prolapses

About three months after my ostomy, part of my colon started to prolapse through the stoma. According to studies, ostomy prolapse rates range from 7% to 27%, with colostomies more likely to prolapse than ileostomies. Two leading causes are a stoma hole that is too big, and the presence of extra colon, referred to as “redundant colon.” I fall into the latter category, and wearing the ostomy belt didn’t have an effect one way or the other.

My doctor explained that if the prolapse isn’t causing problems and is easy to reduce, it’s better just to live with it and keep an eye on it. I did this and worked with my ostomy nurse on options to reduce the prolapse by shrinking it and pushing it back into the stoma.

Proposed remedies included putting a cold compress on the stoma, or pouring a few tablespoons of granulated sugar on the prolapse, which should cause it to shrink. I never tried the sugar method, but found that cold water from a shower nozzle caused it to shrink and I was able to push it back into the stoma. My ostomy nurse also gave me a belt with a prolapse cover that put pressure over the stoma to contain it.

Despite my efforts, my prolapse continued to grow — eventually protruding as much as 4 inches — and became more difficult to reduce, making it more difficult to change wafers. My team agreed a stoma revision surgery was reasonable.

There are multiple surgical revision options if a prolapse is causing significant problems. One surgery revises the stoma

and puts in mesh to prevent the colon from prolapsing. Another alternative is a local repair where the surgeon pulls out as much prolapse as possible, stitches up the base, and cuts out the prolapse. It can be repeated if the prolapse returns.

Seven months after my colostomy, I chose the latter. The revision took about 30 minutes. I spent one night in the hospital and had minimal discomfort. The prolapse did return three months later, but so far, seven months later, it remains small and easily manageable. If it gets difficult to manage again, I will opt for another simple revision surgery in hopes there will be less redundant colon left to prolapse.

Skin Maintenance

Surgical repairs and revisions can make unwanted bulges quickly disappear, but there are no such simple surgical fixes for compromised skin. This makes regular maintenance and vigilance imperative.

Ensuring the ostomy wafer seals well to your skin is one of the best ways to avoid blowouts and leakage, and to protect your skin. In his 10 years with a colostomy, Eric Stampfli has learned what a difference the right soap makes. “Only wash with Ivory soap. It enables the wafer to stick much better because it doesn’t have any moisturizers or additive that will leave a film on your skin,” says Stampfli, 65, who is in his 48th year as a T11 para. “I

The author says his colostomy hasn’t hurt his sex life or his scuba life.



also put the wafer under my arm for a minute or two to warm it up, and make sure the skin is completely dry before applying it.”

By following Stampfli’s advice, I haven’t had a leak or blow-out ... yet. I generally change my wafer every two to three days, and that includes days when I’m swimming or bathing. Other good suggestions include using a blow-dryer — with no heat if you don’t have sensation — to dry the skin around the stoma, and with heat to warm up the wafer.

Even with careful application, an ill-fitting wafer can exacerbate skin problems. Mark Fuglevand, a C6 incomplete quad who got a colostomy five years ago, has had problems with skin breakdown because of stool getting under the wafer. He has a flat stoma and a spastic stomach which would pull away from the wafer. “For me avoiding skin breakdown is finding a proper-fitting wafer,” says Fuglevand, a 46-year-old United Spinal As-

sociation member. “I found a flat, very flexible wafer called the New Image by Hollister, which stays on three or four days without leaking.” But even with the right wafer, runny stools can still get underneath to cause weepy skin. Changing the wafer more often is the best solution.

Arnow has an indent next to his ostomy that makes achieving a good seal with the wafer tricky. To keep his skin healthy, he fills the indent with a round protective seal made by Eakin. As an extreme ocean kayaker, Arnow found that his spray skirt, which seals around his waist and keeps water out of the kayak, also constricts his ostomy, and, if anything is coming out, can cause a blowout. He says, “I reinforce and build up the wafer with a ‘Y’ barrier” — an elastic adhesive strip that lifts and provides extra wafer support around the stoma.

Another ostomy challenge can be skin irritation or breakdown around the stoma. “I use a nonalcohol adhesive wafer remover so it doesn’t pull on skin,” advises longtime *NEW MOBILITY* editor Tim Gilmer, 79. Gilmer got his colostomy six years ago, in preparation for a flap surgery after over five decades as a T11 paraplegic. His bit of advice has served me well, especially when I’ve needed to change a wafer on the fly, because the adhesive remover leaves skin clean and ready for a new wafer to stick on the skin.

Skin-protectant barrier wipes and sprays are another option, though none of the people I’ve interviewed use them. For Stampfli and me it is because, with sensation, some barrier wipes containing alcohol are painful to compromised skin.

When skin does break down, Gilmer uses a fungicide powder to absorb moisture and help heal skin. A method I employ to heal weeping or open skin is to wash it, pat dry and apply a 40% zinc oxide paste like Desitin or Boudreaux’s Butt Paste. I leave it on for five to 10 minutes, then wipe it off and reapply a wafer. Other times, I’ll put a thin film of zinc oxide paste on the red area around the stoma and apply the wafer. The caveat is that the wafer won’t stick where the zinc oxide paste is, but usually this clears up the skin by morning when I check and change the wafer again.

Poop Problems

With a colostomy it is vital to take steps to stay regular and manage the consistency of your stool. To avoid constipation, most colorectal surgeons recommend drinking at least 64 ounces of water or other noncaffeinated beverages a day, and taking a fiber supplement for bulk, like the psyllium husk found in Metamucil. For Gilmer, the first step is taking time to fully and completely chew food. “I’m always the last one at the table because I’m very careful to do this,” he says. Gilmer adds that eating too many carbs will back him up, so he focuses on getting a mix of fruits, vegetables, protein and fewer carbs in small-to-medium portions, along with water at each meal. For good motility, Arnow strives to keep things loose enough to avoid large, hard stools that can get obstructed. “When I haven’t had enough fruit, this

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can happen,” he says. “I make a conscious effort of eating blueberries and flax seed and drinking plenty of water.”

When things do slow down, Gilmer takes a capful of Miralax to get things going. Many ostomates rely on regular doses of milk of magnesia. When my digestion slows to a crawl, I will take two Colace stool softener capsules in the morning and at night and a capful of Miralax powder prior to bed. This helps within a day or two, albeit sometimes uncomfortably, as hard stools pass through the stoma. Talk with your surgeon for guidance on which laxative might work for you.

“Ghost poop” may sound like something from a bad horror film, but rectal mucus is a real challenge for some ostomates. It happens because even though stool no longer goes through the last part of the colon, the walls of the colon continue to produce mucus. A brief digital stimulation usually helps get rid of excess mucus. Stampfli adds the precaution of putting a thin feminine hygiene pad in his underwear. “This accomplishes two things — it absorbs any excess mucus, and it provides a bit more padding to protect your butt from pressure ulcers,” he says.

If rectal mucus becomes excessive, painful or is accompanied by bloody discharge, it can be a condition called diversion colitis and is something to ask your physician about. “When/if diversion colitis does happen, a doctor can prescribe an enema with short-chain fatty acids that will provide nutrients to the colon wall, which usually helps,” says Dr. Taylor. M

COLONOSCOPIES FOR COLOSTOMIES

If you have a colostomy, it is still important to get a colonoscopy for cancer screening. Your colonoscopy should include the end of the colon, the part that is no longer hooked up. Ask your doctors about it if they don't mention it first.

Resources

- “Colosto-Mania,” newmobility.com/colostomy-pros-cons
- Coloplast, products.coloplast.us/products/ostomy-care
- Hollister, hollister.com/en/ostomycare
- Ibtnotuiy Ostomy Support Belt, amazon.com/Ibtnotuiy-Abdominal-Colostomy-Patients-Parastomal/dp/B07DXK2847?th=1
- “Making Sensible Ostomy Solutions,” newmobility.com/making-sensible-ostomy-solutions
- “What Is Diversion Colitis?” verywellhealth.com/diversion-colitis-treatment-options-4169406
- “Why Some Wheelchair Users Wish They'd Chosen a Colostomy Sooner,” with “Irrigating a Colostomy” sidebar, newmobility.com/why-some-wheelchair-users-wish-theyd-chosen-a-colostomy-sooner



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TRAVELING WITH AND WITHOUT A CAREGIVER

For many wheelchair users, deciding whether to travel alone or with a caregiver or companions who can help you can be tricky

BY JENNY SMITH



Nicole Roy

I still remember landing in Philadelphia, wrangling my small luggage with three days of clothes onto my lap, pushing through the busy terminal and catching the downtown train to my hotel. By myself. The trip was for a checkup with the surgeon who performed my Mitrofanoff bladder surgery and to visit a few friends in the area. I didn't have my mom tag along. The sense of independence was beyond liberating. As corny as it sounds, I felt like a grown-up. I had traveled overseas regularly for work with co-workers, but navigating the streets of a large city on my own was intensely gratifying.

For many wheelchair users, deciding whether to travel alone or with a caregiver or companions who can help you can be tricky. As appealing as solo travel is, not everyone is physically able. On the flip side, sometimes you can travel

alone, but doing so comes with unexpected costs. How can you know if you should go it alone? And when is it better to travel with help? That answer is different for everyone.

As a C6-7 quad, not all travel is doable on my own. I decided to make that short trip by myself since I was familiar with Philly, had friends and family nearby for what-if scenarios, and, most importantly, because my time away was brief enough that I could wait to do my bowel program and showering until I returned home.

When it comes to deciding whether to travel alone or with a caregiver and how to do so, there are no definitive solutions, only what works best for you. I spoke with three wheelchair users with different needs to see what their approaches are and what they've learned on the road.

“Recently, I’ve been using care.com, but for over a decade I used Craigslist.”

