

Physical Exams Accessible Detroit Cushions Explained

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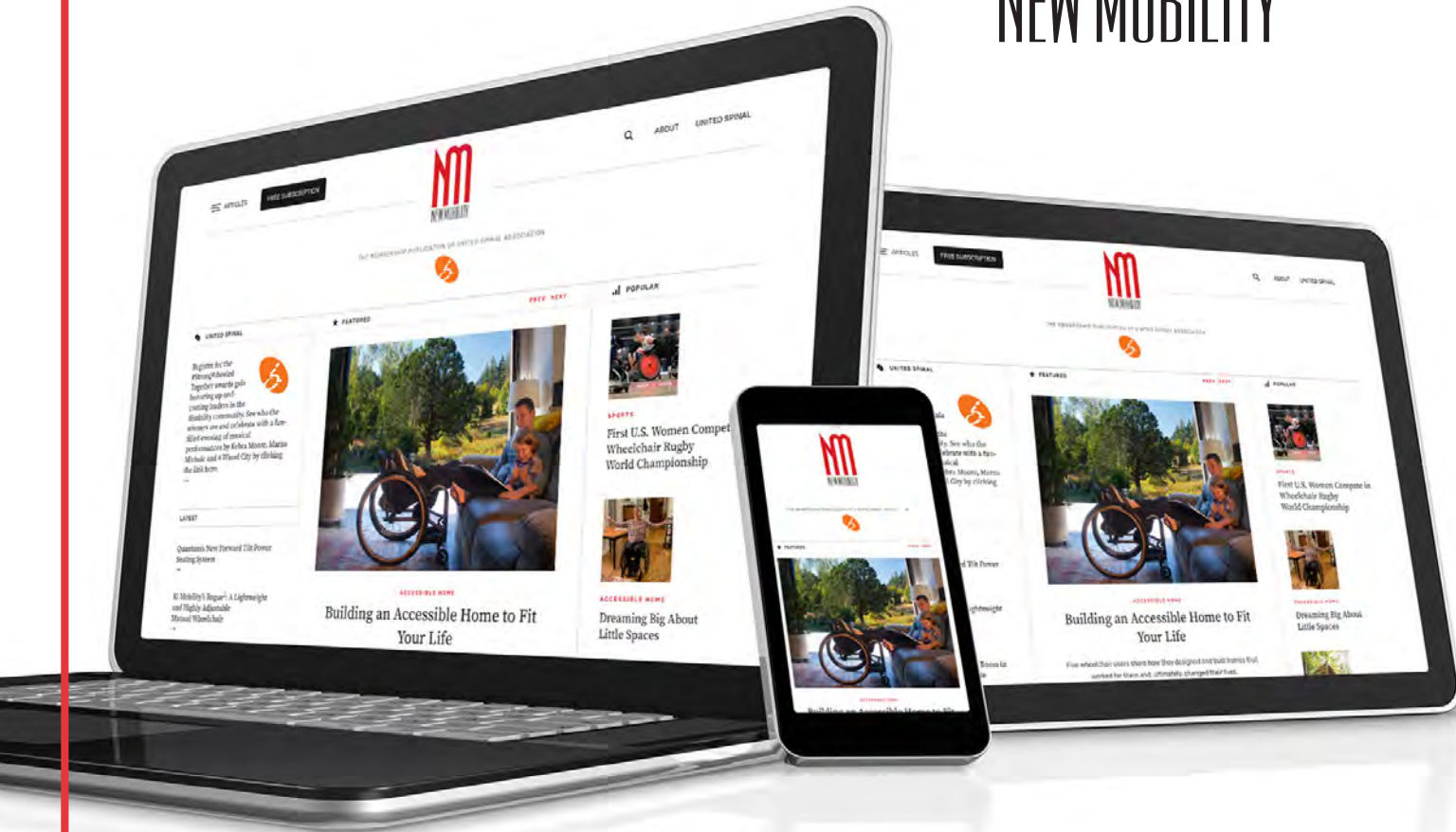
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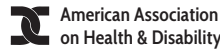
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BRONZE



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COVER STORY

MENTAL HEALTH

After paralysis, a lot of resources are devoted to our physical rehabilitation, but far fewer to our emotional, psychological and spiritual coping. **CASSANDRA BRANDT** shares how the teachings of stoic philosophers gave her concrete lessons for finding peace with disability. **JENNY SMITH** explores effective measures wheelchair users can take to build emotional health.

24

FEATURES

18 THE BEST WHEELCHAIR CUSHION FOR YOU

There are countless wheelchair cushions to choose from, and pressure relief is just one of many important considerations. **SETH MCBRIDE** explains the different types of cushions available, and the pros and cons of each so you can confidently select the right one for your body and lifestyle.

22 ACCESSIBLE DETROIT In recent years, Detroit has shed its reputation for bad weather and lost jobs and emerged as a vibrant city with world class culture and architecture. **STEVE WRIGHT** explores the many attractions of Detroit's enjoyable, compact and accessible urban core.

40 LET'S GET PHYSICAL Whether it's due to inaccessible medical equipment or doctors' ignorance of your specific disability, many wheelchair users feel like they get shortchanged at their physical checkups. **JOHN BEER** gives tips on how to get more out of your medical exams.

43 DRIVING INCLUSION Nathalie McGloin didn't know anything about auto racing until 10 years post-SCI, when she got behind the wheel of race car at a local track day. **CHERYL ANGELELLI** reports on the first female quadriplegic driver to compete in sanctioned races and the work she's doing to get more people with disabilities involved in motorsport.

DEPARTMENTS

- 4 BULLY PULPIT**
- 5 BEHIND THE STORIES**
- 6 SHARE**
- 8 POSTS**
- 10 UNITED NEWS**
- 12 DAY IN THE LIFE**
- 14 GEAR HACKS**
- 16 ROADMAPS**
- 46 WHEELCHAIR LIFE 101**
- 48 FUNCTIONAL FITNESS**
- 50 PRODUCTS**
- 56 LAST WORD**





**NEW MOBILITY IS THE
BIMONTHLY MAGAZINE OF
UNITED SPINAL ASSOCIATION**

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PRODUCTION MANAGER: DEANNA FIKE

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New Mobility (ISSN 1086-4741) is published bimonthly by United Spinal Association, 120-34 Queens Blvd., Ste.320, Kew Gardens, NY 11415. Periodicals postage paid at Flushing, NY and additional mailing offices.
POSTMASTER: Send address changes to: *New Mobility*, United Spinal Association, 120-34 Queens Blvd., Ste. 320, Kew Gardens, NY 11415.

Subscription rates: **\$16.95/year; \$21.95/year in Canada; \$26.95/year** International via Airmail. Copyright 2022, all rights reserved. Reproduction without permission of any material contained herein is strictly prohibited. We welcome comments; we reserve the right to edit submissions.

Periodicals postage paid at Flushing, NY and additional mailing offices.

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BULLY PULPIT

By Ian Ruder

TRAPPED IN THE KITCHEN

Huddled by the gas fireplace in the corner of my kitchen, I worried the winter storm had broken me.

For most of the previous week I'd been eating, sleeping and living within a 5-foot radius of the fireplace. Forecasters had warned an "arctic blast" would bring snow, ice and record low temperatures, but having weathered many previous "blasts" — including many that never blasted off — I thought I knew what I was in for. I was wrong.

Mother Nature's initial onslaught felt like she had devised an exhaustive plan to trap me in my home. I live at the bottom of a steep hill and there is only one road in and out. Within hours of knocking out the power and internet, multiple 40-plus-foot trees had fallen and blocked that road. The areas that weren't covered in foliage and broken limbs glistened with a thick sheet of ice.

Any thoughts of escaping in my adapted van vanished when a neighbor reported a tow truck with chains and 4-wheel-drive had failed to rescue another vehicle on the hill and ended up just as stuck. With 60-70 MPH wind gusts and blowing snow, the 11-degree temperature seemed like the most manageable of the outdoor obstacles.

Indoors, the opposite was true. The frigid cold had invaded my house when the power went out, and now the only thing keeping me warm was a heavy blanket my attendant nailed around the doorway into the kitchen. Every time he pushed aside the blanket to check on me a gust of cold blasted into the room.

The first night, before the blanket went up, the fireplace struggled to keep the room above 60 as temperatures outside fell. I could feel my aging quad muscles tightening up and my neck throbbing. Thankfully, the blanket provided enough insulation to keep the room close to 75

degrees and maintain a 30+ degree difference with the next room.

On day two, we relinquished my bedroom to the cold and rolled two exercise tables into the kitchen's other corner. With cabinets replacing the guard rail, a stool serving as a headboard and an old foam mattress topper, I enjoyed a surprisingly restful sleep while the howling wind bombarded my roof with falling ice and branches.

The last remaining floor space between my prime fireplace spot and the bed went to the surprise MVP of the storm: my \$20,000 Permo-bil USB charger. For over 15 months I've been struggling to get my new Permobil F3 power chair ready for daily use, but seemingly everything that could go wrong has gone wrong.

After months of doing little but collecting dust and generating frustration, I finally found something it truly shines at: recharging all the electronics my attendant and I relied on. Reading for 7-8 hours day on an iPad has a way of draining your batteries, not to mention your passion for reading.

With a battery-powered lantern, a gas stove top and an intermittent mobile hotspot, this setup carried me through the emotional highs and lows of one of the most stressful non-medical events I've endured as a quad. Still, even with an emergency escape plan (thanks to a generous neighbor with a Sprinter van and chainsaws) I felt trapped. My home — my sanctuary — felt more like a refuge, and a vulnerable one at that.

As much as my setup protected me from the harsh elements, the storm ripped through any illusions I had about how independent I truly am. It reinforced my deep appreciation for my attendants and support system and reminded me how critical it is that we strive to enhance similar systems and make sure that disabled people aren't left in the cold.



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.

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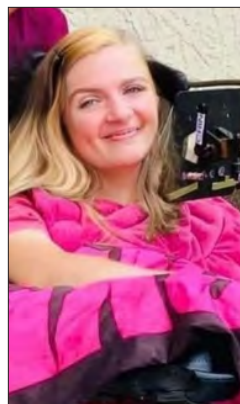
Developing winning concepts for a recurring column is one of the trickiest and most time-consuming aspects of publishing a magazine, but with the debut of “Roadmaps” this issue, I think we may have found the secret to success: Get three powerhouse creators together and let them cook. “Roadmaps” is the long-simmering brainchild of authors **Rebekah Taussig** and **Hannah Soyer** and illustrator **Haley**



Brown. Taussig and Soyer both went to grad school at the University of Kansas, and all three were fangirls of each other on social media. “A couple of years ago I texted Rebekah and said ‘How cool would it be if we got to do something together?’” says Soyer.

Inspired by bestselling author Cheryl Strayed’s “Dear Sugar” column (now in book form as *Tiny Beautiful Things*), “Roadmaps” is a fresh take on an advice column for disabled people. “What we liked about the Cheryl Strayed advice column was that it wasn’t advice — it was more focused on human connection communities, and asking how are we doing? How can we do this? What’s the path?” says Taussig. “That’s why the name of it was so fun. ‘Roadmaps’ suggests wanting to put down some paths and options and frameworks for us to think through things.”

Good writers have a way of making seemingly disparate things seem like natural bedfellows, and that’s exactly what **Cassandra Brandt** does with ancient philosophy and quadriplegic life in her third book, *Seven Secrets of a Sedentary Stoic: Pursuing a Path to Post Paralysis Peace*. We’re honored to have an excerpt featured in this issue, but I highly recommend you download or buy the entire book. Brandt’s writing is honest and accessible and the lessons she draws from ancient Greek and Roman philosophers will have you rethinking your own approach, whether you’re a quad or not. “I’ve found that by being open and honest in my writing, I can help other people open up and be honest with themselves,” she says. Brandt is currently working on a self-help book for high-level quads, in addition to writing for various outlets.



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

“Airlines had better wake up and realize our money is as good as anyone’s.”

JANUARY-FEBRUARY 2024

The Airline Whisperer: How One Wheelchair User is Making Air Travel More Accessible from the Inside

Great article! As an above-knee amputee that does life on crutches mostly, the airport and the plane are nightmares. Talk about being treated subhuman – TSA detains me every time while I’m in an airport wheelchair, constantly wiping down the chair with bomb residue wipes and wand me for long periods. This is after they decide to process you as you sit in a corral for at least an hour until an agent comes to clear you – ludicrous! I’ve avoided going to the onboard bathroom on crutches so far and dread that beyond words. Airlines had better wake up and realize our money is as good as anyone’s and we should not be penalized with degrading treatment because we are mobility challenged and require equipment to ambulate. I’d love to engage in an airline panel for them to see how it feels on the receiving end when we are at their mercy!

Regie Lartz
Newmobility.com

@wheelchairtravel is incredible! [John Morris’s] reviews are absolutely perfect, and he gives excellent tips! I used his blog for our trip to Munich and Amsterdam and couldn’t be happier.

yasamanbest
Instagram

What an exciting start to the year! So well deserved, John!

Institute for Human Centered Design
Instagram

Adulting with CP

Thanks for sharing this story. I wish I had parents like yours. Trying to normalize your life.

My dad left everything to my mum, and she did what was in her best interest, even knowing that if I didn’t get the treatment the doctor recommended, I would be in chronic pain for an undetermined time.