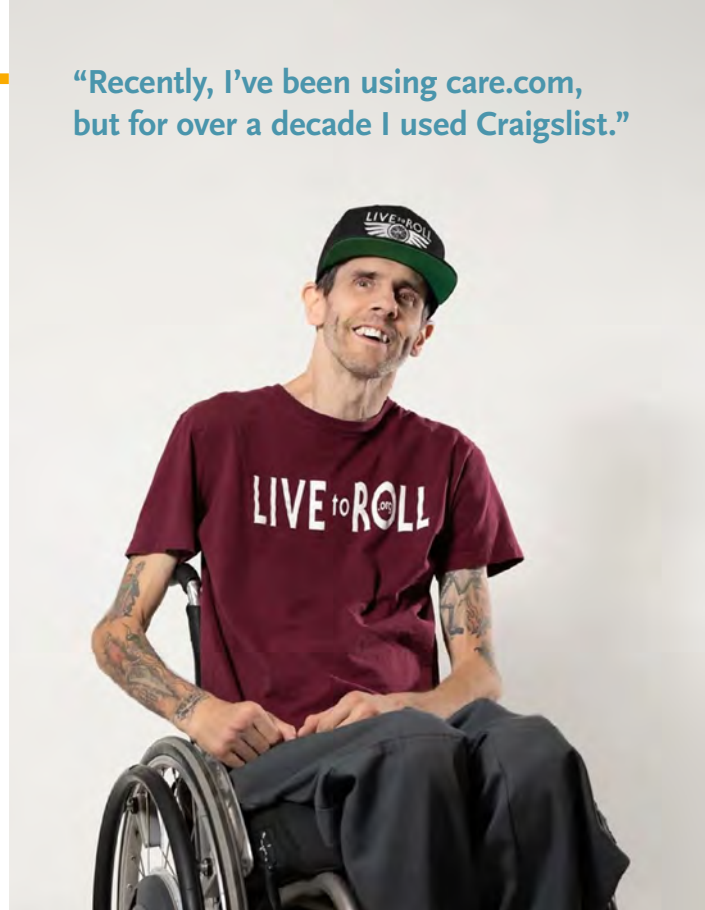
A SIMPLE SOLUTION: ADVERTISE

As the founder of a nonprofit and a longtime rugby player, Shawn Fluke is no stranger to travel. Fluke is a C5-6 quad and needs assistance when he hits the road for rugby tournaments. His solution for finding someone to help with bowel care and showering is to advertise at his destination. “Recently, I’ve been using care.com, but for over a decade I used Craigslist,” he says. “I place an ad two or three weeks before my trip. And I usually get a few responses.”

He vets potential hires via phone interviews. “I would talk to them and do a phone interview and see if it is going to work,” he says. “I’ve been fortunate that it’s worked out for the most part. Although, I have had a couple of mishaps.” When a caregiver no-showed, Fluke had to scurry to hire another person the morning that the care was needed.

Since Fluke only has help for bowel care and showering, he still needs to navigate transferring in and out of mile-high hotel beds. “About 90% of hotel beds I can’t transfer into, but I’ve always been able to get the maintenance person — even a front desk worker — to remove the box spring,” he says.

Despite often having family at rugby or conferences, they don’t usually take on any caregiving responsibilities. For an upcoming rugby tournament in Switzerland, Fluke asked his brother to travel with him. So, is his brother coming as a caregiver or as a brother? “He is kind of coming as a mix, and that’s why I am splitting his ticket with him,” he says.



Fluke shares more tips each week on [youtube.com/livetoroll](https://www.youtube.com/livetoroll).

LET A VACATION BE A VACATION WITH A CAREGIVER

For C4-5 quad Corey “Pheez” Lee, traveling without assistance is out of the question. Further complicating the issue is that Lee is now a husband and father to two young boys. His wife is capable of handling his care, but having her do so comes with a cost. “I want freedom to travel alone with my spouse,” he says. “But then, because she has to take on all of that stuff, it’s not really a vacation.”

In 2014, he and his wife drove to Baltimore, Maryland, so he could have intensive therapy at the Kennedy Krieger Institute. “We traveled with a caregiver on this trip, and it was super helpful. About 40 minutes from the house, I had a bowel movement,” he says. “So, it’s like, what do we do now?” They decided to stop at a hospital. With the help of the caregiver, he got cleaned up. “Who would have watched our 3-year-old if I didn’t have the caregiver with me?” he says.

The caregiver was also helpful in maintaining a daily routine and alleviating that responsibility from his wife. Lee said the Department of Veterans Affairs paid for 4 hours of care per day, but he had to pay for the other 20 hours, plus meals. Lee also paid for a separate room for the caregiver.

Lee is learning to manage the delicate balance of needing assistance but not letting it impinge on his travel. On his family’s first trip last year, Lee traveled with his nephews, sister-in-law and mother-in-law to Hershey, Pennsylvania. “Thank God for them,” he says. “When we arrived at the hotel, the Hoyer we rented didn’t fit under the bed. They ran up to Target to get bed risers and set up the air mattress I use.”



Lee (pictured with his caregiver) would like to travel alone with his wife, but “then it’s not really a vacation” for her.

JUMPING IN AT THE DEEP END

Nicole Roy didn't have the luxury of slowly learning how to manage her care while traveling. After coming home from spinal tumor surgery as a T9 para in August 2022, she was back to work as a strategic account executive by the beginning of September. She had been sent home without rehab, sitting in a folding hospital chair. With four days' notice, a new boss requested that she attend a work conference in Minnesota. "Because I had switched positions, nobody knew my situation. So, I told myself, 'We're doing this.' I was so naive," Roy says.

After watching hours of YouTube videos and making three calls to the airline — and receiving three different answers — she drove herself to the airport for her first flight. She used a luggage strap to fasten her luggage to the frame of her chair like she learned in a video. "Oh, my gosh! I wish I had a video.



Roy's first trip was tough, but she learned a lot about asking for help.

The cracks in the sidewalk, every speed bump and rumble strip ... the luggage kept falling. I didn't account for any of that," she says.

Her flight to Minneapolis went smoothly, and she eventually found a ride to the conference, despite two Ubers refusing to give her a ride. From the outside, it looked like she had figured everything out. A colleague even mentioned, "You acted like you had it together." "The truth was," says Roy, "I was a wreck on that trip. I was nervous. I was nauseous. Looking back, I never should

have traveled. My body was not ready."

Rather than being scared off from traveling, she's implementing all she's learned into planning her next trip. "Someone is driving me to the airport and will help me get my luggage inside. I'm flying by myself but meeting two [non-disabled] friends," she says. "I'll have my own room, but just having an extra helping hand available relieves some of the stress of traveling."

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FOUR QUESTIONS TO ASK YOURSELF WHEN DECIDING IF YOU NEED TRAVEL HELP

1. How accessible is the place I'm going?

Accessibility, or lack thereof, can be the determining factor if a caregiver or helping hand is needed. But this isn't always a black-and-white decision. I rank my destinations in three categories: Accessible, Do-able, or Crap shoot.

Accessible places are manageable alone. Crap shoots are full of sketchy accommodations that make me ask how lucky I feel. Do-able is somewhere in between. Even if the location falls into my Accessible category, we all know accessibility varies. Always be ready for the worst.

On a recent road trip to Nashville, I stayed at a hotel chain that had been perfect for me in another city. When I opened the door to my accessible room, to my surprise the bed was ... low! Too low to safely transfer out of bed by myself. So, I asked to look at another room. I ended up in a regular room that was tight in the bathroom, but I could transfer safely.

2. What do I need from a travel companion and who best fits this profile?

Choosing the right person to travel with is difficult. Expectations for the caregiver's responsibilities need to be clear. I have a page-long job description for a "travel buddy" that outlines everything I need help with — or might need help with — depending on what accessibility we find there. I don't want to blindside anyone.

But even when you go prepared, things may not work out. For a work trip to the Middle East, I had an experienced nurse accompany me. Perfect fit, right? Except this nurse was freaked

out by the bowel program. This caused considerable tension and scheduling conflicts throughout the 10-day trip.

Time after time, my best experiences of traveling with a caregiver happen when my PCA, either current or former, traveled with me. They know the routine. Hopefully, you already get along. And you know each other's likes and dislikes.

3. How will we split the bills?

The tricky part of traveling with somebody who will provide some personal care is what — or if — to pay them. These expectations need to be clearly defined before the trip begins. Who is responsible for the plane ticket, hotel and food? What about drinks? Snacks? While uncomfortable to talk about, it's better than either of you having unmet expectations.

4. Is my plan safe?

The final consideration about whether to travel alone or with a companion is safety. While I'm willing to take a risk, I'm not going to be stupid. When I was meeting co-workers in Atlanta to fly to Europe and on to Central Asia, their plane was delayed and it looked like they weren't going to make the connection. I had to decide whether I should board an 8-hour flight with no access to a bathroom, then get to a hotel with no accessible transportation. I decided I needed to wait. Thankfully, their flight arrived, and we made the connection, but some things I know I can't do without some assistance.

— JENNY SMITH

DRIVING CALIFORNIA'S PACIFIC COAST HIGHWAY

BY LILLY LONGSHORE



Thomas Ciszewski/Unsplash



California's Pacific Coast Highway is one of the most beautiful and famous stretches of road in America and had long been on my must-do list before my husband and I finally checked it off last year with an unforgettable road trip. Covering over 650 miles from the luscious redwoods of Leggett in the north, to the sunny beaches of Dana Point in the south, PCH, also known as Highway 1, packs more stunning locations per mile than any other road I've driven.

Google says if there's no traffic you can drive the entire stretch in a little under 12 hours — but don't even think about it. Though beautiful, a lot of the driving is curvy and hard. On top of that, you'll want to leave plenty of time to see all the sites and explore. We gave ourselves 12 days to cover around 450 miles, starting at PCH's inception in Leggett and following it down to Santa Barbara. I ferreted out as many accessible trails and boardwalks as I had time for, appreciated historical sights and quaint towns along the way, and had a fabulous adventure-filled journey. Obviously, not everyone can take that long, but rest assured, no matter how long you have, there will be plenty to do and see.