I’m almost 50 now, and I still struggle with some things. FYI, I don’t have CP. My disability is Functional Neurological Disorder.

Jason Reynolds
Newmobility.com

Independence Through Art

I’d never heard of the Association of Mouth and Foot Painting Artists before – love that it exists to support artists like this!

Sherrie
Newmobility.com

Day in the Life: Tyler Turner

Nice to read stories of people living life in their wheelchair. My husband is a T4 also and gets up at 4:30 a.m. to go to his job!

TriciaHopkins
Instagram

Jonathan Sigworth: Building a Global Community

Absolutely love this article. Jon, You are doing such amazing work that benefits all of us, even a quadriplegic like me in the United States. I too am frustrated at the paradigm of our



system that we cannot earn money and pay for care. It is outdated. Keep doing what you do! #inclusion #disability #independence #advocacymatters

happyonwheels
Instagram

WEB-FIRST CONTENT

Makeshift Accessibility Mishaps that Define the Holidays

Thank you for making me laugh out loud and for giving me courage and motivation to take the challenges of my family members’ houses more in stride.

Laura
Newmobility.com

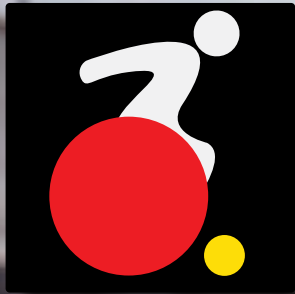
David Holmes: The Boy Who Lived – A Refreshingly Balanced Look at Life of Stuntman Paralyzed on Harry Potter Set

This is a very heart-wrenching story that I totally relate to after a life-changing horrific event left me a T3 complete paraplegic. I cannot wait to watch this movie, as I totally understand all the unseen complications. I too have a syrinx! We remain positive and continue to be as adventurous as possible as this is life, and it’s still beautiful and mysterious.

Soozi Dinnie
Newmobility.com

MAXIMIZE YOUR INDEPENDENCE

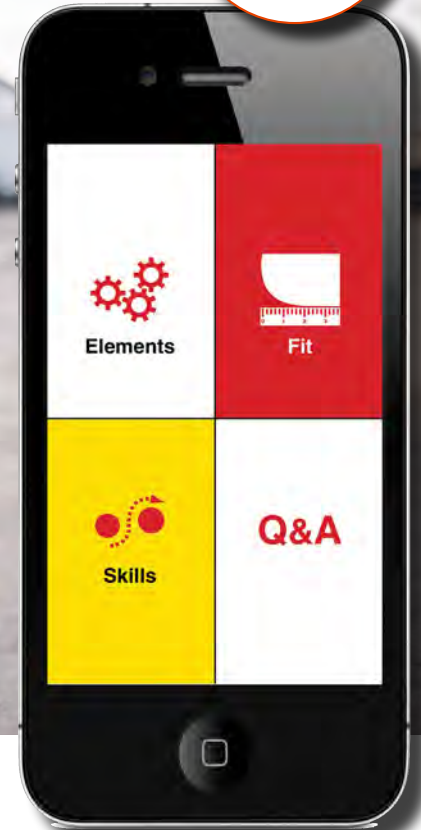
with the 'My Wheelchair Guide' Mobile App



When choosing the right manual wheelchair, one size does not fit all.



POWER WHEELCHAIR INFO COMING SOON!



Finding the right manual wheelchair is hard, we make it easy!
My Wheelchair Guide makes choosing the right manual wheelchair easier and more efficient. (*Search 'MWG Manual' in Google and Apple app stores to download.)

Now, all the necessary tools and resources to guide you through manual wheelchair selection, delivery and maintenance are at your fingertips. This comprehensive app covers the entire process of getting a wheelchair, providing practical information to evaluate your needs, wants, and concerns from beginning to end.

THE MY WHEELCHAIR GUIDE FEATURES:

- Self-assessment & maintenance checklists
- Customizable to-do lists
- Wheelchair skills videos
- Illustrations on wheelchair types, parts, & accessories
- Critical health considerations
- Organized hub that integrates the contacts essential to getting a wheelchair
- Ability to take notes within the app using text, pictures, or voice recording
- Q&A section

Whether you're a beginner or advanced wheelchair user, My Wheelchair Guide will help you discover greater health, mobility and independence.

[HTTPS://UNITEDSPINAL.ORG/MY-WHEELCHAIR-GUIDE/](https://unitedspinal.org/my-wheelchair-guide/)

"The app will be a handy reference providing credible and practical information about usage, maintenance, and health issues that wheelchair users face daily."

— Tanya L., Physical Therapist/
 Assistive Technology Provider



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Co-developed by:





Jenna Bainbridge

Making Broadway History

Jenna Bainbridge is set to make history as the second wheelchair user to appear in a Broadway musical and the first to originate a role there. “Ali Stroker did it first, now let’s open the floodgates for many more,” Bainbridge wrote on her Instagram page after being cast in *Suffs*. *Suffs* tells the story of the women’s suffrage movement leading to the passage of the 19th

Amendment, which in 1920 granted women the right to vote. Bainbridge is part of the show’s ensemble and will be playing a variety of characters. *Suffs* starts previews on March 26 and opens on April 18 at the Music Box Theatre in New York City. Learn more at suffsmusical.com.

AI Offers a Helping Hand for Software Developers

“Anybody who has trouble using a traditional keyboard or mouse will benefit hugely from Copilot Voice,” says Beatrice Tohni, a software engineer with hypermobile Ehlers-Danlos syndrome, which affects her joints and makes typing painful and difficult. “[Copilot Voice] cuts down on a lot of the busy work that goes into coding.” Tohni works for Microsoft and harnesses its artificial intelligence tool to predict her intentions and enter more commonplace code, reducing her number of keystrokes. This lowers her risks of joint dislocation and helps her better manage pain. Microsoft says that while the tool helps all developers work faster and better, it greatly benefits those with limited finger mobility and other disabilities. Find more examples at bit.ly/3ScafKU.



IZ Adaptive

Stylish IZ Adaptive Clothing Now More Affordable

Adaptive clothing brand IZ Adaptive is slashing prices by up to 50%. The brand has long been known for modern, fashionable and functional clothing, but also for prices out of many consumers’ budgets. Founder Izzy Camilleri says making her products more attainable has been a goal for a long time.

“We are aware that our prices have [not been] accessible to many people,” she says. “Our prices have been where they are because producing in North America and the overhead costs of running a business [are] very expensive. We are now manufacturing offshore, enabling lower manufacturing costs, which we are passing on to our customers.”

The new pricing went into effect Jan. 31 on their bestselling items, including jeans, sweats and chinos. Previously priced at \$80-\$126, these items have been reduced to \$60-\$70. As IZ Adaptive works to scale their production, some items will be shipped right away. Customers will also be able to preorder items that sell out fast.

Camilleri says it’s always been her goal to make her clothing more affordable and recognizes the financial barriers the disability community faces. “Things are more expensive since [the pandemic], and here I am taking a bold step and dropping my prices,” she says. “I’ve always wanted to be in this position.”

She also hopes to expand the brand’s reach by adding footwear, lingerie and accessories in the future. Browse their collection at izadaptive.com.

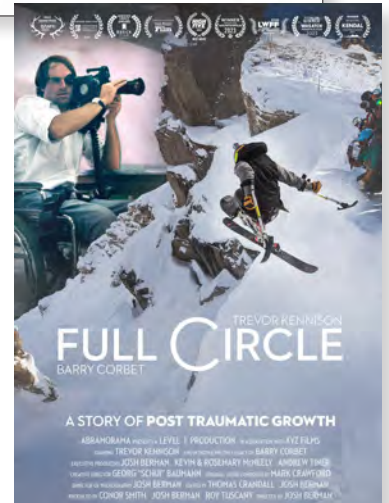
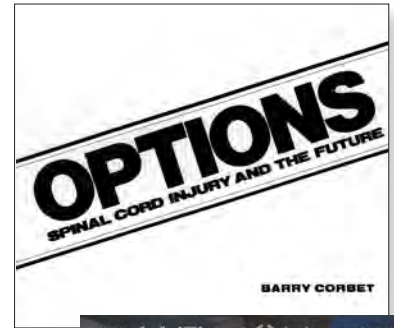


Options: Spinal Cord Injury and the Future

The recently released documentary *Full Circle* weaves the stories of sit-skiier Trevor Kennison and longtime New MOBILITY editor Barry Corbet. Much of the power of the movie comes from Corbet's writings via his 1980 book, *Options*, a how-to manual for thriving with a spinal cord injury, based on Corbet's own experiences and those of SCI survivors across America. With the release of the film, Corbet's family has made *Options* available in digital format for the first time.

"Barry Corbet passed away in 2004 and is still much missed. Much has changed in the over 40 years since *Options* was written; some things have improved, others have not. But the words in this book, and the people portrayed within it, are as relevant and important as they were in 1980," writes his family.

Go to fullcirclefilm.co, where *Options* is available in pdf, epub and web-based versions. You can stream *Full Circle* on Netflix.



More Workers with Disabilities Means More Corporate Success

Compared to before the pandemic, greater numbers of people with disabilities are working, and they may be making their employers wealthier than their competitors, according to a survey by professional services firm Accenture. The report shows that 37% of working-aged people with disabilities are employed, compared to 29% five years ago, and it's a workforce that's bringing its own rewards: The findings show the 103 most-inclusive employers are making 1.6 times more revenue, 2.6 times

more net income, and two times more economic profit than other companies. Inclusive companies are "25% more likely to outperform on productivity,"

Accenture says, and "interest in disability inclusion is clearly increasing." Survey partners included Disability:IN, a global organization of companies promoting inclusiveness; and the American Association of People with Disabilities. accntu.re/4bhFOHz.



Disability Film Challenge

Disabled filmmakers will vie for \$15,000 in grants in the 2024 Easterseals Disability Film Challenge from April 2-7. Over the course of five days, participants from all over the world will write, shoot and edit a short film based on this year's genre, "Buddy Comedy." In addition to the grant money, winners will receive mentorship meetings with industry executives, Dell Technologies computers, and more. Previous film challenge participants — like Danielle Perez, who voiced Sun-Spider in Marvel's *Spider-Man: Across the Spider-Verse* — have landed roles in popular TV shows and movies. Registration is open and more info is available at DisabilityFilmChallenge.com.



The cast and crew of *Smash or Pass* at the 2023 Easterseals Film Challenge Awards ceremony.

By Shannon Kelly

Brooke Ellison, Advocate, Scholar and United Spinal VP of Technology and Innovation: 1978-2024

United Spinal Association is sad to report the loss of Brooke Ellison, Vice President of Technology and Innovation, who died February 4. Known for her wisdom, warmth, and formidable intellect, she tirelessly served other wheelchair users as a true scholar-advocate.

After receiving attention for being the first spinal cord injured



Brooke Ellison

quad to graduate from Harvard, Ellison emerged as a stem cell research advocacy leader early in her career. She kept to a rigorous speaking schedule, running for New York State Senate to agitate for adequate embryonic stem cell research funding and founding her own nonprofit, The Brooke Ellison Project. Her advocacy for stem cell research and her work as

a medical ethicist led her to the world stage: The World Economic Forum appointed her a Young Global Leader in 2014. As an associate professor at Stony Brook University, she taught a master's level course on Stem Cells and Society.

For many, she had been a household name since 2004 when Christopher Reeve adapted her book *Miracles Happen* for the small screen as *The Brooke Ellison Story*. She published a second memoir, *Look Both Ways*, in 2020.

As the leader of United Spinal's Tech Access Initiative, Ellison used her experience to connect with both professionals from Silicon Valley and technology users from the disability community. She united both fronts around the common cause of digital accessibility and universal design.

"Brooke had an undoubtedly brilliant mind, and she was also kind," says United Spinal President and CEO Vincenzo Piscopo. "Her leadership was compassionate but, at the same time, fearless and visionary. She was always thinking beyond the obvious. She left a true legacy for our community, and she will be remembered by all of us."



LeBlanc

Crafting State-Level Solutions to Improve Wheelchair Repair

United Spinal is working with state legislatures across the country to create policy solutions that address wheelchair-service challenges and extensive repair delays.

"We hear from our advocates on a frequent basis," says Steve Lieberman, United Spinal's director of advocacy and policy. "The topic of wheelchair repair comes up at nearly every one of our monthly Advocacy Live calls. Our job is to make sure that lawmakers in every state understand the specific needs of wheelchair users to have reliable and accountable service when their chairs are in need of repair." The requested changes include:

- Guaranteed routine preventative maintenance coverage through insurance.
- Educating wheelchair users to safely self-repair parts, including batteries, battery chargers, caster wheels and tire tubes.
- Stronger regulations for the provision of loaner chairs.
- Increasing use of telehealth to enable clinicians to evaluate virtually those wheelchair users unable to get to a clinic.
- Holding providers accountable to use certified technicians for servicing the wheelchairs they sell.
- Eliminating the prior authorization requirement for complex rehab technology repairs.
- Providing a clear and transparent pathway for customer support to review repair needs and timely follow-ups.

If you are dealing with wheelchair repair issues or are aware of any state legislative action on wheelchair repair, contact United Spinal's team at policy@unitedspinal.org.

Meet New Member Tiffanie LeBlanc

SCI from birth, Age 44 from Lafayette, Louisiana
Hobbies: Drawing, writing, blogging

Why did you join United Spinal?