UNDER THE GIANTS

Before we started our adventure down PCH, we spent two nights in Arcata to take in the redwoods. The majestic Redwood National and State Parks start near Crescent City. Shrouded in the redwoods' shade, alternating with bands of green-hued sunlight, I made my way to Klamath along U.S. Route 101, and stopped at Trees of Mystery. Its giant Paul Bunyan and Babe the Blue Ox are great for little kids, and a gift shop, museum, cafe and accessible gondolas over the tree-tops provide a nice variety at this touristy but pleasant stop.

But 10 miles down the road, Prairie Creek Redwoods State Park had what I really wanted — miles of accessible trails through this wonderland. Of the trails I rolled, the Karl Knapp/Prairie Creek Foothills Trail is especially marvelous. This peaceful loop formed of packed dirt and fir needles meanders 2.5 miles along Prairie Creek, beneath some of the tallest, most majestic redwoods in the world. I used my manual chair with a free-wheel, but the visitors center does offer an all-terrain track chair. Words cannot describe the beauty and magnificence along this path.

After rolling through the redwoods, I headed south on U.S. 101 for a scenic day of driving. At Scotia, I took the 31-mile Avenue of the Giants, which parallels U.S. 101 through more towering redwoods. I stopped at Grandfather Tree Gifts in Piercy to see an ancient 1,800-year-old redwood and peruse artistic redwood carvings, T-shirts and souvenirs. The shop and grounds are wheelchair-friendly. I passed through Garberville and other small towns until Myers Flat, where I rejoined U.S. 101.

LEGGETT TO SAN FRANCISCO

Now our journey down PCH would begin. Leaving Leggett, the road winds past rocky cliffs, tall forests and sunny meadows. After a few hours of leisurely travel and in need of food and a restroom, I lucked out to find Tony's Seafood Restaurant in Marshall, planted on the edge of the continent. It combines great food, a great waterfront view and nice accessible facilities.

I chose Fort Bragg for my first stop, as it was an easy, unhurried distance from my last stop in Arcata, and was close to Mendocino, which I wanted to see. The quaint town of Fort Bragg grew up around a former military garrison established there in 1857. I was ready to settle in for a couple of nights at the Seabird Lodge and explore. I discovered the Noyo Headlands Trail, a 5-mile paved path edging the shoreline near downtown. It cut through rocky terrain with



sandy stretches, and I watched seabirds catching air currents and crashing waves as I rolled, stopping occasionally to read the informative interpretive signs scattered along the trail.

North of Fort Bragg, MacKerricher State Park's Laguna Point Interpretive Trail runs a short 0.6 miles but offers great sea views and plenty of scurrying ground squirrels. With a nearby trestle bridge and looping boardwalk, it's an ideal place to hang out.

The charming town of Mendocino lies 10 miles south of Fort Bragg. Fans of '80s TV-hit *Murder She Wrote* will be excited to find Jessica Fletcher's stage house here. I had no idea. Briefly I wandered through the rustic town, where accessible shops were hit or miss. I grabbed a cup of coffee at wheelchair-friendly Goodlife Cafe & Bakery and got back on the road.

The next 100 miles covers rocky cliffs, oyster-filled bays, and beaches with varying degrees of access. The Russian River area is a great place to adventure from, and if you're looking for a fancy overnight, you'd be hard-pressed finding better than AutoCamp Russian River in Guerneville. You can sleep under a grove of redwoods in a fully outfitted accessible cabin. For more redwoods, Muir Woods National



Clockwise from top left: Prairie Creek Redwoods State Park; MacKerricher State Park's Laguna Point Interpretive Trail; Mendocino charm; a raft of sea otters.



Monument, just north of San Francisco, is a can't-miss. The park's 1.5-mile loop may not sound long, but it's easy to fall under the spell of these awesome canopies.

THE BAY AND BEYOND

San Francisco has enough accessible highlights to fill multiple guides, but if you're looking to maximize your sightseeing time, you could do a lot worse than pulling off PCH and using the Golden Gate Bridge Plaza as a base to explore the surrounding area. The plaza offers amazing views in all directions — possibly better for wheelchair users than on the bridge itself because the bridge's guardrails obstruct seated views — and you can find many stunning paved

trails within easy rolling distance. We enjoyed two nights of family time with my niece in San Francisco, then drove 115 miles south to Monterey.

Monterey is home to the world-class Monterey Bay Aquarium and plenty of exciting shopping and dining. I loved the aquarium's open-deck "Life on the Bay" exhibit, but my biggest delight was a baby sea otter who dove down inside the huge otter tank and hovered inches from my face. I think the little guy was attracted by my salmon-colored jacket. In town, Cannery Row vibrated with life and smells of seafood. If you need to work off a tasty meal or two, you can catch the 18-mile Monterey Bay Coastal Recreation Trail just a few blocks from Cannery Row. I wheeled past the palm-dotted seashore, rocky coastline and sailboat-filled marina to Old Fisherman's Wharf, with its souvenir and snack shops clustered along a timeworn pier.

Heading south from Monterey, road signs warned of a closure ahead due to seasonal flood damage. Thanks to the proximity of the harsh ocean and often-extreme conditions on the road, this is a regular occurrence up and down PCH. I drove as far as I could anyway, to see what I knew to be picturesque coastline vistas. I passed spectacular views of the rocky Pacific coast, lengths of white sandy shores, and waters so blue it hurt my eyes. I made it south of the dazzling Big Sur region, near the tiny hamlet of Lucia, before having to double back toward Monterey and detour down U.S. 101, arriving in the small coastal city of Morro Bay.

MORRO BAY

A true gem, Morro Bay surprised me with a "raft" of sea otters, where great numbers of them float together in the water, claiming a portion of the bay as their home and nursery. At any time of day, I could roll to the waterfront and watch as they groomed and scratched, twirled and paddled around. One mama was still nursing her baby, who was nearly as big as she was. Adding to the magic was that Morro Bay's sidewalks, boardwalks, parks, shops and restaurants are largely accessible, making it a treasure in my book.

Just past the otter nursery, Morro Rock rises an impressive 576 feet out of the coastline. Historically a sacred spot to the native Salinan people and a navigational aid for mari-



“Pismo Beach delighted me with miles of sandy beach and an accessible pier with a ramp leading to the sand.”



The author borrowed a free beach wheelchair at Sandcastle Inn and explored the expansive shoreline of Pismo Beach.

ners, today it is a state historic landmark and nesting site for cormorants and peregrine falcons. If you want to hit the beach here, a city-owned beach wheelchair is available for free at the parking lot.

Originally, we planned to leave Morro Bay and head inland to check out Sequoia National Park. Flood-damaged roads forced us to change our plans, so we extended our stay in Morro Bay and kept exploring. I took a day trip north to the scenic headland of Ragged Point, past a beach brimming with elephant seals, as well as south to the cities of Pismo Beach and Santa Barbara. Pismo Beach delighted me with miles of sandy beach and an accessible pier with a ramp leading to the sand. I borrowed a free beach wheelchair at Sandcastle Inn and explored the expansive shoreline, including the area beneath the substantial pier.

My husband did not want to get into areas of heavy traffic closer to Los Angeles, so we made Santa Barbara our southernmost destination. Santa Barbara offers the iconic California scene of palm-lined sandy beaches against blue waters for as far as the eye can see. The wide, accessible Santa Barbara Coastal Trail goes for 2 miles along Cabrillo

Boulevard and leads to the doable but very bumpy Stearns Wharf, giving access to a gorgeous waterfront. Shops and restaurants along this famous, old deep-sea wharf provide entertainment and reason to linger.

A few miles north of town, I toured the accessible areas of Old Mission Santa Barbara. Built in 1786 by the Spanish, the remarkable, archaic structures are still viable. The mission includes a multiroom museum with period artifacts; antique documents and pictures; a quaint gift shop and peaceful courtyard, all of which are accessible. The garden and cemetery are not wheelchair-friendly. The adjacent St. Barbara Parish with its cathedral ceiling and warm natural lighting is accessible and still offers weekly mass. Franciscan friars, following their values of caring for the poor and promoting social justice, still call this ancient mission home.

After days of travel, I had a solid idea of what California's northern and central coasts had to offer. Throughout my trip, I was deeply moved by the effort and care consistently taken for inclusivity by the state parks, hotel and restaurant owners, and the people. This visit left a pleasing impression on me and a sincere desire to return for more. **NI**



DON'T LET YOUR BOWELS GO ON HOLIDAY WHEN YOU DO: TIPS TO MAINTAINING REGULARITY WHEN YOU TRAVEL

BY JOANNE SMITH

Whether it's a trip home to visit family, a weekend getaway, flying to the islands or heading off on an adventure tour, it's a time to relax, have fun, soak up the sun and indulge in delicious food. But we all know enjoying too much of Uncle Bob's famous mac and cheese, tucking into rich, delicious local cuisine and/or sipping one too many creamy tropical cocktails can make our neurogenic bowels feel a little neglected or, worse, over-

whelmed. This has the potential of ruining part or all of your vacation.

Let's face it, savoring a daily breakfast croissant or a warm baguette while wheeling the streets of Paris is hard to resist. But all that gluten has the potential of backing up our bowels for days, or longer. While this might seem worth the risk, constipation can contribute to low energy levels, abdominal discomfort, gas and/or urinary incontinence from added pres-

sure on the bladder. All of these consequences, especially the last, can dampen our travel experience and result in ruined plans, unintended expenses and unneeded stress.

Upon returning home, it can take days or weeks to regain some semblance of balance to regular bowel programs. As a nutritionist, I've spent a lot of time figuring out how to prevent potential bowel issues, keep things moving manageably, decrease stress, avoid excessive weight gain and maintain energy levels without sacrificing the ability to enjoy local fare.

By following a few easy steps, planning, and being mindful, you can immerse yourself in new culinary adventures, savoring unique foods and flavors without worry. Bon voyage and bon appetite!

BOWEL BASICS

First, no matter your destination, stick to your regular bowel-management routine as much as possible. Bowels love routine, but if you suddenly adopt a Mediterranean lifestyle and start eating dinner close to midnight, sleep in, and switch your routine from morning to midday, your bowels might go rogue.

Next, plan ahead. Any vacation involves planning. You've put considerable time, effort and money into organizing your vacation, so put the same energy into planning for your bowel program. For example, if it's been your dream to scuba dive at the Great Barrier Reef, book your dive on a nonbowel-routine day to avoid possible mishaps in your wetsuit. Planning also includes ensuring you've packed all of your bowel supplies and medications. This may seem like a no-brainer, but when you get caught up with packing spare tires, inner

tube patches and adaptive equipment — plus booking accessible hotels and trying to sort out transportation — these necessities can easily be forgotten. Once you discover that you've left your laxatives at home, you'll be scrambling to find the nearest pharmacy, which may not carry your same brand or dosage. This can lead to intestinal irregularities or accidents. This is not the way you want to start or spend your trip.

Similarly, if you rely on nutritional supplements to help answer nature's call, take them along with you. Just like with bowel medications, different desti-

nations will not necessarily have the same products, strains or dosages, and changing these up can lead to undesirable effects. I recently drove to Key West for five weeks and made sure to pack my regular fish oils, probiotics and hemp seeds — and below I explain why these three are my must-haves when traveling. When we arrived, my friends laughed at my stock of health goods, but within two days they were feeling “vacation constipation” and reaching for my hemp seeds to mix into their smoothies.

VACATION CONSTIPATION

Vacation constipation can become an issue for any traveler, regardless of age or disability. It can occur for any number of reasons, such as changes in altitude, schedule, diet and stress levels — and travel-related stress can be enormous for users of mobility devices due to the risks for devices getting damaged or lost, and resulting loss of function, independence and well-being. If you haven't had a bowel movement for three or more days, consider yourself constipated. Here are some ways to prevent and/or relieve it.

Stay Hydrated: Dehydration slows the movement of waste through our intestines and contributes to hardened stool. Many people with mobility impairments, me included, intentionally dehydrate themselves prior to and during flights because of the challenges of accessing tiny onboard washrooms. Add in flying altitude, and you have a perfect recipe for vacation constipation before your trip has even begun. Some people also dehydrate over the duration of their holidays because of limited or nonexistent accessible washrooms. To combat the risk of dehydration:

- Drink at least 2 liters per day leading up to the day of your flight.
- Drink 500 milliliters of water as soon as you land.
- If you day-dehydrate during your trip, drink 16 ounces or 2 cups upon waking and do a preventative pee before leaving your accommodation for the day. When you get back, drink another 50 ounces over the course of the evening.
- Search online for major hotels or fast-food restaurants close to where you'll be going for the day. These facilities usually have accessible washrooms so you won't have to parch yourself.
- In warmer climates, keep a water bottle handy while exploring. Consider drinking coconut water, which replenishes electrolytes lost when sweating.

Maintain Fiber Intake: When it comes to keeping your bowels on track, fiber is your friend. Fiber is critical to proper functioning of the large intestines and can help prevent or reverse constipation. It provides roughage that passes through the digestive tract relatively unchanged while simultaneously softening stool, which promotes regularity. When traveling, we're often tempted by new varieties of refined carbohydrate-rich foods and tend to eat more of them than we normally would at home. Think pastries, naan, baguettes, croissants, cakes, bagels and pasta. While delicious, these high-carb items are low in fiber. Enjoy these foods, but



The author loves to travel and has invested a lot of time figuring out how to make it work.

don't go overboard with your consumption. Have a couple bites of the baguette instead of the whole thing. Share that Danish with your friend. Then balance your intake with fiber-rich foods. The bonus is that fiber will also help balance your blood sugar levels to sustain your energy so you can partake in all your planned activities, and it's beneficial for weight management as you're eating those carbs. Here are some easy tips to increase fiber intake throughout the day:

- Add hemp, ground flax or chia seeds to your breakfast smoothie or yogurt. If I'm going out for breakfast or staying in a hotel, I take along a Ziploc bag of hemp hearts. Just 3 tablespoons of hemp hearts provides 3 grams of fiber. People with spinal cord injuries should shoot for 19 grams per day.
- If staying in an Airbnb, stock your fridge with hummus and baby carrots and pack high-fiber travel snacks to eat throughout the day.
- Make sure you have some vegetables every day. Keep it simple and have a salad for lunch and a side dish of vegetables with dinner.
- When trying local breads and pasta, incorporate whole grain versions if they have them.

Take Probiotics: A healthy balance of good bacteria in the intestines can enhance peristalsis and help prevent constipation. Not only will the following fermented foods help maintain regular bowel function, but they will also enhance your overall immunity:

- Eat yogurt or kefir for breakfast several times a week.
- Order sauerkraut as a side dish or to load on your bratwurst sausage.
- Take a daily probiotic supplement, preferably one that contains 8 billion to 15 billion microorganisms and has at least five different bacterial strains, including *Lactobacillus acidophilus* and *Bifidobacteria*.
- To help ward off altitude-induced constipation and potential stomach upset from unfamiliar bacteria, two to three days before I leave on vacation, I double up on my daily probiotics.

Take Omega-3 Fish Oils: Fish oils can help alleviate constipation. These healthy fats help to lubricate the intestines and soften stool. Take one to two 1,000-milligram capsules to help prevent or manage constipation. As with any supplements, always consult with your health care provider first.

Keep Moving: Holidays are a time when we tend to throw our regular exercise routines out the window. It's also challenging to keep active when you're stuck on a plane or sitting in a car on a long road trip. However, physical activity and movement not only help to burn off calories, but they also play a crucial role in maintaining regular bowel function. Make it a routine to:

- Take daily, leisurely wheels along the boardwalk and exploring the surrounding streets. These are relaxing ways to keep moving without feeling forced into a monotonous workout routine.
- If you're able and so inclined, rent a handcycle or go swimming.

WHY YOU SHOULD GET TRAVEL INSURANCE

On the off chance you take all the steps I've listed and still end up with bowel problems, travel insurance could be your get-out-of-jail-free card. A friend got a kidney infection while traveling in Europe. The medications he was prescribed gave him a bad case of traveler's diarrhea and subsequently made him miss his flight home to Canada. His insurance not only covered new flights home for him and his wife, but also the extra nights in the hotel, cab fares and all other associated expenses.

TRAVELER'S DIARRHEA

You're now equipped to keep things flowing, but what to do if they don't stop flowing? Traveler's diarrhea from the introduction of new dishes and/or unfamiliar bacteria from foods and drinks can wreak havoc on your travel plans. Here are some strategies to help prevent and manage this digestive dilemma.

Drink Alcohol in Moderation and Avoid Foods High in Processed or Saturated Fats: Vacations are meant to be fun, but introducing or overindulging in ice cream, candy, chips, alcohol and greasy fast foods is known to cause the scoots. The extra fat in a lot of these foods breaks down in the colon, causing the release of extra fluids, which will suddenly have you propelling your chair at speeds you never thought possible. Be hyperaware of what and how much you're eating and drinking. Ask yourself if that extra order of deep-fried shrimp is really worth it.

Know and Listen to Your Body: Part of the travel experience is trying new foods, but if you're lactose intolerant at home, you're still lactose intolerant in Rome. Skip the gelato.

Increase Soluble Fiber: You read that right. Fiber acts as a regulator of bowel movements, regardless of whether you are suffering from constipation or diarrhea. For diarrhea, soluble fiber can help absorb excess water, leading to better-formed stools. Fiber also helps maintain a healthy gut microbiome, providing nourishment to beneficial bacteria, which improves digestion.

- Eat oats for breakfast.
- Snack on apples and sunflower seeds.
- Include legume and lentil dishes in your regular meals — they're loaded with soluble fiber.
- Increase these fiber-rich foods gradually.

Eat Foods That Bind: If you've been spending more time sitting in the lavatory than the lounge chair, then bananas, white bread, eggs and applesauce can help bind. ■

JAIMEN HUDSON

Eyes in the Sky

By Alex Ghenis





Photo by Jaimen Hudson



Hudson and his wife, Jess.

BEFORE HE RACKED UP CREDITS filming for Netflix, PBS and the Australian Broadcasting Company, and before he ever dreamed of amassing over 200,000 Instagram followers, Jaimen Hudson found himself in the same situation as so many others after spinal cord injuries: seeking some job or pursuit that would provide him purpose.

As the son of boating tour guides in the southern coastal town of Esperance in Western Australia, Hudson envisioned a life working on and around the water. “My earliest memories are of just being around the ocean,” he says. With beautiful bays, white sand beaches and, nearby, the 105 islands of the Recherche Archipelago, Esperance is driven by the marine tourism industry. Hudson earned his scuba license by age 10, and in high school, checked off the courses and certifications that would help him to work in marine tourism. His goal was to be a deckhand by graduation and to keep building from there.

He spent time diving among the corals and migrating whales, and rode dirt bikes on the flowing sand dunes for the adrenaline rush. But in July 2008, at age 17, a motorcycle accident brought Hudson’s plans to a halt. He came up short on a dune jump and flew over the handlebars, resulting in a C5 SCI.

Less than a year after his injury, Hudson started thinking again about his future. “I told my mom I wanted to hate going to work on Monday just like everyone else, because I didn’t want to sit around at home,” he says. “I wanted to have a purpose and feel like I was contributing.” He stayed close to the water, filling a number of roles in the family’s boat touring business—answering phones, accounting and, eventually, managing it too.

Discovering Drones

By 2015, Hudson was itching for something new. There weren’t many accessible activities in Esperance, and the combination of work and parties was growing dull. It was perfect timing, then, when a customer brought a new drone along on a boat tour to a nearby

island. The client was filming promotional footage for a soon-to-be-released model drone. At the end of the trip they gave Hudson some of the footage. “I was blown away with how cool the perspective was,” he says. “I started thinking, maybe this is something I could do from my wheelchair, perhaps that [it] could be my new hobby.”