I became a member upon the recommendation of a friend. I enjoy being a member of United Spinal because it allows me to meet individuals like myself and we are able to get ideas from one another. Something that works well for me may also help someone else and vice versa.

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

My power chair stands as my paramount mobility aid, offering unparalleled freedom and independence.

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

If there's one aspect I yearn to transform for individuals relying on mobility equipment, it's their accessibility to it. My fervent desire is to streamline the path for people to obtain resources that enhance their independence and enrich their lives.

Nominate Community Leaders for SWT Awards

The StrongWheeled Together Awards celebrate the best and the brightest wheelchair users from around the nation. Nominations open on March 17 in the following award categories:

- **Community Voice:** honors an individual who is outstanding at their craft and at deepening disability representation in American public life. This award is open to artists, content creators, filmmakers, musicians, photographers, playwrights, spoken word artists, and writers.
- **Community Visionary:** honors an individual advancing the fields of technology or business, while exemplifying ideals

around civic engagement and social responsibility—especially when it comes to the disability community.

- **Community Builder:** honors an individual who has made lasting contributions to the social infrastructure of our community through

advocacy, community organizing, or professional activity that impacts opportunities for advancement and the rights landscape for people with disabilities.

This year, one of the three winners will be selected at random to receive a custom power or manual wheelchair from Permobil. The Awards Ceremony will take place during the annual StrongWheeled Together Conference, October 17-19 in Las Vegas. Submit your nomination at unitedspinal.org.



King Khazm (center) accepts a 2023 SWT Award.

Ask the ADA Expert

Q: I made an appointment at a hair salon and showed up to find out the salon was in a private home that was completely inaccessible. I couldn't even get in the front door! When do private homes have to be accessible?

United Spinal Director of Accessibility Codes and Standards Marsha Mazz explains:

Businesses that operate in private homes must comply with the ADA if they are places of public accommodation, meaning that they offer goods and services to the public. They must meet the Department of Justice ADA Title III definition of a "place of public accommodation." The definition contains an exhaustive list of 12 categories of public accommodations, but nearly every business that serves the public is included in this list in some way.

Very few homes are constructed to include a business, so they are not considered places of public accommodation. Live/work units are the exception: They have special features that allow a business occupancy to be combined with a dwelling unit in one structure, typically a townhouse or similar multistory unit. Under most state and local building codes, the work portion of the unit must be fully accessible, including a bathroom if it serves the business. The residential portion of the unit is not required to meet the ADA Standards.

Most new homes are constructed without the foreknowledge that the owner will want to open a business in the house. So, the future owner of the home cannot rely on the building code to require the necessary accessibility. Sometimes the owner must obtain a permit to legally operate the business. Depending on the local code requirements, the owner may have to make certain alterations to the home prior to opening the business, including changes to make the business more accessible.

However, when a homeowner opens a business in their home and alterations are not required, the barriers to access remain in place. This is where the ADA may come to the rescue. The business owner/homeowner is responsible for removing barriers to the extent that doing so is "readily achievable," meaning it can be easily accomplished without too much difficulty or expense. Such businesses are often very small, with limited resources, and their barrier removal obligations under the ADA are limited to match their resources.

Once a business establishes that barrier removal is not readily achievable, they are still required to consider alternatives to barrier removal. For example, the hair salon operator could offer to come to the customer's home or to refer them to a nearby salon that is accessible. Doing nothing is generally not acceptable.

Do you have a question for our ADA expert? Sign up for United Spinal's newsletter to submit questions: unitedspinal.org/newsletters.

DAY IN
THE LIFE



PASTRY CHEF JESSICA KRUGER

Jessica Kruger doesn't mind when people call her stubborn. Stubbornness has given her strength in moments of uncertainty, ever since falling from a ladder at age 15 and becoming an incomplete quadriplegic.

Stubbornness is what she relied on when two pastry schools told her there was no place for someone like her in their programs. Undeterred, she found a school where she was welcomed.

So, when the Vancouver, Canada, native finally graduated from pastry school in 2019 and started her own business, "The Stubborn Baker" seemed like the perfect name.

What started out as making sweet treats for family and friends has grown into a steady business of creating custom

cakes, cookies and cupcakes to help new and repeat customers celebrate the milestones in their lives. Her Instagram page is flooded with pictures of her amazing edible art.

But Kruger, 31, who shares a home with husband and resident taste-tester, Juan, says running a baking business is no cakewalk. She is CEO, head pastry-chef, chief accountant, and delivery driver all in one. And when she is not in the kitchen, she can be found setting up her retail booth at the local farmer's market or teaching one of her cookie-decorating classes.

The eight-to-12-hour days and occasional all-nighters up filling orders are long, but even during the tough parts, she's reminded how lucky she is to be doing what she loves and bringing joy to others. Here is what a typical day looks like.

7:00 a.m. I am not really a morning person, which is funny because everyone thinks bakers love mornings. I prefer to work late instead of waking up early. After getting ready, I usually take our dog, Molly, for a walk, check my email and manage my social media pages before heading out the door.

9:30 a.m. It's a short, 10-minute drive from my house to the commissary kitchen where I rent space. The space includes an industrial oven, cold storage, a sink and other baking essentials. Other than a lowered worktable and placing oven mitts across my lap to balance the hot trays when they come out of the oven, there are not a lot of adaptations I've had to make to my workstation. ... I have a supplier that delivers my ingredients and a part-time assistant that helps prep, so by the time I hit the door and have my coffee, it's time to start baking.

10:00 a.m. Mixers are whirring and I'm in the zone. We're cutting cookies and making the lemon icings and coloring them. Batter is being scooped and my assistant is rolling out dough, which is the thing I find the hardest to do. Since I'm an incomplete quad, my right hand doesn't fully open and close, but my left hand functions pretty normally.

11:30 a.m. I head to the grocery store to grab a few items we're low on. I have a big plastic box I place on my lap and take into the store. I get a lot of curious stares because I am usually hidden behind a stack of 20-pound bags of flour,

and people are like, "Are you OK?" or "That's a lot of butter."

1:30 p.m. A couple of cakes and dozens of vanilla shortbread cookies are all out of the oven, cooled and waiting to be decorated, which is where I get to be creative. People are amazed at how steady my hands are and that all my work is done freehand. Decorating happens in stages. There is a lot of drying that needs to happen before you can move to the next step. On average it takes about five minutes to decorate each cookie.

WHEN I'M NOT WORKING: I LOVE PLAYING WHEELCHAIR RUGBY.

FUN FACT: AS A CHILD, I SPENT 4 YEARS ABOARD A SAILBOAT MY DAD BUILT AND TRAVELED TO 37 DIFFERENT COUNTRIES.

BEST THING ABOUT BEING A BAKER: MAKING PEOPLE'S MOST SPECIAL EVENTS A LITTLE BIT MORE SPECIAL.

The most time I've spent decorating one cookie was 30 minutes, but it was a pretty intricate design.

3:00 p.m. My stomach starts to remind me I haven't eaten yet, so I take a quick 10-minute break to scarf down the lunch I prepared the night before. I do love sweets, but I don't snack on my creations, not because they aren't tasty — it's just after you've been tasting things while baking and working on something for hours, it starts to lose its appeal."

6:00 p.m. I'm carefully loading a cake into my midsize SUV for delivery to a customer. I've never dropped one of my

cakes! Depending on the size of the cake, I either carefully sandwich it between some larger, heavier boxes in my hatchback or place it in the footwell on the passenger side and slide the seat all the way forward so the cake doesn't slide. And I am usually bundled up because I have the air conditioning on full blast no matter what season it is to keep everything from melting. I also often use a large cookie sheet on my lap to help transport cakes. Of course, the bigger the cake, the harder it is to manage, so I have someone help me with those deliveries.

7:30 p.m. I've been working really hard on balance in my life, so I try really hard to be home early on the days that are less busy. Juan and I have a Hello Fresh subscription, so it's an opportunity to make and eat dinner together.

11:00 p.m. I'm one of those people who feels robbed if I don't get my Netflix time at the end of the day. I'm currently watching *Working Moms*. I just feel like I need that time to unwind.

12:00 a.m. Lights out ... and sweet dreams, of course!

Follow Jessica on Instagram @thestubbombaker.



GEAR HACKS

By Seth McBride

QUAD SNOW PLOWING

I don't hate snow. I just hate what a pain in the ass it is. Pushing through it is either hard or impossible. And if you can push through, snow coats your wheels, pushrims, casters and any surface it touches, and then despite your best efforts to knock and towel it off, it inevitably follows you inside, leaving a trail of puddles as it melts.

I know I'm not alone. When I polled other wheelchair-using staff at New MOBILITY about what they did when snowy weather came, the answer was three for three: "Stay inside." But the more I think about it, "pain in the ass" isn't the whole story. Lots of things are a pain in ass as a wheelchair user — and I don't hate all of them. Getting my hand-

cycle into my truck bed is a giant pain, but I do it because it means I'm going for a ride. The thing about snow is that for most wheelchair users, the pain in the ass just isn't worth it.

Now that I live in a place where snow falls and then sticks around for weeks, sometimes months, I've had to reassess my relationship with the stuff. I could handle staying inside for a day, maybe two. After that, cabin fever is real. So, to take some weight off my wife's snow shoveling shoulders and to give myself something productive to do, I started to think about ways that I could help plow our driveway and parking area.

My dad, who lives on the adjoining property, has an ATV and he just happened to have a snowplow attachment for it. These kits have a plow blade attached to an arm that you bolt onto the front end of your ATV. A similar model is the Kolpin ATV Switchblade Snow Plow System, available for \$400 from Tractor Supply Co. Once the plow is attached, you raise and lower it via the push-button winch control. The ATV has an automatic transmission, so shifting isn't an issue, and you operate the gas with a thumb throttle. The hardest part about adapting an ATV is getting on it. For me, this meant figuring out one of the more awkward transfers I've dealt with in my 20+ years as a quad. It goes something like this:

Wedge my chair at 45 degrees to the mid-point on the ATV. Put my right foot on the ATV's foot platform, bend forward and lever my butt up onto the ATV frame. At this point I'm kind of stuck. My butt is resting on the rear



wheel guard, and I don't have leverage to push myself upright. So, I slide down a little, which blocks my right knee against the front wheel guard and gives me just enough stability to move my hands up and lift my butt onto the seat. Deep breath. Left leg up then shimmy farther onto the seat. Then rock backward while lifting my right leg up, which gives me just enough room to clear the handlebars with my leg.

See, pain in the ass. But I'm happy to do it because now I'm sitting on an ATV and ready to go plow some snow! I lower the plow down, hit the gas and I'm off. Hitting the brake lever is an adventure with my quad hands but if I feather off the throttle about 10 feet before the edge of our parking pad, I can push the snow off the pavement and get myself stopped before snow, me and the ATV go tumbling down the hill.

The only physical adaptation my dad had to make to the ATV was to the reverse foot pedal. We used a flat piece of aluminum as a lever and bolted it to the ATV frame. A tie rod attaches to the one end of the lever and runs down to the foot pedal. When you push the lever up, it depresses the pedal and lets you shift into reverse. After my first pass, I raise the plow, push the lever up, shift into



Figuring out how to plow the snow can be the antidote to cabin fever in some parts of the country.

reverse, back up and make another pass. Despite not having functional trunk muscles or a backrest, my hands on the bars gives me enough upper

body stability to control the machine. I have to round my back forward so my posture looks like the old man from *Up*, but it's more stable than you'd imagine. Once I have snow built up, the limited braking becomes less sketchy because the piles serve as guard rails.

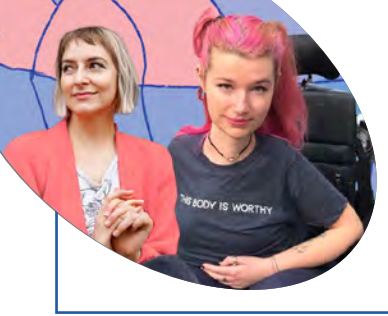
It takes an hour or so to clear our 400-foot driveway and parking pad. By the time I'm done, I'm red-faced and sore and a lot less grumpy than I had been sitting inside. The plowing isn't perfect — my wife still has to clean up with the shovel and someone has to plow every few inches of snowfall or the ATV isn't heavy enough to push it — but since my previous contributions to snow removal were nonexistent, I'll take it.

I transfer back down into my wheelchair and roll inside. My wheels are covered in snow, casters too. I wipe them down, wait for the leftovers to melt and towel up the puddles. It's still a pain in the ass. But today it's worth dealing with.



Power Plows

Power chair users, you too can join the snowplowing fun. Back in 2011, we reported on a guy, Charlie McCoy, who made a V-shaped plow from an old motorcycle seat, a handle from a sweeper and some extra aluminum siding, which he attached to his Jazzy chair via bungee cords. McCoy claimed he could plow drifts up to 16 inches high. Over the years, other power chair users have devised similar systems — one with square tubing and what looks like an ATV plow blade. And Nordicplow.com sells a plow that you can attach to an Action Trackchair.