He began watching the limited number of YouTube videos available on how to fly drones. “I was wondering how I would be able to utilize my hands—I’ve got zero dexterity,” he says. Within weeks, his parents and girlfriend encouraged him to buy a drone and to just sell it if he couldn’t operate the thing. Recreational drones had only been on the market for five years, and top models were thousands of dollars, so Hudson bought a cheaper drone and outfitted it with a camera. Then he headed to Blue Haven Rock, a nearby outlook with turquoise-colored coves.

On March 8, 2015, Hudson posted his first drone video to his Instagram account, @jaimenudson. It was a simple 360-degree spin above the scenery, including a speedboat towing a water skier, and showed that Hudson could create some beautiful shots. “I just became addicted to it,” he says.

Within weeks, his Instagram became a regular stream of aerial photos and videos of landscapes, surfers and boats. In August that year, Hudson posted his first wildlife shot: a whale off Blue Haven Beach. That was followed by a pod of dolphins surfing the waves, whales in groups—even swimming under a paddleboarder—and yet more beach and surfing scenes. It helped that Hudson didn’t need to modify the drone controls. “That made life so much easier,” he says, “since I could basically buy any drone at the moment and just fly it straight out of the box.”

On weekends, Hudson and a companion would drive down the coast to launch his drone and search for good scenes. “I was lucky to capture some unique wildlife scenarios that sort of went viral online,” he says. “No one else had really seen wildlife from a

drone’s perspective back then.” A surfing video in December 2015 got more than 30,000 views, while two more of dolphins riding the waves in 2016 attracted 17,000 and 23,000 views. Soon Hudson was getting messages for interviews and being written up in print and online, becoming a growing presence in the world of wildlife photography. In 2016, he put together his first drone photography calendar, which he sold at the family business and the local farmer’s market.

Combining Sky and Sea

During those first years of droning, Hudson received a visit from a family friend that ended up paying big dividends. As a nature filmmaker and video producer with four decades of experience, Leighton De Barros makes shows and documentaries with big names like National Geographic, Discovery, the BBC and the Australian Broadcasting Corporation, filming mostly diving and marine wildlife. De Barros remembered Hudson as “a vibrant little kid” from when he hired the family boat for some work on an ABC show in the mid-1990s. “The next time I saw [Jaimen’s dad], he said, ‘Would you like to see him? He’s in a wheelchair,’” says De Barros. “I’d vaguely heard about what he was doing, and then he showed me, and it was quite spectacular.” The career filmmaker saw something special in Hudson’s early videos.

De Barros eventually took up droning himself, knowing it could be good for his business. In 2017, Western Australia required all commercial and some recreational drone users to take classes and get licensed. In a stroke of luck, Hudson parked right next to De Barros at a droner-certification course in Perth. “So we reconnected by fate,” De Barros says, “and he’s showing me his footage and I said, ‘You know, we should do a documentary on your work, because it’s really quite spectacular.’” He says Hudson has “the eye of a camera person” and is a natural at framing shots and creating smooth



Hudson with one of his trusty drones.



Hudson grew up working in and around the marine tourism industry in Western Australia. A spinal cord injury in 2008 briefly took him away from the water, but he found his way back as a drone photographer.



Hudson sells calendars featuring his stunning photos.

motions with his drone work.

De Barros wished to showcase Hudson's work, share his story, and afford him new filming opportunities that could build his skills in the process. He also thought that Hudson could learn how to move beyond well-crafted one-off social media clips and into capturing multiple shots that could tell stories of wildlife and be sold to wildlife film producers like the BBC and Australian ABC.

Hudson went all in on the project, which was about more than just his past. He suggested a documentary that started with his personal story and drone work, and then showed him training to scuba dive again. De Barros loved the idea and wanted to direct the film. The result, *Jaimen Hudson: From Sky to Sea*, earned multiple four-star reviews and national acclaim. Unfortunately, doctors nixed the scuba plans partway through the story out of concerns that Hudson couldn't cough hard enough if he inhaled water, but ultimately Hudson was able to snorkel among fish and a curious humpback whale. The film showed Hudson as a family man—with his wife, Jess, and two young kids—a drone operator, and a dreamer.

"That experience of being back in the ocean again was just unreal," Hudson says. "As soon as my lips touched the saltwater, it was just like all these memories of being in the ocean came flooding back to me, and I felt almost immediately at ease, like the ocean welcomed me back with open arms."

De Barros and Hudson were both thrilled with the outcome. De Barros wants to find backers for even more documentaries to showcase Hudson's journeys. One recent pitch fell short, but he's hopeful for the future. At the moment, *Jaimen Hudson: From Sky to Sea* is available for streaming in Australia only.

Coasting Along

Hudson still goes out droning most weekends, a task he can do on his own since he bought a car with a lift and hand controls. Over the years, he has developed a business strategy for his droning. At one point, he explored land-based droning and worked in the desert with a Japanese film producer. That kind of hired film work, he says, is always hit or miss, and time spent filming involves a lot of waiting. "I guess that's the nature of marine wildlife or

any wildlife," he says. "It makes you realize the value of the clip you might have, because if they can license it from you, they obviously don't have to pay for weeks of production."

These days, Hudson focuses on that kind of licensed drone work instead of filming gigs. His licensed drone work is featured in documentaries such as *Magical Land of Oz*, which is available for streaming through PBS and in a yet-unreleased documentary on Netflix.

He and Jess took over the family business in 2018. They now have a wheelchair-accessible van for land tours and are converting part of the office into a couple of wheelchair-accessible hotel rooms. "That's obviously something very important to me," Hudson says, "just ensuring that our tourism offerings are accessible to all, not just [nondisabled] people." Hudson has also been involved in local disability work, providing input to the government and tourism industry in Esperance. His Instagram continues to grow, with over 200,000 followers. A recent reel garnered more than 940,000 likes—numbers he never dreamed of when he uploaded that first clip of Blue Haven Rock in 2015. **MI**

UNITED SPINAL'S WORKING GROUPS

OUTDOOR RECREATION

This group boosts awareness of the need for equal, inclusive access to outdoor recreation. It compiles lists of accessible outdoor recreational equipment available to purchase, rent or borrow; engages with federal, state and local entities about promoting access to parks and recreational spaces; and creates robust community resources on topics such as Beach Access and Mobility, Accessible Camping and Accessible Winter Activities and Recreation.

Illinois member Bill Bogdan got involved with the group because he wants to ensure wheelchair users have equal opportunity to enjoy nature, and recently worked with a local forest preserve to get an adaptive kayak launch installed in a Chicago suburb. "I can kayak independently by using that dock, I don't need any help. I can take my kayak from my van, get it down to the pier, shoot it down the kayak launch, and then transfer from my wheelchair into the kayak," he says. Bogdan hopes other states follow suit and stresses the importance of getting out there. "I think the more people with disabilities get out there and enjoy nature, the more local governments will see that this is an important issue."



Bill Bogdan demonstrates an accessible kayak launch.

EMERGENCY PREPAREDNESS

The Emergency Preparedness working group was created in tandem with the organization's Ready to Roll initiative to address the reality that wheelchair users are often more vulnerable to the effects of natural and man-made disasters. The working group provides information to enable wheelchair users to make informed decisions about their safety, and assists governments and other organizations in proper disability-focused emergency preparedness activities. The group authored a wildfire preparedness guide that includes tips on evacuations, transportation, loss of power, smoke inhalation, and needed supplies. More recently, it assembled winter-safety guides for wheelchair users. These include the warning signs of frostbite, recommended winter clothing, and tips for preparing your vehicle and wheelchair. "Winter weather is not universal, and knowing how to take care of yourself and what you need to take care of yourself is not universal either," says Andy Weyant, a C4-5 quad and working group member from New York. "Every one of us should know our needs for our specific situation, and if anything goes wrong, ... what we need to do to continue moving forward."



From severe winter weather, to fires, to hurricanes, the Emergency Preparedness group offers resources and support.

SINCE 2022, UNITED SPINAL HAS BEEN ORGANIZING MEMBERS INTO WORKING GROUPS THAT ARE TACKLING OUR COMMUNITY'S MOST PRESSING ISSUES. BY SHANNON KELLY

Learn more: unitedspinal.org/working-groups



Annie Streit and her long-time caregiver, Megan Meyers

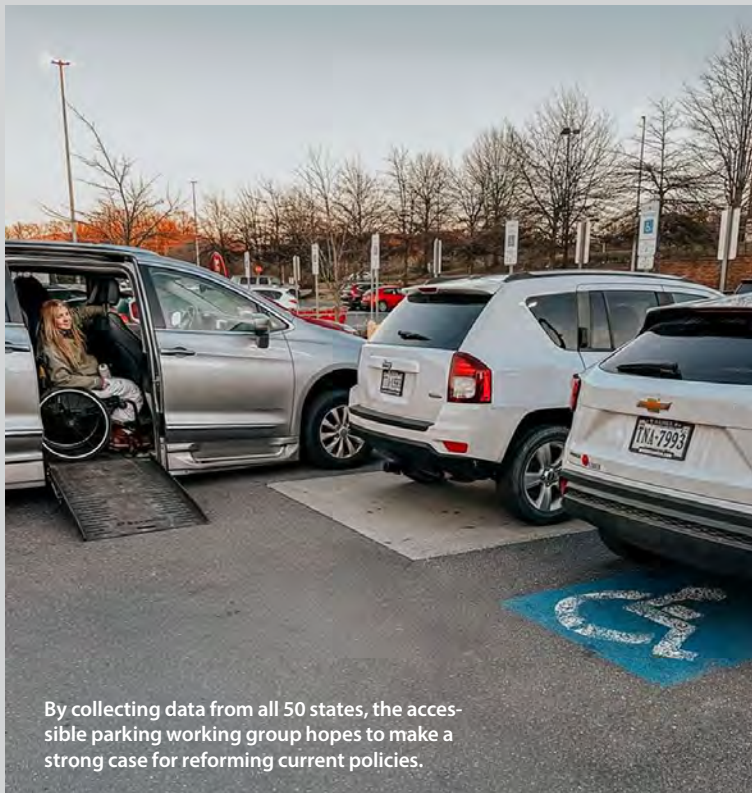
Photo by Chad Merda

CARE SUPPORT

United Spinal's Care Support working group combines advocacy efforts, education and peer support to help wheelchair users navigate their caregiving needs in the face of the ongoing shortage of care workers. Group member Melinda Simms, a C4-7 incomplete quad, started relying on her husband as a care provider when she lost access to her care support team during the pandemic. "We live in a rural area where home care is hard to come by. When [the pandemic] hit, the agency could no longer provide caregivers, since many of them were sick and quarantined," she says. The Department of Veterans Affairs formally recognized her husband as a PCA and offered him a monthly stipend and health insurance. She has made it a priority to work with other veterans to help connect them to benefits that they may not be aware of.