ROADMAPS

By Rebekah Taussig and Hannah Soyer

NOT WHAT I IMAGINED FOR US

Dear Rebekah and Hannah,

It's been a few years since my spinal cord injury. In a lot of ways, I've adjusted to this new life. I learned how to drive again, I'm back at work, I've made some accommodations to our house, which helps. Still, when I look around at my life, this is not what I imagined for myself. I want to go on skiing trips with my wife, chase my grandkids around the yard. I even wish I could clean out the gutters. I'm grateful to be alive, but I can't help but feel cheated out of the life I was supposed to have. My wife wants me to see the silver linings in everything, and I try to be positive for her. My injury has made life so much harder for her, and I don't want to make things even worse by being a downer all the time. I want to feel optimistic and count our blessings, but the loss feels so great. And I can't get past the fact that these are her losses, too. How can I be the happy husband she wants me to be when I know my injury has taken so much from us and the life we dreamed of living together?

Signed,

Not What I Imagined for Us

Dear Not What I Imagined for Us,

It's one thing to grapple with your own loss. It's a whole other animal to feel responsible for someone else's, isn't it? At least, it has been for me.

About a year after I started dating the guy I'd eventually marry, my body derailed everything. I'd dealt with pain and spasticity most of my life, but this was a new kind of debilitating. Some days the pain was all I could think about. While I was going from doctor to doctor, trying to sort all this out, I watched as his life bent to the force of my pain. It became our first topic

of conversation, shaped our weekend plans, forced us to leave the party early.

One new rhythm to our days started before the sun came up when he'd help me do stretches. The routine always ended with trying to stand for 30 seconds. This particular morning, the air felt especially cold and the morning darkness impenetrable. As I stood, I felt the pain in my lower back start to throb and my leg muscles clench. He gripped me tighter, and I forgot to breathe as I counted each slow second in my head. I was so angry — that this was our morning, that this pain was swallowing my life whole, and maybe worst of all, that he — this lovely, kind, generous man — was pulled into this nightmare with me. And then, right when I thought my fury and ache were about to punch out of my body, I felt him nuzzle his nose into the side of my face. "I like holding you," he said. I heard myself make a sound like a wounded animal, a yelp. It felt terrible and wonderful to be loved this way. To witness tender affection thriving in the midst of acute distress. It's hard to describe that awful contradiction, but I think you might understand it.

He and I have been together for almost 10 years now. In those years, he was diagnosed with cancer, and we had a baby as we sheltered in place during a global pandemic. None of it is what we dreamed for ourselves. But more life means more pinpoints on the map that can offer perspective, and here's what I see now, that I didn't see that dark morning.

When I set out on this journey with my partner, I thought that my body — my

disability — was a distinct kind of weight he shouldn't have to shoulder. The more life we've lived together, though, the more I've realized "weights" come in as many forms as there are atoms. Can you even have a partnership without a house full of them? Would you even want to? The longer we're together, the more partnership seems to be about building a structure that can hold all our weights — a structure that holds space for grief and frustration, that makes us feel safe enough to trust each other with our heaviest parts.

And your structure seems to have taken a hit. This is not what you imagined when you pictured yourself enjoying these years with your wife and grandkids. That loss is real and undeniable. This life is going to look different than you expected. There is nothing weak or wrong about grieving it.

And also — and this is the counterintuitive part — when our plans fall apart, we have an invitation to reimagine. Whenever you're ready, you might ask each other: What other shape could our life take? Who else might we be or become? What other dreams are waiting to be realized? Or maybe, a question as simple as "Where are the best adaptive ski resorts?" What if the work wasn't a choice between the happy husband or the downer husband? What if your assignment was simply to bear witness to every single piece — the impenetrable dark and the soft nuzzle? What if the project was two partners dreaming of a structure big enough and flexible enough to hold all of the pieces?

Love,

Rebekah



Dear Not What I Imagined for Us,

I've had days where my heart feels like a pit that I'm carrying around in my chest, with the goal of no one else seeing the depth of that dark hurt. My parents, my friends, my helpers. Especially my helpers: I need them, and I don't want to be a downer while they're around and risk them not liking their job. If you're reading this and have caregivers, please know that you deserve to feel the full spectrum of your emotions and are allowed to have bad hours, days, etc. This is something I'm constantly working on reminding myself. Feeling like you need to be positive around others when you're not feeling positive at all can be exhausting — you're putting on a mask to cover up what's actually going on inside, and the effort of keeping that mask from slipping is tiring.

Even in therapy, there are moments when I can't quite bring myself to fully open up to my therapist, specifically around the great tangled mess of emotions I feel around romance and sex.

In some ways, I feel like I'm still tied to the story of needing to spin heartbreak into a lesson, instead of just letting the heartbreak be what it is. Sometimes I feel like if I actually unbury the grief, it will consume me, and what I've had to learn, over and over, is that even when it does consume me — when I go around my days feeling like a dark, foggy cloud has descended past my shoulders — I'll still emerge on the other side.

Pain is a scary place to exist in. Think about how much we do as a culture to avoid it. But the truth is, pain, heartbreak, grief — it's all real, it's all normal, it's all a part of life. Not too long ago, my therapist suggested that perhaps by allowing myself to be sad, anxious, etc., around my helpers, I'm also reminding them that it's human to have more emotions than simply happy, that feeling these emotions is human, that being human is, well, OK.

My disability is genetic and has been a part of who I am for as long as my memory goes back. I'm 29 years old.

I don't have kids or grandkids. I'm not married. I really can only imagine what you've gone through. But the desire to remain positive for someone who you spend the majority of your time with and who you care deeply about rings true to my experience, too. And I'm wondering if perhaps allowing yourself to grieve and rage and all the other uncomfortable emotions we try to avoid but shouldn't will actually give your wife the gift of recognizing that if she needs to, she can do this, too. That neither one of you are alone in this, and that you'll live the highs and lows, together.

Love,
Hannah

*Roadmaps authors Rebekah Taussig and Hannah Soyer don't claim to know it all, but they have been traveling the disability road for quite some time and would love to share their experience with you. Please email questions to messyroadmaps@gmail.com. For more on the authors and illustrator Haley Brown, see *Behind the Stories* on page 5.*

HOW TO CHOOSE THE BEST WHEELCHAIR CUSHION FOR YOU

BY SETH MCBRIDE

What type of cushion to use is one of the most important decisions you make when setting up your wheelchair. The right cushion can keep your skin safe, improve your posture and enhance your stability. The wrong cushion can lead to pressure injuries, spasticity and pain.

Cushions come in all different types, from foam, to air, gel, honeycomb, custom and more. So which is the best for you? Like with most mobility aids, the best wheelchair cushion depends on your body, your level of mobility and your daily life. Here are nine things to consider when getting your next everyday wheelchair cushion.

PRESSURE RELIEF

This is what my rehab therapist told me to put “on the top” of the list. Joking, but it’s true. Pressure relief is often the top concern of therapists who do seating evaluations. If you have limited or no sensation, have dealt with pressure injuries before, or have difficulty repositioning yourself, finding a cushion that evenly distributes pressure is critical to keeping pressure sores away.

Custom cushions like Ride Designs Custom 2 (see sidebar, page 21) often show the most even pressure mapping — where you sit on an electronic pad that plots areas of low and high pressure. ROHO air cushions come in a close second. Important note: Many wheelchair users overinflate their air cushions, which helps stability but negates the pressure distribution benefits. For proper pressure relief, you have to sit in the air cells, not on top of them.

Gel cushions, like the ubiquitous JAY J2, often score in the midrange for pressure relief, as do lesser-known Supracor Stimulite cushions made from a rubberlike honeycomb structure. Off-the-shelf foam cushions often score worst for pressure relief, but there are huge variations based on the shape, density and contour of the foam. Pressure mapping of different materials can vary a lot based on your body type and seating position. So, if pressure relief is your primary goal, it would be ideal to map a variety of cushions with a qualified therapist.

STABILITY

When you transfer off the pressure map and go about your day, stability becomes an important part of selecting the right cushion. A high-profile ROHO that maps great and feels good when you’re upright might lose some of its luster when you bend forward to pick something off the ground

and the change in pressure vaults you out of your seat. Single-compartment air cushions offer the least stability of any cushion type. Air cushion manufacturers combat this problem by offering cushions that can lock the airflow between different compartments. ROHO offers cushions with two compartments (Dual Compartment) and four (Quadro Select). Ki Mobility’s StarLock cushion lets you lock the air in every cell. Multicompartment air cushions offer better stability than single-compartment, but they’re still not as stable as most other cushions.

Foam cushions typically offer the best stability. Contoured foam offers more stability than flat foam, and a custom foam cushion like the Ride Designs Custom 2 will lock you into your seat better than any other cushion on the market. (More on this below.) Stimulite and gel cushions also offer good stability. Combination cushions — like the ROHO Hybrid Select, ROHO Hybrid Elite, Vicair Active O2, JAY Fusion with air insert or the Permobil Corpus Ergo Air for power wheelchairs — offer the stability of foam with some of the pressure-distribution benefits of air cushions.

POSTURAL SUPPORT

If you have wonky hips, scoliosis or any other postural issues, then postural support or correction can be an important consideration. Most cushion types, whether gel, foam, combination or honeycomb, come with contoured options designed to keep your legs in place and your pelvis in a neutral position. Multicompartment air cushions can also accommodate some postural issues. How well they work depends on your body’s particulars and your level of function. In a nonparalyzed body, muscles do the work of postural support. The fewer working muscles you have, the more you may benefit from external postural supports.

Custom cushions, like a one-off from a seating clinic or one from Ride Designs, can provide excellent postural support and correction. But remember that posture isn’t a static thing: If you’re going with a custom cushion, be prepared to do regular follow-up visits with your seating professional to make sure that your cushion still fits your body. A custom cushion that no longer fits properly can cause pressure injuries, edema and/or increased spasticity. Also, remember that the more postural support you have, the more you’re going to be locked into a single position. This can be great for some. For others who have the function to move around more — like scooting forward in your seat to get dressed or reach for a cabinet — being locked in place isn’t always a good thing.

TRANSFERS

Air cushions suck for transfers. They don't provide a stable surface for a hand or sliding board when you want to get out of your chair. Of course, this can be overcome with strength and technique, but it does add a degree of difficulty. Foam, gel, honeycomb and combination cushions all provide a more stable surface to transfer from. Cushions with a deep seating pocket — which can be great for pressure immersion, stability and postural support — can also make transfers more difficult because you have to get your butt back out of that pocket.

DURABILITY

With a foam cushion, you should be checking for compression or deformation after a year of use. Of course, they can and do last longer, but the more that foam compresses, the less effective it is for pressure reduction, and uneven compression can cause stability and postural changes. Air cushions can last for years, or you can poke a hole the first week you have it and suddenly be sitting on your seat rails. If you have an air cushion, always have a backup and patch kits — which is doubly important when you're traveling. Gel cushions used to start getting stiff after a couple of years, although manufacturers say this is less of an issue now. Still, if you have either a gel or honeycomb cushion, it's a good idea to start thinking about a new one at the two-year mark.

ADJUSTABILITY/ MODIFIABILITY

Multicompartment air cushions are simple to fine tune. You unlock the airflow valve, shift your weight and positioning, and lock it again. Vicair cushions, which have compartments filled with air packets, are similarly easy to adjust. To let yourself sink into a section more, remove some air packets. To make a section firmer, add more packets.

You can take an electric carv-

ing knife to foam or honeycomb cushions to cut out a section without compromising the integrity of the rest of the cushion. Why would you ever want to do that? Maybe you're downgrading your cushion from everyday use to sports-only and you need to modify it to fit on a handcycle or in your sports chair. Maybe you've had a pressure sore on your coccyx. If you cut a notch where your coccyx normally rests, you can let it free-float.

Combination cushions are difficult to modify, although the air cells at the back do offer some adjustability. Cushions with a gel pocket are also hard to modify or adjust. If you can't or don't want to make structural changes to your cushion, Stimulite offers a wedge that you can use to raise the front by 1 or 2 inches.

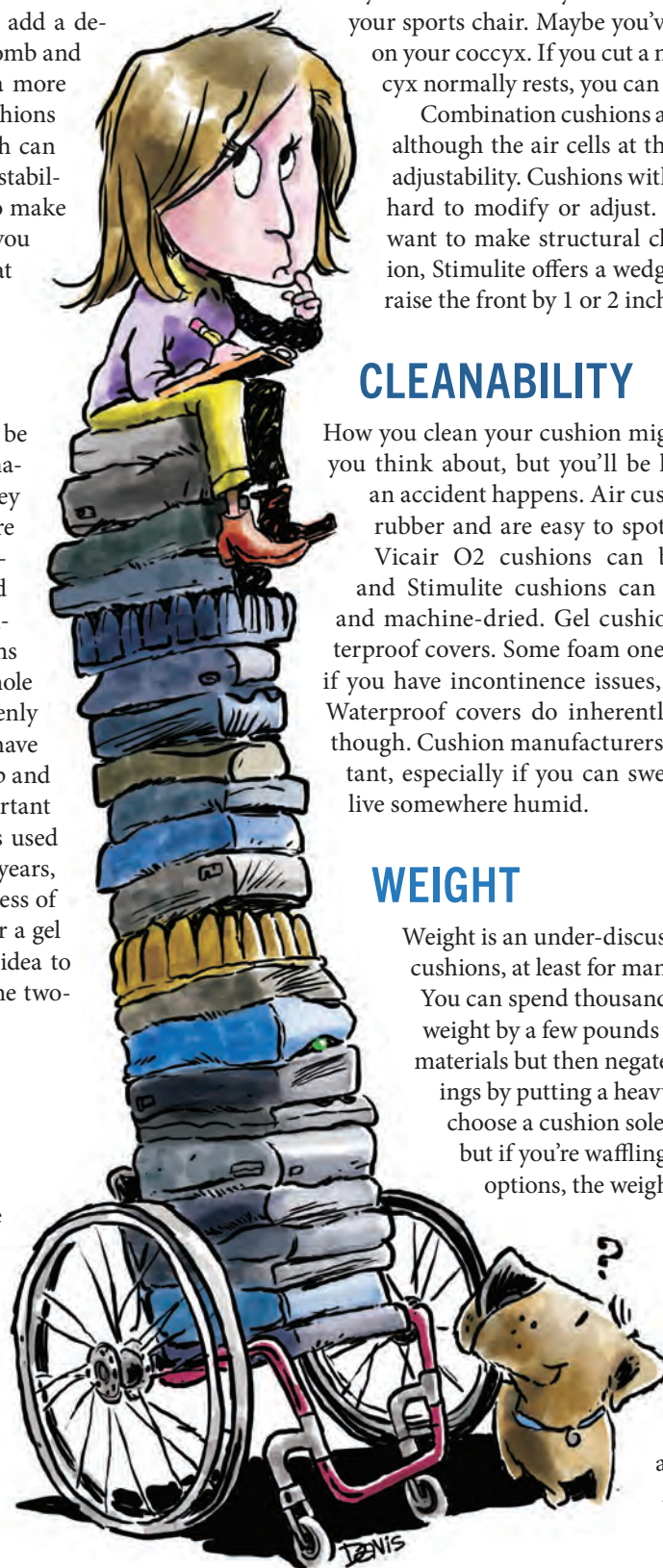
CLEANABILITY

How you clean your cushion might not be something you think about, but you'll be happy you did when an accident happens. Air cushions are made from rubber and are easy to spot-clean or handwash. Vicair O2 cushions can be machine-washed, and Stimulite cushions can be machine-washed and machine-dried. Gel cushions tend to have waterproof covers. Some foam ones do, others don't, so if you have incontinence issues, it's worth checking. Waterproof covers do inherently limit breathability though. Cushion manufacturers say airflow is important, especially if you can sweat, are active and/or live somewhere humid.

WEIGHT

Weight is an under-discussed consideration for cushions, at least for manual wheelchair users. You can spend thousands of dollars to reduce weight by a few pounds with advanced frame materials but then negate all those weight savings by putting a heavy cushion on it. Don't choose a cushion solely based on weight — but if you're waffling between two similar options, the weight can "tip the scales."

Gel cushions are the heaviest. A 16-inch-by-16-inch JAY J2 Deep Contour weighs a whopping 6.27 pounds. Ironically, air cushions aren't that light either. A 16-inch-by-16-inch high-profile ROHO



weighs 4 pounds. Honeycomb and combination cushions are often in the midrange. A Stimulite Contoured weighs 3.25 pounds and a ROHO Hybrid Select, 3.2 pounds. Foam is typically the lightest. A Ki Mobility Axiom S cushion weighs about 2.2 pounds, depending on size, and a Ride Designs Java comes in at 2.3 pounds. The Ride Designs Custom 2, also foam, is the lightest wheelchair cushion we've found, coming in at 1.8 pounds.

PRICE

I know, everything is expensive. Most quality wheelchair cushions retail in the \$450-\$550 range, which can bring an insurance copay of \$100 or more, plus the cost of appointments at a seating clinic. You can find deals at online DME shops if you don't want the insurance hassle or don't have insurance, but you're still going to pay around \$350 or more for a good cushion. Although, for less than \$100, you can find a simple foam cushion like the Axiom G, or a simple gel cushion like the Elements from Comfort Company.

A custom cushion is only available through a seating specialist and can run into the thousands of dollars.

If you're broke and without insurance, or the type of person who thinks poorly of the medical-industrial complex, do-it-yourself options are available. You can buy a variety of foam types and densities anywhere from JOANN Fabrics to Walmart, all of which can be cut, glued or duct-taped into

THE MOST IMPORTANT TAKEAWAY IS THAT EVERY TYPE OF CUSHION HAS ITS PROS AND CONS.

whatever configuration you want, although you'll need to figure out a cover ... pillow case anyone? Or you can buy a 2-inch thick hexagon gel cushion off Amazon for \$30 and cut it to whatever size you need. DIY is decidedly not therapist-approved, but can be an option for those with good sensation and mobility or if you need a backup or sports cushion without forking over a ton of money.

FINAL THOUGHTS

That was a lot. The most important takeaway is that every type of cushion has its pros and cons. Spend some time thinking about what you like about your current cushion, and what you don't. Think through what considerations are most important to you and try to find a cushion that balances them. Don't be afraid to ask for help. A good seating specialist, be they a physical therapist, occupational therapist or assistive technology professional, will listen, ask questions and understand that your needs extend far beyond the clinic.

MM



- Detailed info on the Top 20 Wheelchair-Friendly Colleges, researched and written by wheelchair users
- Personal stories and photos of wheelchair-using students at every school, plus advice from successful grads
- Resources and scholarships for wheelchair users



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CUSHION TYPES

AIR — Inflated cells that adapt to your body weight, available with different numbers of compartments and profile heights.
 Pros: Pressure distribution.
 Cons: Stability, heaviness.
 Common Brands: ROHO, Vicair, Star.

FOAM — A piece of foam.
 Pros: Stability, lightness.
 Cons: Pressure relief, durability.
 Common Brands: JAY, Comfort Company.

COMBINATION — A combo of foam and air in varying configurations.
 Pros: Balances stability and pressure relief.
 Cons: Modifiability.
 Common Brands: ROHO, Varilite, JAY, Vicair.

GEL — A pouch of gel that adapts to your body, usually atop a layer of foam.
 Pros: Balances stability and pressure relief.
 Cons: Heaviness, limited postural support.
 Common Brands: JAY, Comfort Company.

HONEYCOMB — Multiple layers of rubberlike material in a honeycomb pattern of varying firmness.
 Pros: Balances stability and pressure relief, lighter than gel or air.
 Cons: Limited postural support.
 Common Brands: Stimulite.

CUSTOM — Usually made from dense foam custom-molded to your body, designed to provide support in areas you need it and offload pressure where you don't.
 Pros: Pressure relief, stability, postural support.
 Cons: Cost, adjustability.
 Common Brands: Ride Designs, Aquila.

SMART — Modern “smart cushions” cycle pressure through different zones and you can control pressure settings via an app.
 Pros: Adjustability, Pressure relief.
 Cons: Cost.
 Common Brands: Kalogon, Ease.

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Museum-Hopping in



The Diego Rivera murals at the very accessible Detroit Institute of Arts

DOWNTOWN DETROIT

BY STEVE WRIGHT

FOR SEVERAL DECADES, some very bad policy, politics and the loss of tens of thousands of good jobs placed Detroit pretty low on many people's travel lists.

Much has changed, especially for those who love urban vacations highlighted by historic architecture, world-class museums, countless entertainment and sports venues, eclectic eats and reliable public transportation. All this and other amenities give Detroit an enduring sense of place and significance befitting a great American city. The core of Detroit is thriving and surprisingly accessible. And yes, for those who ask — the streets are safe, even far into the night.

MAIN STREET ADVENTURES

Woodward Avenue is an excellent place for any wheelchair user to start exploring downtown Detroit. Often referred to as "Detroit's Main Street," Woodward runs 27 miles from the Riverfront to Pontiac, Michigan. Over a century

after making history with the first mile of concrete-paved road in America in 1909, Woodward now is ideal for wheelchair users, with wide sidewalks and densely packed attractions.

To maximize your time or simply save your energy, the QLINE, Detroit's free streetcar, runs along Woodward for 3.3 miles from a point near the Detroit River to the New Center area. It has accessible seating near its doors, and each boarding station has a gently ramped boarding platform so the streetcar can be rolled onto directly with no worries about broken lifts or driver-activated ramps.

As a lifetime Detroiter and an ADA coordinator for Disability Network Wayne County Detroit, Jaime Junior is no stranger to the QLINE and the dos and don'ts of accessing the urban core. Junior, who has cerebral palsy, notes that while the QLINE is a great amenity, sometimes its tracks can interfere with crosswalks when they are not well maintained. She also urges caution traversing crosswalks, as a surprising

number of them are riddled with man-hole covers.

Because she is an ADA coordinator who sets the bar high, Junior can be an exacting evaluator. Owing to existing challenges, she gives the core of Detroit



Jaime Junior

her B-/C+ grade for overall accessibility. "As a resident and somebody who visits a lot of museums, stores, services, etc., I think downtown Detroit can always do better," says Junior. "Downtown needs to prioritize keeping the sidewalks open and smooth, which is good for people with disabilities, older

people, families with strollers — even package deliveries.”

To avoid crossing too many wide streets, depending on the route, wheelers can take advantage of the elevated Detroit People Mover. The accessible mover serves 13 downtown stations along a 3-mile loop. Junior says the system is pretty good about maintaining the elevators up to the boarding platforms that allow flush-level entry. The fare is 75 cents.

A great place to start exploring Woodward and downtown Detroit is Campus Martius Park. Just a few blocks north of the Detroit River, Campus Martius Park was named the No. 1 public square in the nation by *USA Today* and is one of the highlights of downtown Detroit’s abundant, accessible public spaces. Other spots worth visiting include historic Cadillac Square in the center, Grand Circus Park on the northern edge of the urban core, and the pedestrian-only Woodward Esplanade that leads to the Detroit River, featuring an ever-expanding wheelchair-accessible river walk.

While you explore, enjoy the views of the city’s historic skyline. Once the fourth-largest city in the U.S. and home to an almost-unmatched industrial center, Detroit still has fabulous, ornate skyscrapers from the 1920s and 1930s. Albert Kahn, the great architect of towers and industry, left a legacy of buildings worthy of the finest seen in New York or Chicago.

MUSEUMS GALORE

Less than a mile west of Woodward, on Berry Gordy Jr. Boulevard, aka West Grand Boulevard, you’ll find the Motown Museum. One of the greatest small museums in the nation, the Motown Museum offers hundreds of gold records, colorful stage costumes of famous male and female acts, and tons of other fascinating memorabilia. Junior praises the museum for adding accessibility to a pair of old houses that Berry Gordy Jr., founder of the Motown record label, bought and expanded into when Motown was more a dream than the star factory that it became.

“Considering it has a great ramp



Emily Obert loves the Museum of Contemporary Art Detroit so much she got married there.

up to the entrance and a good elevator to the second floor, I’d give Motown a high grade for having great access despite it basically being in an old house,” says Junior. For athletic wheelers, there’s a QLINE stop just north of Grand, and decent sidewalks all the way to the Motown Museum. For transit, roll a couple blocks west to the Fisher Building — more on it, next — and for a \$2 dollar fare you can take the 16 Dexter Bus two stops to Poe Avenue, and roll on to Motown.

On the way back to the core of Detroit, pause to gasp at the Fisher Building, nicknamed Detroit’s largest art object. Kahn’s 1928 art deco masterpiece soars 441 feet, clad in marble, mosaics, painted ceilings and much brass and bronze. You’ll find shops and an accessible theater in the large lobby.

Virtually across the street is another of Kahn’s triumphs, the Neoclassical, 15-story Cadillac Place. It opened in 1922 as the headquarters of General Motors and, at the time, was the second-largest office building in the world. In the 1970s, GM moved to the monolithic Renaissance Center on the Detroit River, so now the complex

houses 2,000-plus employees of the state of Michigan.

Only a few Q-stops away is the Museum of Contemporary Art Detroit. Housed in a 22,000-square-foot, low-rise industrial building designed by Kahn to be an auto dealership, the museum offers a rotating selection of modern art and hosts a diverse array of events and guests.

As a wheelchair user with a master’s degree in mechanical engineering from Massachusetts Institute of Technology, Emily Obert is supremely qualified to comment on the building’s accessibility. “I’m biased, because I got married there, but they really did a great job on the one-level entrance — not a segregated accessible entrance — and the open space is great for access,” says Obert, a T6-7 paraplegic.

Obert, who works on accessibility and equity at Ford Motor Company, also gives high marks to the Motown Museum and has a must-stop spot for foodies looking for a fun, accessible meal near both places. Baobab Fare opened in early 2021 and its East African cuisine and goods have already earned it a James Beard Award and

recognition in the New York Times.

“Baobab gets that perfect balance between sweet, sour, salty, tangy,” says Obert. She recommends the samaki: lightly fried fish with sauteed onions served with fresh corn salad, fried plantains, stewed yellow beans and coconut rice or spiced rice pilau. “Everything on the menu is delicious.”

Aside from a tiny slope at the front door, Obert gives Baobab high marks for overall inclusion based on accessible restrooms and an open floor plan that has lots of accessible seating.

Halfway between Baobab Fare and the Museum of Contemporary Art, at the Warren Avenue QLINE stop, sits the granddaddy of all Detroit’s museums — the Detroit Institute of Arts. Spanning over 650,000 square feet and featuring 100 galleries, DIA is one of the largest and most significant art museums in the country. The museum is most famous for Diego Rivera’s “Detroit Industry Murals,” a series of frescoes consisting of 27 panels depicting industry at Ford and Detroit. Controversial when completed

in 1933, the murals have since been designated a National Historic Landmark in 2014 and were considered by Rivera to have been his most successful work. Other highlights include William Randolph Hearst’s armor collection and a massive selection of American art. Both Junior and Obert praised DIA’s accessibility.