Now she is sharing the knowledge she's learned on the job and her personal experiences of working with caregivers. "A lot of times people know their list of things that they should ask [but] they don't really know why they should ask those things," says Simms. She collaborated with other advocates to create guides on best practices for hiring and training caregivers.

Simms also joined other advocates, caregivers and health care professionals for United Spinal's care support webinar. The webinar gave caregivers the opportunity to discuss what they need to provide the right care for their clients.



By collecting data from all 50 states, the accessible parking working group hopes to make a strong case for reforming current policies.

Photo courtesy of Rachelle Chapman

ACCESSIBLE PARKING

The most popular working group strives to improve accessible parking laws and regulations throughout the U.S., while raising awareness of common barriers encountered by the disability community.

The group aims to bring public attention to the importance of access aisles, the hashed lines next to the accessible spaces that allow room for people with disabilities to get in and out of their vehicles. The group is also gathering documentation on the numbers of parking placards and accessible spaces available in all 50 states.

Once the data is compiled, they will bring it to the U.S. Department of Transportation to ask for increasing the federal requirements on the minimum numbers of accessible spaces. "We're hoping [that] showing the numbers will really create change. Going about such a big issue is tricky — [you've] got to break it down and have real goals," says Shelley Jaspering, a C7 quadriplegic and member of United Spinal's Iowa chapter.

Getty Images

SOLUTIONS FOR OVERACTIVE BLADDER

Overactive bladder, also known as spastic or reflex bladder, is one of the most common challenges of living with a neurogenic bladder, characterized by lack of control due to nerve damage. Bladder spasms occur with spinal cord injuries of T12 or higher. It is vital to address spasms with your urologist, because “accidents” are the least concern: The spasms also create high bladder pressures that can lead to permanent kidney and bladder damage.

Fortunately, there are a variety of options to help you control your bladder. Two options that address all urinary accidents do so by enabling urine to flow freely from the bladder if intermittent cathing isn’t working. One is an indwelling Foley catheter, which goes through the urethra, and the other is a suprapubic catheter, which goes through a surgically created hole near the navel. Unfortunately, neither option addresses spasms. Leading urologists say it is important to manage bladder spasms, and suspect that long-term use of indwelling Foley or suprapubic catheters without also addressing spasms can lead to permanent bladder shrinkage.

The first and easiest option for quieting the bladder is oral medications. Such medications were notorious for their troublesome side effects, but newer medications have far fewer. “I take Myrbetriq, which doesn’t give me any side effects,” says Matt Fritsch, 41, who has been a T6 para for 20 years. “Myrbetriq is super-expensive and my last insurance didn’t pay for it, so I was taking Ditropan, which gave me massive cottonmouth and horrible constipation.”

When oral medications aren’t effective or the side effects aren’t tolerable, urologists are turning to Botox injections to quiet the bladder. Yes, the same injections in vogue for

making facial wrinkles disappear can also help you stay continent. “I’ve been getting Botox for eight years and it quiets my bladder enough to enable me to cath every five hours or so and not have any issues,” says Bruce Hammer, 72, an inventor and entrepreneur who is in his 43rd year as a C6-7

quad. He says each Botox treatment lasts about six months. Like Fritsch, Hammer experienced unwanted side effects from Ditropan. “It made me feel lightheaded and gave me really bad brain-fog,” he says.

An option that permanently quiets the bladder, and increases its capacity, is to surgically enlarge the bladder, known as bladder augmentation. Augmentation also makes intermittent cathing easy via a surgically created tube in the belly for emptying the bladder. The downside is that it’s major surgery. “I spent three weeks in the hospital recovering,” says Tami Ridley, 64, a C6 incomplete quad. “I got my bladder augmentation 26 years ago when I was going to law school, partying with my friends [and] having a great life but being hard on my bladder and getting constant UTIs,” says Ridley. “My surgeon said bladder augmentation will be healthier for me. It was and is – [and] it continues to work great. It’s easy to empty and I can hold about 1,000 cubic centimeters.”

— BOB VOGEL

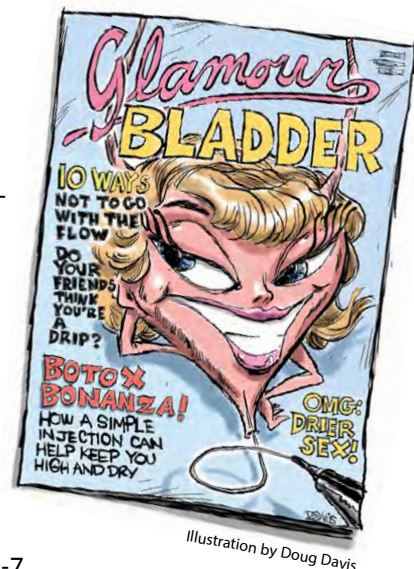


Illustration by Doug Davis

MEMBER TIPS

“Prior to Botox, I was on Ditropan, but it really messed up my thinking. A urologist taught me an old school trick: Crush one Ditropan pill and put it into a 50 cc syringe, add tap water and put it into your bladder through a catheter, and leave it until the next time you cath. It quiets the bladder, but doesn’t cause any side effects.”

”

— Bruce Hammer, Sonoma, California



UNITED SPINAL RESOURCE CENTER MOST FREQUENTLY ASKED QUESTION

MY BLADDER WAS QUIET UNTIL ABOUT A YEAR AFTER MY SCI, BUT NOW I'M WETTING MYSELF EVEN WHEN I CATH REGULARLY. WHAT SHOULD I DO?

SCI NURSE AMY DANNELS-McCLURE RESPONDS:

Prior to your injury, the bladder muscle and sphincters worked in unison. When the bladder would squeeze to urinate, the sphincters would open and you would be able to urinate. Post-injury, they both try to contract at the same time, a highly ineffective way to try to urinate as the bladder is trying to release urine against a closed door. This miscommunication occurs with injuries to the spinal cord above S1 and is referred to as "upper motor neuron neurogenic bladder."

One challenge with bladder management after an SCI is that it changes. How you effectively manage your bladder needs to be reviewed at least annually or when anything changes. For example, when you start seeing incontinence episodes for the first time, it is time to see your urologist. Even if you think your bladder is empty, urine leakage is often a result of incomplete bladder-emptying as there is a failure of your bladder to store the urine and/or the inability of your bladder to release the urine, which creates involuntary overflow urination or incontinence. You may see this increase over time as your body starts to respond to consistent incomplete bladder-emptying. Your bladder wall may start to weaken from being overstretched with high volumes of urine, along with the sphincter tightening randomly.

Help your urologist help you to create the best bladder management program to fit your lifestyle with these preparatory steps:

- Keep a bladder diary. Keep track of fluid intake, output and incidents.
 - Ask about a urodynamics test to get a clear picture of how your bladder is functioning.
 - Develop a fluid schedule that will work for you.
 - Keep track of how often you have a bowel movement and the consistency of the stool. There is a proven connection between constipation and inability of the bladder to fill and empty successfully.
 - Keep track of your medications and how often you take them.
- When you talk to the doctor, listen and ask questions. Ultimately this is YOUR journey and one that needs to work for you while supporting a healthy bladder.

RESOURCES

BEST NEW MOBILITY ARTICLES

Options to Manage Bladder Spasms:

newmobility.com/manage-bladder-spasms

Why quieting the bladder is vital, and the dangers of untreated bladder spasms. Eight bladder-quieting options, from oral medications and topical gel, to Botox injections.

FDA Approves Botox:

newmobility.com/fda-approves-Botox

When to consider Botox and how the procedure works. Wheelers share their experience with Botox.

Guidelines and Options for Indwelling Catheter Users:

newmobility.com/guidelines-options-indwelling-catheter-users

Important considerations for users of indwelling Foley and suprapubic catheters, including the importance of managing spasms to help avoid bladder atrophy.

Suprapubic Revisited:

newmobility.com/suprapubic-revisited

Possible long-term complications of an indwelling Foley. Reasons to consider a suprapubic catheter, the procedure, and long-term management of a suprapubic.

What About Bladder Augmentation Surgery?

newmobility.com/what-about-bladder-augmentation-surgery Bladder augmentation criteria and surgery explained. A wheelchair user shares his experience.

BEST OF THE WEB RESOURCES

United Spinal Resource Center:

Types of Bladder Management After SCI:

unitedspinal.org/types-bladder-management-after-sci

A look at the primary methods of management for neurogenic bladder.

Bladder Augmentation: What, Why, How?

youtube.com/watch?v=3BGXh10cMxs

An animated video explaining and showing how bladder augmentation is performed.

“ My bladder is so spastic that I get the max dose of Botox, and still need to take Myrbetriq capsules. The combination keeps my bladder quiet for about four months, then I start to leak and I add Ditropan XL, which will keep the spasms at bay for another few months. Then I'll schedule another round of Botox and start the cycle over again.”

”

— Matt Fritsch, Orangevale, California





OWN IT

By Regan Linton

MEASURING SUCCESS: SETTING OUR OWN DEFINITIONS

I'm getting fed up with measures of success that are foisted on us.

Not because I'm averse to setting standards or expectations ... I am actually pretty keen on setting goals, or having ways to evaluate the impact of various aspects of our lives.