“They have a grand staircase, because that’s what buildings had back then, but the main entrance has been reoriented to a level entrance from the south side of the building,” Obert says of the Neoclassical DIA, opened in 1927. “There also is free accessible parking close to that entrance off of Farnsworth Street.

“They have some of the biggest elevators around — some likely used for moving exhibitions — and there are lots of elevators throughout the building,” she says. “The main bathrooms are accessible, but the doors are a little hard to push open. DIA has a single accessible restroom near their classroom. It’s not obvious where it is, so they could improve signage, but it’s excellent for use with a personal care assistant.”

Obert offers an insider’s tip for visitors to Detroit looking for an added experience in the expansive, high-ceilinged court that displays the world-famous Rivera murals. “Everybody loves the Rivera murals and I’d have to say it’s my favorite too,” she says. “Check the calendar. They do some Friday night events there. I saw a concert in that room.”

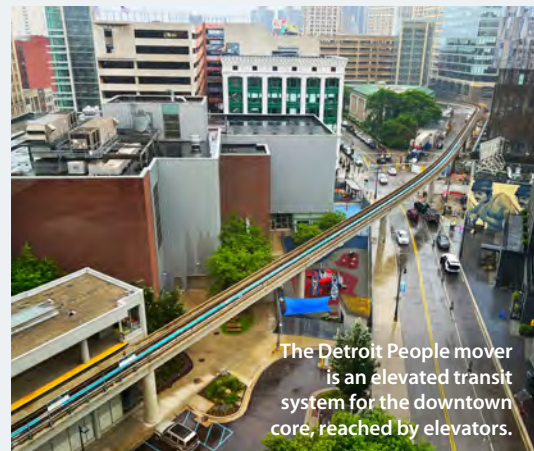
MI



The Motown Museum features record covers its hall of fame and lesser know acts. The space has outstanding wheelchair maneuverability.



The Detroit Riverwalk



The Detroit People mover is an elevated transit system for the downtown core, reached by elevators.



The wheelchair-accessible QLine provides free transit along three miles of Woodward Avenue.



Wheelhouse Detroit



American Coney Island — a downtown Detroit legend for decades.

DOWNTOWN DETROIT

→ WHERE TO GO

Motown Museum: motownmuseum.org. Admission is \$20, with guided tours only, so book in advance.

Detroit Institute of Arts: dia.org. Admission is \$18.

Museum of Contemporary Art Detroit: moca-detroit.org. Suggested admission is \$10.

→ WHERE TO EAT

Baobab Fare: baobabfare.com.

Buddy's Pizza: buddyspizza.com. Buddy's originated Detroit-style square pizza.

American Coney Island: americanconeyisland.com. Motown coney — spicy chili, mustard and onion-topped dogs with snap — have been around for over a century.

→ WHERE TO STAY

Hilton Garden Inn: hilton.com/en/hotels/detdghi-hilton-garden-inn-detroit-downtown/rooms. Centrally located — and close to Ford Field, Greektown, Opera House, and Music Hall — the Hilton's rooms with roll-in showers are often found for \$175 per night.

→ HOW TO GET AROUND

QLINE: qlinedetroit.com. The streetcar is free and accessible.

Detroit People Mover: thepeoplemover.com. Fare is 75 cents.

Detroit buses: detroitmi.gov/departments/detroit-department-transportation/bus-schedules. Fare is \$2.



Mo Pop Hart Plaza

Download it now!

United Spinal Association

DISABILITY ETIQUETTE GUIDE

Tips on Interacting Respectfully with People with Disabilities

Making PEACE with my Spinal Cord Injury

BY CASSANDRA BRANDT



AN EXCERPT FROM
*SEVEN SECRETS OF A
SEDENTARY STOIC:
PURSUING A PATH TO
POST-PARALYSIS PEACE*

Outside the window the summer sky is impossibly blue and oblivious to my plight on this bed. Sorrow pierces my heart, and a sob catches in my throat. The skilled nursing facility is alive with staff rushing about hustling residents into showers, pushing med carts, tending to droning call bells and haunting cries. The surgeon’s voice echoes in my mind every moment: words like “permanent” and “complete.”

Closing my eyes, I see myself on my feet, in my work boots and harness on the iron. Longing fills my soul and is only compounded with the next intrusive fantasy: flying down a desert highway, left arm out the window; another, racing my daughter across Canyon Lake.

I glance down at the call button, placed near my face so I can hit it with my cheek, but it has shifted too far from the reach of my straining neck. My arms lay limp at my sides, immobile on their pillows, even as my brain commands them again and again to move.

My brother will be here soon, I remind myself. He will bring that little red book again. What were some of the things he read yesterday? Something about my power? Deep within myself I have the strength if I look?



MEETING MARCUS

I was 32 years old when I sustained this spinal cord injury, a passenger in a car accident. My able and autonomous body that had allowed for my independence and enjoyed its gratification was instantly immobilized from the shoulders down.

I could no longer support my child or live on my own as an adult out in the world. I would have to depend on others, ask for help, sacrifice my pride, dozens of times a day. Me, who always made guys split the checks on dates and refused child support for years. My pride and ego were absolutely crushed. A peaceful future felt less attainable than ever. How could I ever find peace of mind in this busted body?

In those acute days, confined to a hospital bed in a facility, no hope of motor function recovery and little hope of going home, my anxiety threatened my sanity. A concerned nurse warned my family: If I couldn't calm down, I wouldn't make it. It was in that dark hour I met Marcus Aurelius.

My brother, an author and autodidact who had studied Greek philosophy, had brought a paperback copy of *Meditations* with him on his flight across the country to his sister's side. How the journal of a long-dead Roman emperor challenged me to persevere in my darkest days has been an irony not lost on me.

The book, actually titled *To Himself*, consists mostly of Aurelius coaching himself in the philosophy of the Stoics. Often containing some self-reproach, the little book is rich with admonishment on how to be more virtuous, patient, strong, wise.

Aurelius used the philosophy of Stoicism to deal with the stresses of daily life as a leader of one of the most powerful empires in human history. My battle couldn't be more different; it's with my

own body. But it didn't take more than a few paragraphs to give me a spark of something like hope. Challenging myself to be strong was exactly what I had to do in my situation too.

Maybe I could use this ancient philosophy to deal with the inevitably incredible stress ahead, navigating life paralyzed from the chest down. If I had ever needed to develop self-discipline and mental resilience, it was post cervical spinal cord injury!

Ancient Greek philosophy focused on reason, and how best to live your present life right. When Hellenistic philosophy formed in Athens, Greek philosophers offered methods for finding peace within yourself, and they taught virtue and universal reason. The Stoics were no exception; based on the

moral ideas of the Cynics, Stoicism was founded in 400 B.C. and moved to Rome where it flourished during the period of the Empire and influenced Christianity.

The name *Stoic* comes from the *Stoa Poikile*, or painted porch, an open market in Athens where the original Stoics used to meet and teach philosophy.

Stoics believed in living a life of virtue in accordance with nature. Similar to Buddhist and Christian teaching, this included aversion to conventional desires for wealth, power, etc. The philosophy also promoted positive perspectives, productivity, patience and peace of mind.

The most famous Stoic philosophers are those of Imperial times (27 B.C.E. to C.E. 476): Seneca, Epictetus and Aurelius.

STRENGTH OF STOICS

Seneca said that it's an act of courage just to live sometimes. In the first months following my injury, I made the choice to keep going again and again. Seneca pitied people who have never experienced misfortune: "You have passed through life with-

out an opponent," Seneca said. "No one can ever know what you are capable of, not even you." Was I capable of this though? In those early days post injury how I cried that I was not. Surely this battle was meant for someone stronger!

Marcus Aurelius: "Look well into yourself; there is a source of strength which will always spring up if you will always look."

I needed that strength to let go of my able body. There's more to life than motor function. It would be foolish to spend my days yearning for a cure. Like Epictetus said, "A ship should not ride on a single anchor, nor life on a single

hope." I had to understand that restored function to my body probably will never happen, and sitting around hoping for it was pretty much futile. What I should dare hope for was to live a decent life with my disability.

I started taking agency of my life again slowly, parenting my daughter and taking control of things like my medications and my finances. After purchasing a van and training a service dog, I began to get out more and recharge in nature. Then it was festivals and concerts and pushing myself through my pain and stress to participate in life and to have happy, healthy experiences. I still have to accept numerous limits my disability puts on my body and life.

"Very little is needed to make a happy life; it is all within



The author and her daughter, Haley

yourself, in your way of thinking,” Marcus Aurelius said. But my way of thinking had to change. I had to focus on what remained, see the glass as half full when the old me with all her privilege couldn’t manage to ever see it that way.

The Stoics emphasized the importance of recognizing the dichotomy of control. I cannot control my central nervous system. I don’t have control of my arms or my legs. I don’t have control of my bowels or my bladder. Subsequently, I don’t have much total control of my own life. But dwelling on externals of such nature is a choice, and in choosing it, I can find I’m wallowing in self-pity quickly. Obsessing about what my body cannot do does not serve me in any way. It wastes my time and energy. So, I separate.

Marcus Aurelius: “If you are distressed by anything external, the pain is not due to the thing itself, but to your estimate of it, and this you have the power to revoke at any moment.”

My estimate of this horrible thing in front of me was that it was too huge, undefeatable. To revoke that, I had to ask myself how valid that was. I am still alive. I haven’t suffered a brain injury. I have a good support system. There are systems in place to get me out in the world living a productive life again. This is the perspective I had to choose. In this scenario, I could do this thing.

The monster that is Quadriplegia can be reduced in stature by admitting it can be dealt with, given a certain degree of perspective changing. My judgment of this event that happened to me could be reexamined too. Perhaps my disability could be seen as less of a tragedy in the light of all the opportunities for self-growth and human connection it would afford me.

The Stoics spoke of “memento mori,” translated literally from its original Latin to mean “remember that you have to die.” They wanted to emphasize that life is brief and fragile and it’s foolish to waste it. Embrace

Marcus Aurelius: “Dwell on the beauty of life. Watch the stars, and see yourself running with them.” I find a certain peace when I’m in nature that feels reassuring and ancient, as raw and real as the dirt and the trees. My connection to it is no less pure without the finger function to feel; I can feel a breeze in my hair, the sun on my face. I can smell the pines and the poppies and marvel at the way the lake glimmers like glass in the sunlight. In times of distress I close my eyes and take myself to the places and people that bring me peace. I return to the Redwood Forest, and Carmel by the Sea. I dig my toes in the sand, take a quick dip in the Pacific before I return to this sedentary body, but it’s without resentment I do.

your inevitable demise and live every day with meaning ... I have prioritized what matters. And I have a message to share.

TRAINING THE MIND

Seneca said we must train our minds to desire what the situation demands. My situation demands endurance and patience so I train for that. How I struggle at times, voicing every ache and burn and symptom when the pain overwhelms me. “If fate can be overcome by tears, let us bring tears to bear upon it,” said Seneca, but if not, then our futile grief must come to an end.

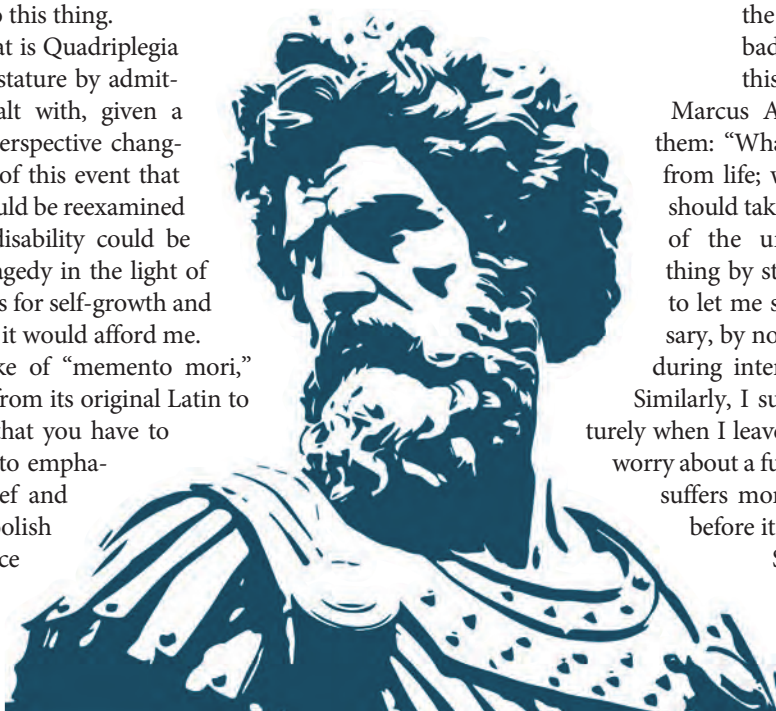
“A high-minded and sensible man divorces soul from body, and dwells much with the better or divine part, and only as far as he must with this complaining and frail portion.” I must dwell with my divine part. My divine part knows no pain, only peace.

Lingering in the past makes me long for the able body I lost, but worries about the future with my disability are also a thief of my peace. I catch those thoughts stealing from my joyful moments and have to redirect my mind. I must not “lose the day in expectation of the night, and the night in fear of the dawn,” like Seneca said. The bad times DO pass. Yes, even in this body.

Marcus Aurelius insisted I could bear them: “What we cannot bear removes us from life; what remains can be borne.” I should take care to not triple the duration of the uncomfortable/stressful/painful thing by stressing about it. I also allow it to let me suffer far beyond what’s necessary, by not living in the present moment during intervals between stressful events.

Similarly, I suffer unnecessarily and prematurely when I leave a present moment of calm to worry about a future event. As Seneca said, “He suffers more than necessary, who suffers before it is necessary.”

Self-control is at the very heart



of Stoicism. For me, it's not dissolving into fits of anxiety over pain and monotonous care. It's fighting the urge to complain and cry and snap. It's not letting my mind go to those places where those emotional reactions feel so inevitable. It's OK to have a cry sometimes, but frequent pity parties don't make my life any easier. Deep breathing and redirecting my mind in those moments does.

STOICISM, MY WAY

The Stoics assure me I have not been relieved of my role as a human being, given this disability. My mind is still intact, and contributions are still required of me. Just because I cannot jump out of this bed on my own accord doesn't mean I'm resigned to stay in it! My role is to be hoisted with a lift into a power chair by my attendants. They rig my technology in front of my face and I do what my nature demands. I write.

I was not born to feel nice or have an easy life any more than the next animal. We all have our work, our tasks, our hardships. I was born for experiences, even when they hurt. I remind myself this when the tasks of the day are difficult to face.

Marcus Aurelius didn't know a disabled woman would one day take him up on the challenges he set for himself. He didn't imagine his message would apply to women at all, sometimes contrasting Stoic strength with womanly weakness, but I'll forgive this bit of ignorance.

Our industrious nature is so much of what makes us humans and brings us peace, regardless of gender, ability or other station in life. I push myself daily to get out of bed, and busy, always busy with my work. Whether it has been donning my blue collar to put in a shift welding with my hands or getting up in my wheelchair to type an article with my teeth, I've preferred not to waste a day.

I speak to myself with the accusatory tone Marcus Aurelius used with himself. No one else is going to do it. No one but me knows how badly I need it. This passage of Seneca especially hits home for this Sedentary Stoic: "Do you think that you are doing nothing if you possess self-control in your illness? You will be showing that a disease can be overcome, or at any rate endured. There is, I assure you, a place for heroism even upon a bed of sickness."

My place in this world is not to become irrelevant, even as inaccessibility and ableism try to exclude me. I still have contributions to make and work to do. So I use what I can: my teeth and technology. My voice.

FINDING PURPOSE

I don't love chronic pain, lost autonomy, or any of the limits this life has placed on me. But I embrace the woman my

spinal cord injury has made me — stronger and more patient and understanding. I embrace the time it has given me to work at my craft and become a writer, which I could never find the time to do sufficiently on legs.

I embrace the mission this disability has imparted on me as an advocate for inclusion and disability rights. And I appreciate the platform it has given me to share what I've learned about mental health. I appreciate also the unique position my disability has put me in to receive the comfort, empathy and tender love and care of so many caregivers. Many people go through this life without a single tender touch or a word and I receive them daily.

Marcus Aurelius: "Accept the things to which fate binds you and love the people with whom fate brings you together but do so with all your heart."

My fate also binds me to a massive community of people with spinal cord injuries whom I eagerly reach out to about the Stoic way. I speak about how the Stoics have taught me to exist more comfortably in this body, perhaps more comfortably than I existed within it when it was able. I'm learning to let go, live in the present, and to calm myself, and there's nothing more exciting.

I have learned that fantasizing about motor function only exacerbates my fear of fully accepting and living the life I have now. Terrorizing myself about potential health complications taking my life early are similarly counterproductive. Instead, I adapt myself to the present. I remain mindful of the good things that can never be taken from

me. I look within for peace. There's little I can do to cure my body but my mind can be mastered.

Epictetus: "No man is free who is not master of himself. A man should so live that his happiness shall depend as little as possible on external things. Authentic happiness is always independent of external conditions."

My external conditions are severe. They cannot be ignored. I still marvel at times that this tumultuous journey is truly my fate. But as Seneca summed it up: "Difficulties strengthen the mind, as labor does the body."

I know the difficulties I face are easily up there with those who have lived through the almost unimaginable. Some who share my fate lament they lack the motor function to end their own lives. Many who have the motor function swear they would find a way to end their lives if they lacked that function. They underestimate the power of the human mind. The mind can be disciplined. Perspectives can change. And full lives can be lived without the body at all.

■

Excerpted from "Seven Secrets of a Sedentary Stoic," by Cassandra Brandt. Available at amazon.com.



The Stoics spoke of "memento mori": Remember that you have to die. They wanted to emphasize that life is brief and fragile and it's foolish to waste it. Embrace your inevitable demise and live every day with meaning.



VetsFirst

VetsFirst is a program of United Spinal Association that assists veterans and their eligible family members in obtaining the benefits they are entitled to, deserve and need.

Our Mission

VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

Our History

As a program of United Spinal Association, VetsFirst has a long and illustrious history assisting and representing veterans and their eligible family members. United Spinal—a VA recognized veterans service organization—strives to ensure the organization remains an instrument for veterans.

About VetsFirst

VetsFirst brings to bear seventy years of expertise in helping America's veterans with disabilities, their spouses, dependents, survivors and other eligible family members receive health care, disability compensation, rehabilitation and other benefits offered by the U.S. Department of Veterans Affairs. We supply direct representation, proactive legislative and regulatory advocacy, individual support and counseling services, guidance on education and employment, timely news and information and valuable self-help guides.

VetsFirst advocates nationally for all generations of veterans, including individuals living with post-traumatic stress disorder and traumatic brain injuries. Our advocacy efforts go far beyond offering words of support and encouragement. We take this fight to Capitol Hill to bring attention to issues that matter most to the men and women who proudly served our country.

Timely Support

We connect with thousands of veterans and active military servicemen and women annually through our call center and online help desk, **Ask VetsFirst**. Our staff takes the time to address each inquiry, offering guidance with questions on military separation, claims appeals, and state benefits. Visit <http://helpdesk.vetsfirst.org/> to submit your questions and receive quick response from our knowledgeable staff.

Valuable Resources

In addition to providing individual support and counseling services, VetsFirst offers timely news and information across the spectrum of issues presently impacting the veterans community, including state benefits, separating from the military, as well as exclusive feature stories on military health care and VA funding and compensation.

Our Core Beliefs

VetsFirst's priorities are based on three core principles that will improve the lives of veterans with disabilities.

Community Integration and Independence— We support policies that help veterans with disabilities reintegrate into their communities and achieve independence.

Timely Access to Quality VA Health Care and Benefits— We support improved access to VA health care and compensation and pension benefits that are the lifeline for many veterans with significant disabilities.

Rights of Veterans with Disabilities— We believe that discrimination against disabled veterans that produces barriers to housing, employment, transportation, health care, and other programs and services must be eliminated.



8 Steps to Understanding and Improving Your Emotional Health after Disability

BY JENNY SMITH

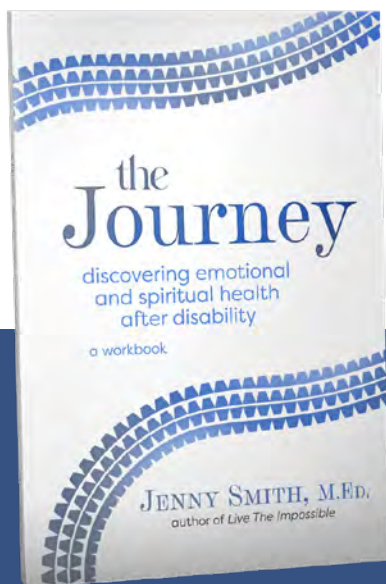
My journey with a C6-7 spinal cord injury began when I was 16 years old. Like most of us, I entered the world of disability without training on how to survive. Yes, we have medical professionals who check in on our physical health, but that's only the tip of the iceberg. What about our emotional, mental and spiritual well-being after the onset of a disability?

After my injury, meeting other women with disabilities in a group setting was what helped me begin to become less ashamed of my disability. I realized I wasn't the only one who struggled with these things. I learned to work on my own mental and emotional health and have continued to do so since.

Last year, after over a decade of using my master's degree in counseling psychology to support my coworkers who were making the transition to live and work overseas, I shifted my focus to my fellow disabled community. I developed a curriculum to help other disabled people understand and work on their emotional and mental health, and called it *The Journey*. To test it out, I signed up a diverse group for three eight-week online sessions.

From May-December 2023, I had the pleasure of discussing with over 20 participants the ways that we can maintain — or regain — our emotional health after a disability. I adapted the material for the eight sessions from models of cross-cultural transition, with an eye toward creating a curriculum that would help people understand their own emotional health and how to improve it. Each session focused on a step toward emotional understanding.

The types of disabilities represented throughout the year included spinal cord injury, stroke, brain injury, multiple sclerosis and others. Not only were people eager to be part of a group, but the participants experienced true community, relationships and growth. The people interviewed in this article all participated in one of the three sessions. Below, they share what they learned in each week's lesson and how it impacted their overall emotional health.



A 2018 study from the Centers for Disease Control in the U.S. reported that adults with disabilities are more than four times more likely to experience frequent mental distress, defined as 14 or more mentally unhealthy days in the past 30 days.

THE PARTICIPANTS



JOHN BRANCH

Decatur, Texas

Age: 52

Disability: C6-7 SCI complete

Year of onset: 2020

John was struggling with depression and drugs when he was paralyzed. A peer mentor gave him hope, and he recently had the opportunity to go to inpatient therapy to become more independent. John looks forward to playing wheelchair sports.



SPENCER KEENE

Louisville, Kentucky

Age: 28

Disability: C4-6 SCI complete

Year of onset: 2019

Spencer is a mechanical engineer who just purchased a patio home with his girlfriend, Katie. He enjoys creating adaptive devices using 3D printing.



SARA NURRENBERN

Evansville, Indiana

Age: 42

Disability: Neuromuscular disorder and Lyme disease

Year of onset: symptoms began in 2018

Sara is an avid crafter and board game player who now participates in an online gaming community. She and her husband are the parents of two children.



NICOLE ROY

Flushing, Michigan

Age: 46

Disability: T3 incomplete SCI due to tumor

Year of onset: 2022

With a full-time job in the healthcare industry, Nicole jumped into the disability world by attending three Abilities Expos during her first year with SCI. Olive is a golden retriever puppy who is training to be a service dog.



CAMILA SOL CERRANO

Santiago, Chile

Age: 35

Disability: C6 SCI complete

Year of onset: 2006

Camila works as an inclusion specialist and helps students prepare for a national exam to enter university. She helps students acquire the accommodations they need to take the entrance exam.



BREE WILLIAMS

Louisville, Kentucky

Age: 35

Disability: C7 incomplete

Year of onset: 2020

Bree hosts a podcast called *The Breezy Way*, works out at the Community Fitness & Wellness Center in Louisville and is mom to a French bulldog named Cookie.

1

Take Time to Reflect

Reflecting is an opportunity to process our thoughts and feelings. It's a chance to look back on events, relationships and emotions with honesty and ask how the current circumstances have changed us. Because we are different. Our physical abilities may be different. Our identity, job and relationships may have changed.

Camila appreciated the opportunity to reflect on her injury. "I had my accident in 2006, so it's been a long time, but I think I needed to revisit my experiences so I could understand the present. I can look back at the events and people to understand — and maybe reconcile — both myself and others," she said. Camila also learned to name the emotions she felt since her injury. "There are certain emotions that felt forbidden after my injury, so it's been important to learn to name those emotions. I've learned to express them and not push them down," she said.

"Doing a timeline and putting emotions with all the events that have happened was the most eye-opening for me," Spencer said. For Bree, looking back on the events since her injury was helpful. "It was good to look back and see what I've overcome," she said.

2

Name What We've Lost

Loss is at the core of disability, especially during the first several years, and then again as secondary issues and aging occur.

"I lost what I thought it meant to be a man, which I thought was physical strength. I experienced a loss of self-confidence, constantly comparing myself to other people and thinking I wasn't enough," John said. "I also lost my faith in God," he added.

Spencer said acknowledging his loss was important. "Rearranging my entire house to make it a little accessible was difficult. Then I had to sell my house and move back in with my parents. They sold my vehicle to get a modified van; that was a decision they made, so I'd even lost the ability to make decisions. I lost my job as an engineer since I hadn't been there long. And my fiance left me," he said. "I'm an engineer and

don't think about emotions much, so naming emotions for the events after my injury was big for me."

While spending an entire session on loss might sound depressing, Spencer said, "It was interesting to hear other people's experiences. Even though we had different disabilities, we all had very similar experiences no matter where we were from."

3

Allow Ourselves to Grieve

Once we can name our losses, we can grieve them. We can experience a variety of emotions with grief, including anger, blame, denial, depression and hopelessness.

Camila said, "For a long time I tried to convince myself that I had to be in a good place emotionally for my family. So, I didn't let myself feel angry or sad since they were taking care of me. But I realized ... from the support group that I needed to experience those feelings to grieve."

Sara felt bitter after her diagnosis. "I've had to acknowledge my bitterness. But then what? I put myself in uncomfortable situations — like going out when I don't want to. The more I do that, the less bitterness I feel because I realize I can do this," she said.