But so many of the metrics that determine "success" in our wider world are out of whack and don't align with the values that many of us would identify as paramount. We've been hoodwinked into thinking that clicks 'n likes 'n swipes 'n followers — and being able to watch an investment portfolio tick upward, or drop bills on a second home or a big machine toy — is "success." Never mind that the followers mostly don't give two hoots about us, the portfolios are often not representing something tangible, and bills are spent on items that are under-used, overpriced and frequently have negative side impacts.

The arbitrary nature of imposed "successes" became super-evident after my spinal cord injury. From the early days post-injury, all sorts of people — friends, family, therapists, randos at the grocery store — dump THEIR ideas of success on you. Often it comes from good intentions, but the sources usually aren't aware of their own biases. Are you gonna walk again? Can you have children? Will you be able to go back to work? Maybe someday roll in a marathon? God has great plans for you.

It gave me great pause. Because at the time, if I got through a day without

puking up my guts, passing out, peeing or pooping on myself, or wanting to pull the plug, that was a hugely successful day!

I often describe my post-injury awakening as a gigantic façade falling: It was like I saw clearly for the first time the way the world was trying to force me into its idea of success, playing by its rules, measuring by its standards ... most of which had no relevance for the unique details of MY life. I began to see it everywhere: the world telling you to place value on something, and if you don't achieve it, you're a big fat Zero.

I'm certainly a big Zero according to many metrics: kids birthed, marriages "I do"-d, marathons run, PhDs bestowed, Oscars or Tonys awarded, inventions patented, six-figure salaries earned, trips to space taken.

According to these Zeroes, I might seem like a human devoid of wild success. But what about some other Zeroes: times fired from a job, people who have sued or divorced me, business dealings where I've ruined people's lives ... or fucks given about many trivial things.

Realities of "success" are more richly nuanced than the world that idolizes the abundance of Elon Musk or Taylor Swift. The Zero, or the absence of something, can also be success. Or, success can be found in un-replicated, exceptional experiences that only happen one time — ephemeral moments that mark your life. Success in less, rather than more.

I've had some memorable "Ones" that have left their mark on my story. One crash on a Vespa in Greece. One makeout session with a random dude in an Italian alley. One family homestay in Brazil. One adaptive rowing race completed (so far). One documentary directed. One move to a different state for love. One heart-wrenching break-up when that love went south.

Perhaps the Ones — the things we've done less but that carry great value — tell us something more profound about our story than the things we've racked up just because.

Particularly for those of us with disabilities, the measures-of-success game can feel diminishing, because the whole of society amplifies accomplishments that we don't necessarily have access to, or that we frankly have moved beyond, given the deeper life experiences many of us have had.

Our unconventional successes are hard for some people to understand. For instance, some may see it as unsuccessful that I have not taken one step in 22 years ... I haven't regained the ability to walk. But, in the absence of walking, I have mastered the vocabulary, dynamics and skills of paraplegic body movement (including 100,000+ transfers in two decades). Boom, success.

And, what about the success of contributions we make to the well-being of our fellow humans? An essay by Sarah Churchwell from the George W. Bush Institute describes



“The success of our lives should be in accordance with the values we set, not those that strangers in the outside world manipulate us into thinking are important.”

how America's founders envisioned the “American Dream” not as money-money-money, but as richness of commonweal – well-being that is extended to and supported by all. If we value commonweal measures, we should be amplifying respect. Creativity. Love of family and friends. Showing up for each other. Building happiness according to our unique skills and interests. Giving something of ourselves. Valuing those things that lack clearly measured returns, and seeing how they overwhelmingly bring us more.

To me, the success of our lives should be in accordance with the values we set, that make our lives unique and extraordinary ... not those that strangers in the outside world manipulate us into thinking are important because they benefit from selling us on consumption, fear or dissatisfaction.

So, when you sit back and take stock, what measures of success matter to you? What stories exist in your big fat Zeroes, exceptional Ones, or in the “less that became more”? Perhaps it's the occasions you donated time or money

with no reciprocal benefit. Floated in water. Smiled at someone, or were smiled at. Survived surgeries. Helped friends through rough patches. Laughed until you cried. Used your imagination to envision something beyond reality. Wondered about the stars. Felt butterflies. Or been in a moment where you told yourself, “I want to remember this forever.” And then forgot it.

Perhaps that's the true measure of success: setting our own definitions of what makes a fulfilling life – not allowing someone else to dictate it.



PRODUCTS

By Michael Franz

SONY ACCESS CONTROLLER FOR PLAYSTATION 5

Early in 2023, I purchased a PlayStation 5, thinking I would be able to play it using my Xbox Adaptive Controller with a third-party adapter. I had read articles about how great the accessibility features were on some of the games that were exclusive to the PlayStation 5, and I was looking forward to trying it. I didn't know Sony had released a patch for the PS5 that locked out third-party adapters.

Once I learned this, I returned the PlayStation 5 and thought it was a lost cause. The day after I returned it, however, Sony announced it was developing a new accessible controller

for the PS5. When Sony released the Access controller in December 2023, I bought another PlayStation 5 and set out to put its accessibility to the test.

Double Your Fun?

The Access controller is a circular pod with eight customizable buttons around the perimeter, a large button in the center, a joystick that can be oriented in any direction, and four 3.5-millimeter expansion ports that can be used to connect additional buttons, switches or joysticks. While that may sound like a lot of customizable inputs, if you've played a PS5, you know it doesn't equal all the input methods available on the regular PS5 controller. If you want to control all of the buttons and joysticks, you'll need to buy a second Access controller for another \$89.99 and pair them. Another option is pairing one or two Access controllers with the standard PlayStation DualSense controller to add more inputs and haptic feedback, motion sensor, and touchpad swipe.

I bit the bullet and bought two Access controllers so I could map every button and joystick and see how the controllers worked together. For my setup, I placed one Access controller with the joystick on the left and the other with the joystick on the right. To customize an Access controller, each one comes with a variety of caps for buttons and joysticks. As a C5-6 quadriplegic, I found that the ball joystick cap worked best with my quad hands. To make it easier to hit the buttons, I used curved button caps on the three

buttons along the top, flat button caps on the three buttons along the bottom, and standard button caps on the two buttons in the middle of each side. The Access controller also comes with a wide flat button that allows the user to hit two buttons along the perimeter simultaneously, and an overhang button that allows for simultaneous use of the large middle button and one of the perimeter buttons.

Setting up the Access controller is simple, made easier by considered accessible packaging, with loops that make it easy to open for someone with diminished hand function. The Access controller connects to the console with a USB-C cable for setup and charging. Once set up, the Access controller can be used wirelessly and has great battery life. After 12 hours of gameplay, I've only used half the battery charge in each controller. Changing button and joystick caps was difficult but doable. It would be much easier for someone with better hand-function.

Once connected to the console, there is a program for mapping each button, calibrating the joysticks and setting up profiles for different needs. My experience using the Xbox Adaptive Controller made this process easy for me, but I don't imagine it would be difficult for anyone with videogame experience.

Pros

I was able to test the Access controllers with three games: Marvel's *Spider-Man 2*, *God of War Ragnarok* and *Ghost of Tsushima*. In each game, I was able to



Franz shows his setup using two Access controllers.

master the controls and do everything I needed to advance through the story. I quickly got used to the layout of the Access controllers and eventually remapped my button configurations. Moving the most-used buttons from the top of the controllers to the bottom edge made playing much easier.

Each game had extensive accessibility options that were simple to find and clearly explained. I could easily turn on features like aim assist, button toggling, and automation of processes that would otherwise require multiple button presses. The accessibility options available in each game were the most impressive I've seen in any of the games that I have played.

At 0.7 pounds, the Access controller is very light and easy to handle. I secured my Access controllers to a lap tray with Velcro, a setup easy to move on and off my lap with quad hands. Compared to my Xbox Adaptive Controller, it was also nice not having wires hanging everywhere.

Cons

The design of the Access controller did have some shortcomings that, in my opinion, could be a problem for some. The circular design of the Access controller led to many accidental button presses. With the buttons so close to each other, it was easy to hit the wrong one, or two buttons at once. This did improve as I played more and got used to the button locations, but it's a problem that will never completely go away. Adding additional buttons with the 3.5-millimeter ports could help, but the ports are limited to four per controller and adding buttons means spending more money.

Besides the proximity of the buttons, it would be nice if the button labels were color-coded to differentiate one from another. Since I can't feel my hands, I use peripheral vision to see which buttons I'm hitting. Because the buttons all look the same, I found myself glancing more than

once to make sure I was hitting the right one. Lastly, a goalpost-style joystick cap would be a great addition as a standard option.

In all, the Access controller is a great product for those looking to use the PlayStation 5. I think most people would benefit from buying two Access controllers, especially quads. If your hand has decent function or it can use the standard PlayStation controller for some buttons and joysticks, one Access controller may be enough. But even though I have some issues with the design, the Access controller does everything you need to have fun and be competitive. The Access controller is only compatible with the PlayStation 5, however. If you are looking for a controller to use with multiple systems like the Microsoft Xbox, Nintendo Switch, and PC, the Xbox Adaptive Controller is the better option.

The Access controller retails for \$89.99. Visit [Playstation.com](https://www.playstation.com) for more information.

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DISABILITY MATTERS

By Greg Moomjy

HOW RELIGION IMPACTED MY GROWING UP WITH A DISABILITY

New Year's Eve 1999 was the first time my parents allowed my siblings and me to stay up past midnight. This made for a killer essay for English class, full of childhood excitement, sparkling cider and *Auld Lang Syne*. This was also the first year I learned about New Year's resolutions. My mom had gotten me a goals chart. That night, with her help, I proudly wrote that by year's end, I would walk unassisted.

We clearly had different definitions of "unassisted," but I believed I'd walk by myself. I went downstairs and told my father, who was holding a video camera. Did I mention I was trying to walk with crutches? I realize now that this was my audition for playing Tiny Tim. And as a child, believing that one day God would make me walk, I'd say I nailed it.

I can still remember my favorite verses from the Book of Isaiah, which evoked images of being able to walk without fainting and run with the strength of eagles. Forgive the pun — but Jesus Christ! If that isn't inspiration porn, what is?

As a child, I was prayed over at my first church service, in the hopes of a miracle cure — a Kool-Aid I unfortunately drank. I thought I would one day hear a basso profundo voice, booming from the sky: "Gregory, thou shalt walk!" Funnily enough, I never thought to pray more or do anything special to comply with our bargain. I expected to be cured because that's what was

promised. Thus began my tempestuous relationship with God, which I now realize reflects my struggle to relate to my disability.

But one day, I abruptly realized God would never cure me. Something inside me utterly broke. In a scene in Disney's original *Aladdin* movie, the monkey, Abu, touches something in the Cave of Wonders that isn't the magic lamp, causing the cave to melt into itself. That's exactly how I felt, and it took until I was in high school to get past it. In the meantime, I wrote plenty of depressing poetry and English essays about how sad I was that I would never walk. Even more stomach-turning was that I was encouraged to and felt expected to write about my medical history. It felt like the trauma of my childhood hospital experiences was the most compelling thing about me.

That's the problem with miracles. They make us complacent, putting the onus on God to better our lives. When God doesn't, we're let down, and the ensuing, complex emotions can take years to resolve. Don't worry, though — when I finally became comfortable with the fact that I would never walk, I realized I'm "inspiring!"

Let's address what church is: a gathering where someone with a degree in how to read the Bible discusses its meanings in our lives. For me it was theater, because my parents would get me out of my wheelchair and walk me

"When you think it's your job to be inspiring, it becomes a crushing responsibility, leaving little room for things like mistakes, complaining, or acknowledging what it's really like to live with a disability."

up to receive communion. But, with the spotlight on me, I became everyone's inspiration.

I did not necessarily believe that I was inspiring, but I grew to believe that there was something about my disability that inspired others. I internalized that. And when you think it's your job, it becomes a crushing responsibility, leaving little room for things like mistakes, complaining, or acknowledging what it's really like to live with a disability. I had to be inspiring because other people said I was. And I couldn't let them down. This phenomenon reached its apex during one Holy Week.

That year, the priest remarked that

the way someone received communion showed the grace of God in real time. I thanked God that the church was dark as I turned purple with embarrassment. Sure enough, that night it took forever to get home because people even came up to the car to tell me I was such an “inspiring example of God’s grace.”

In the long term, inspiration porn can lead to depression, because you start to believe that you don’t have a right to experience emotions like other people. Or that the difficulties of life as a disabled person are there for you to overcome in order to inspire others with the example of your strength. This lasted until my 33rd birthday, when I told someone that I thought the world needs more disabled theologians. The next day, I listened to Judy Heumann’s podcast. She was speaking to disabled theolo-

gian Amy Kenny, who wrote *My Body Is Not a Prayer Request*. I got the book.

Kenny’s reading of the Bible is inclusive. Suddenly, I saw myself reflected in these canonical stories which many of us know regardless of our beliefs. God became a Creator who believes in biodiversity, and disability became a crucial part of his creation. It was neither a curse nor something to overcome for the benefit of others. Kenny discusses how Jacob’s hip was permanently dislocated after he wrestled with the angel. Therefore, disability became a permanent marker of his contact with the divine. The prophet Ezekiel had a vision of God in a throne with wheels. Kenny argues that this could be seen as God using a wheelchair. I would add that in Ezekiel’s vision the wheels are made from angels and other heavenly creatures. The imagery

essentially demonstrates a theological model for caregiving: Even God is dependent on others to move.

Culturally, religion is something almost everyone can relate to in some way. The Bible teaches that we are all created in God’s image. Therefore, seeing God as disabled is just as powerful as disability representation in pop culture. For me, thinking of a disabled God helps to confront ableism. We all know that disability can be an incredibly isolating experience. Viewing disability as an attribute of the divine gives disabled people their own divinity. In the final chapter of her book, Kenny describes heaven as a totally accessible public space or a night out with a group of friends where everyone’s needs are understood. Seeing disability as part of God’s plan is a first step towards accomplishing that reality.

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IN THE MEDIA

By Teal Sherer

DAVID HOLMES: LIFE AFTER BEING HARRY POTTER'S STUNT DOUBLE

David Holmes learned that his documentary *David Holmes: The Boy Who Lived* was nominated for a BAFTA Award in the middle of giving a speech. "I was literally doing a talk at the UK's largest disability roadshow and as I was reading my speech off my phone, I saw the text message. 'Congratulations! We've just been nominated for a BAFTA,'" says Holmes. "That's pretty mental news, isn't it?"

Currently streaming on Max, *The Boy Who Lived* takes us behind-the-scenes of the Harry Potter films. Holmes was Daniel Radcliffe's stunt double, and in 2009 Holmes broke his neck, sustaining a C6-7 SCI, while rehearsing a stunt during the filming of *The Deathly Hallows: Part 1*.

When I talk to Holmes over Zoom from his home in Essex, England, he has just finished a two-hour physio session that includes training holding his breath in his pool. "My record is four minutes, 25 seconds holding my breath," he says. Just as he's portrayed in the documentary, Holmes is charming and vulnerable. You immediately want to be his friend.

Teal Sherer: Congratulations on your BAFTA nomination. How has it been putting the film out into world?

David Holmes: It's been really humbling. I was always very conscious that Harry Potter means a lot to a lot of people, and I didn't really want to bring my story to life because obviously, breaking your neck is not the most positive things to be associated with the film franchise. But I've waited for long enough and realized, what's the harm in putting it out there now? The original audience have grown up and are rediscovering the film with their own kids.

TS: You said that being a stunt man was the best rehearsal to becoming a quadriplegic. Can you share more about that?

DH: Creating stunts is problem solving. It's breaking something down to its smallest parts. So when you put it together for the stunt itself, not only can you perform it but you can perform it more than once because quite often they want three or four takes. I am also very good under pressure because I've spent my whole life under pressure in gymnastics competitions as a child and as a stunt performer,



and now with my spinal cord injury. I have to navigate this body every single day and I've learned to work my way around it, like an engineer works out a problem. I'm losing neurological function on the right side of my body, and I don't know where that ends up. But one thing I know is I'm not ready to give up.

TS: Watching the documentary, I loved seeing your close and enduring friendship with Daniel Radcliffe, and, of course, all the behind-the-scenes footage of you doing stunts. Can you share one of your favorite moments working on the Harry Potter films?

DH: Well, you are talking to the first Quidditch player in the world. I did the first broomstick test on the first film. That was my first day's work. They strapped me to a truck and drove the truck down the runway at the studio. I'd already read the Harry Potter books so I was imagining flying and dodging Quaffle balls and reaching for Snitches. And that's



Radcliffe and Holmes have become good friends since collaborating on the Harry Potter films.



Holmes raves about his Trekinetic chair (above right), “I cannot sell that chair enough because for the last 10 years I’ve had one, I’ve been able to travel the world and go places that you wouldn’t normally expect a wheelchair to go.”

how we discovered how Quidditch was going to be filmed. It was the best job in the world, and I miss it everyday.

TS: Let’s talk about the wheelchair you are using in the poster for the documentary. I’ve never seen a chair like that. It’s really cool.

DH: That chair is by a UK company called Trekinetic. The founder of the company was a carbon fiber seat maker for Formula One. He was sitting at an airport watching a young boy struggle trying to get over a threshold in his wheelchair. And he just sat there, and he drew a sketch. That sketch turned into a prototype, and it got a bit of government investment.

The chairs are not cheap, but they get you over snow, sand, over mud, you name it. I cannot sell that chair enough because for the last 10 years I’ve had one, I’ve been able to travel the world and go places that you wouldn’t normally expect a wheelchair to go.

TS: What advice do you have for someone who is newly disabled?

DH: Forgive yourself first. Whatever put you in that situation, whatever challenges you are faced with, even if it is a freak

accident or it’s your fault, forgive yourself. Like there’s no point. Hate and blame only hurts you the most, you know? Learn emotional intelligence like self-love, that comes with eating well, exercising, mental health, and breathing properly. And learn to accept that life is going to be hard, and then embrace the suck. Because the more you embrace it, the stronger you become.

TS: What’s next for you?

DH: I have a book deal and I am currently finishing that off. That comes out September and I’ll go on a two-week book tour. I’m working with a biotech company on this catheter device that I want made. I do public speaking and I have an HBO miniseries that I’m trying to get off the ground. I’ve just been asked to speak in front of the UK’s largest legal industry conference in front of 3,000 lawyers. And that’s talking about disparity around disability in the legal industry. That is something I take very seriously. I should be doing a piece for the British Grand Prix this year, where I’m going to be a passenger in a car that breaks 200 miles an hour. And next month, I am setting my head on fire while I’m sitting in my shower chair naked. Yeah, someone’s going to be submitting a portrait of me to the National Portrait Gallery in London. I don’t sit still.

MEMEWATCH



Meme by @adam__lucio

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LapStacker Retractable Carrying System: Reviewed

The LapStacker retractable carrying system was designed to keep everything from a few papers to a stack of carry-on luggage from falling off your lap. Cheryl Angelelli reviews the lightweight, unobtrusive strap system to see if it makes getting through her day any easier.



60 Years Paralyzed and Hungering for More

After a couple of hard years of medical issues, Tim Gilmer was dreaming of making a late-life comeback at age 79. Then a jogger on a dark country road threw a wrench into his plans. Gilmer reflects on the difficulties of aging with paralysis and how, complications and all, he's still ready for more.

Applying to College as a Disabled Student

Anja Herrman had the usual mix of excitement and nervousness as she applied for colleges — with the added twist that she had to think as much about ramps and systemic accessibility as she did about academics and sororities. She shares how she got through the process and how tapping into the experiences of other disabled students was a huge help.

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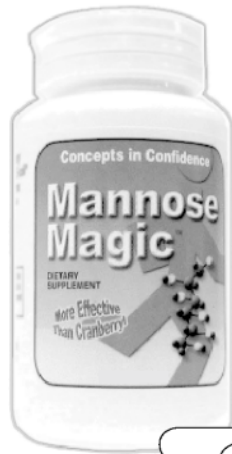
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