While some people experience anger, bitterness and depression after their disability, others avoid grief completely. "I learned that I haven't truly allowed myself to grieve over my injury. I numbed my feelings, so this is something I'm in the process of tapping into with my therapist," Bree said. "I've also had to grieve the loss of people I thought would never leave my side."

Nicole also realized she hadn't let herself grieve. She said, "I told everyone who asked how I was doing, 'I'm OK. My legs just don't work anymore.' I was determined to not be like the patients I saw in the hospital rehab unit who hated life and were angry, resentful and difficult to be around. Instead, I was going to be like the people I saw on social media who have it all figured out, and get on with my career and life." But faking it wasn't sustainable. "It was a hard dose of reality when I realized I was in complete denial about my paralysis," she said. "I had convinced myself I was doing great when I hadn't allowed myself to grieve one of the most difficult events in my life."

For John, grieving involved accepting responsibility. "I chose to put drugs in my body that evening. I did it to myself. In a way, it's healing to say that because I'm admitting the truth. I'm not blaming God or my family of origin. I made the choices that put me in this chair," he said. "But I also felt shame. Most people didn't know about my addictions."

4

Be Willing to Transition

With a disability, life changes. The question is: Are we willing to adapt to life with a disability? Transition is an intentional decision to be willing to adapt to life with a disability. It's internal. Emotional. Mental.

One way Nicole has mentally transitioned was to allow herself to admit she's disabled and be OK with it. "Having this mindset of transition has helped me accept what life with an SCI involves and work through the challenges of bowel and bladder instead of suffering in silence and feeling ashamed," she said. "I'm more willing to ask for help rather than act like I can do everything like I did for so long."

Some people transition and adapt to circumstances more naturally — or out of necessity. "I wanted to get back in society," Spencer said. "It's frustrating with all the SCI stuff, but I enjoy working and being out and about. But in some parts of life, like personal care, I couldn't rely on family members to help, so I had to take charge to hire caregivers."

Talking with others in our group helped Camila transition into adulthood. "I was 17 when I was injured and I had to enter adult life when I was dependent on my parents. I started working full time for the first time in 2021, so I felt like I was late in moving into adulthood," she said. "It wasn't late; it was the time I needed for me to be ready physically. I finally understood that this year."

5

Live in the Tension of Paradox

Life with a disability can be crappy. Sometimes literally. It can also be pretty darn great. The thing is, most of us have a hard time seeing that both can be true at the same time. We can learn to live in a state of paradox, where two *opposite yet equally true* statements can exist at the same time.

Sara said the concept of paradox kept coming up in conversation after learning about it. "It's important to remember both the good and the bad, especially in a situation like ours," she said. "I think acknowledging the bad helps me stay motivated and set goals. But remembering the good parts of my life helps me reconcile the bad. Not necessarily 'get over' the bad, but reconcile with it."

6

Learn Coping Strategies for Stress and Trauma

Life with a disability is full of stressors: health complications, time and energy constraints, and financial responsibilities. We need to learn how to have healthy coping strategies to manage stress.

"I'm learning to cope with stressors," Sara said. "It's an ongoing process because I've had anxiety my whole life. In therapy, I'm learning how to practice mindfulness. I'm trying to remember that I can only control myself. I can't control anybody else," she said. "I'm learning to just kind of breathe through and exhale that negativity in those hard situations."

Bree has learned she needed help to cope with the stress of disability and the trauma she experienced from her car accident. "I'm now seeing a therapist. And I love it!" she said. "She's the only one to get me to cry and I never knew how much of a relief that could be."

John knew he needed to find positive coping strategies, especially with his past addictions. "I needed to change from how I was living pre-injury. For me, the most important strategy is going back to my relationship with God. If I don't, I *will* return to my addictive behaviors," he said. "I'm also in a 12-step program. I need to work with people who understand disability and addiction, and [I need to] have a sponsor."

7

Refill Your Emotional and Mental Resources

We often hear proverbs or sayings about the importance of "filling your cup." With all the stressors we experience with disability — along with the losses — we need to find new ways to refill our emotional, mental, physical and spiritual cups.

"I have found little things that bring me joy like washing my face and doing what I call my minifacial helps me relax before bed," Nicole said. "Also, I have begun decluttering my home, which sounds like work, but I found it's helping me to feel better."

Sara learned that to refill her emotional and social resources, she needed to try something new. “Going to Gen-Con [the largest tabletop game convention in North America] was a huge deal for me. That was completely outside my comfort zone,” she said, laughing. “I traveled with a friend. I was without my husband and kids for the first time in years, and I spent an entire day by myself at the convention, taking care of my own needs, and doing my own thing. I went up on a stage in front of thousands of people in a costume we created. I still think about that weekend and am encouraged.” Sara said, “On a smaller scale, just trying to make lunch or coffee dates and getting outside of the house is a big help for me.”

“I refill my cup by doing crafts,” Bree said. “I also started reading again and joined a book club. And I’m going to church again.”

8

Find Meaning and Purpose

To thrive in this world of disability, we need to find purpose and meaning in life. We can find meaning when we set goals and try new things, help others, and find meaning in our circumstances.

John is finding his meaning and purpose in helping people with disabilities who struggle with addiction. “I know a lot about addiction, mental health and disability and I think there are many addicts who are disabled, and they are hopeless,” he said. “I want to be a voice of hope to others. My goal is to take this wherever God wants to take it.”

“I am still figuring out what my purpose is,” Nicole admitted. “I honestly thought being an independent, driven career-woman in the field of health care was my purpose. I realize none of that is important and it’s not what I want people to

remember me for when I’m gone. I want to help people navigate the challenges of health care. I am not sure what that looks like yet, but I’m praying for God to lead me.”

The Benefits of a Group

The feedback from the participants after they completed the sessions suggests that the process had helped people understand their emotional health and, in many cases, take positive steps to improve it.

“It was important to be with other people with disabilities,” Camila said. “There’s a loneliness that comes with our disabilities. So, to learn and grow within a community was the most powerful part of the experience. It gave me a sense of belonging.”

“In the group, I knew I was with people who could relate,” Spencer said. “A therapist can’t really relate in the same way,” he said. “In every session, we learned from each other. And since we had all spinal cord injuries, we always ended up talking about poop and pee.”

For John, the group put a face to disability. “I got to hear the life experiences of people who’d been injured longer than me. I heard about their challenges and where they experienced success. I knew that I wasn’t alone,” he said.

Nicole finds that she’s still processing everything she learned in the group. “There was so much I had not thought of or dealt with. That being said, I feel much more equipped to deal with the emotions and times when my mental health is not so great,” she said. “I also realize I have nothing to be ashamed of, and it’s OK to not have it all figured out. I met some amazing people who I know I can reach out to for genuine support or a kick in the bum if I need it.”

Author Jenny Smith has adapted the eight-week experience into The Journey, a workbook that allows readers to tackle the eight stages on their own. The Journey is available wherever you buy books. A Spanish edition will be released soon. Find out more at jennysmithrollson.com.

UNITED SPINAL MENTAL HEALTH RESOURCES

United Spinal Association offers members a bounty of mental health resources. Whether you are looking for in-person help, virtual support, or trying to learn more about a specific issue, United Spinal has an option suited to your needs.

For in-person support, there is no better place to start than United Spinal’s nationwide network of 45 chapters and 100 peer support groups. For virtual support, United Spinal hosts a diverse selection of regularly scheduled online discussion and peer groups.

Additionally, all United Spinal members are entitled to a one-month free trial of BetterHelp, the world’s largest online therapy platform. BetterHelp employs over 20,000 licensed and vetted therapists and offers four ways to talk with your therapist: video conferencing, phone, live chat and texting.

For more articles on mental health, don’t miss United Spinal’s rich archive, which tackles everything from PTSD, to suicide, depression and much more. If you are in a mental health crisis, dial 988 for immediate assistance.



- United Spinal mental health content: unitedspinal.org/category/ablethrive/health/mental-health
- United Spinal chapter network: unitedspinal.org/support/chapter-network
- United Spinal peer support groups: unitedspinal.org/peer-support-groups
- Schedule of United Spinal virtual discussion and peer support groups: unitedspinal.org/events-usa
- BetterHelp free trial: unitedspinal.org/member-special-offers



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AIRBNB'S ADAPTED CATEGORY HOMES BRING THE FUN TO ACCESSIBLE TRAVEL

BY SETH MCBRIDE

I've stayed in dozens of Airbnbs over the years — from a “barndominium” in Colorado to a chic, art-filled apartment overlooking Bogota, Colombia — but never in anything as unique, or as accessible as the house I stayed in this past summer with my family.

We needed to get away from house projects for a long weekend, and the “Tuscan Villa,” as the owners of the Wenatchee, Washington property called it, fit the bill. It was one level, and large enough for me, my wife, two kids and a dog, plus room for my parents to visit for a night.

Every entrance was step-free and easy to navigate, even with my two-year-old daughter on my lap. There were not one, but two bathrooms with roll-in showers, and the floors were all threshold-less concrete. In fact, almost everything in the house was made of concrete — from the faux-wood ceiling beams (yes, they looked like real wood), to the sinks, countertops and even the Tuscan-style murals adorning a few of the walls. The place was quirky and it was fun, which was exactly what Airbnb had in mind when it launched its “Adapted” category in 2022.

“The Adapted category is designed to make it easier for people with mobility needs to find unique and cool homes, including treehouses, A-Frames, cabins and more,” says Suzanne Edwards, Accessibility Standards Lead at Airbnb. “As a wheelchair user and frequent traveler, I know that accessible accommodation can often mean booking a functional,

yet sterile, place to stay. I'm really excited that the Adapted category can help provide magical travel experiences for members of the disability community. I get inspired browsing the category and have added many spots to my personal travel wishlist.”

Homes in the Adapted category, which now boasts over 1,100 listings all over the globe, provide a baseline of access. Every listing must have step free access to the guest entrance and step free access to a bedroom and bathroom, and at least one accessibility feature in the bathroom — whether that's a roll-in shower, a grab bar or a shower bench.

“We understand that everyone has different needs, so we want to provide detailed information about a home's accessibility features to help guests determine if a listing will work for them,” says Edwards. “We have an incredible, welcoming Host community and we recommend guests reach out to the Host with any questions about their home or neighborhood before booking.”

My stay showed how powerful that baseline can be. When my son ran out to the garage to play on the ping pong table, I could roll right out and play with him. When I needed to go pick up a couple of forgotten dinner ingredients, it was a solo mission. It all felt very normal, and very comfortable — a feeling that's rare for a wheelchair user staying in another person's home.

Some homes in the category have these basic access features, others more extensive, like roll-under sinks or ceiling lifts. Every wheelchair user's needs are different — what works for one may not be ideal for another. To that end, Airbnb provides photos of the accessibility features in every Adapted category listing, along with door widths and a layout diagram. As an experienced traveler, I've spent countless hours looking at vacation rental photos, trying to sleuth whether the bedroom was on the main floor, or guessing whether the bathroom door was wide enough to fit my manual wheelchair.

To look through Adapted category listings and have detailed, verified access info made the booking process easy and stress-free. When we arrived at the house, there were no surprises lurking. I could get in. I could use the bathroom. I could wake up and make my coffee. I could play with my kids and cook dinner with my wife. I never really had to think about the access. We could simply enjoy our vacation.

There are far too few fully accessible private homes in the U.S., and while the Adapted category surfaces certain accessibility features, it's not always perfect. For example, at the Tuscan Villa, the controls for the shower were too far from



WOULD THIS BARRIER-FREE CHALET IN CANADA MAKE YOUR WISHLIST?

Photo Courtesy of Geoffrey Gillstrom

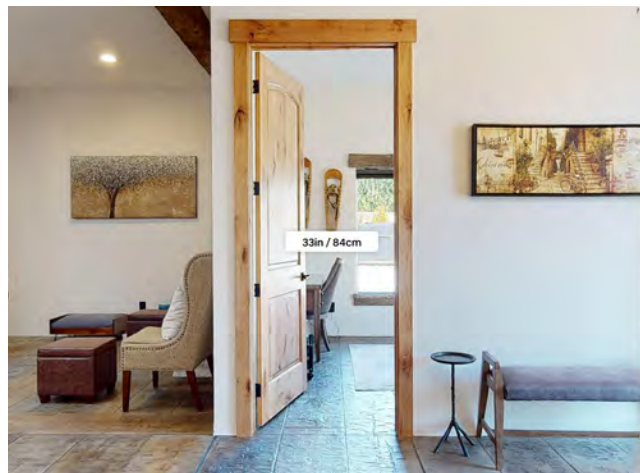
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EASTSIDE TUSCAN VILLA IN EAST WENATCHEE, WASHINGTON



GUEST ENTRANCE AND PARKING



ENTRANCE WIDER THAN 32 INCHES

Photos: Courtesy of Airbnb Community

the bench for me to be able to reach, and though the living room was enormous, the couches were packed together. I had to move one to be able to transfer onto it and read Marvel books with my son. But compared with most of my vacation rental experiences — being lifted up steps to get in the front door or piggybacked to the second floor to go to bed — these were minor hiccups.

Airbnbs in the Adapted category, like the one my family stayed in, are some of the most unique you'll find in the travel sector — such as a biopassive villa in Spain or an urban garden oasis in Oregon.

Outside of the “Adapted” listings, there are still a wide range of listings with accessibility features across the globe. Thanks to Airbnb’s Accessibility Review, introduced in November 2021, guests have additional peace of mind that accessibility features added by Hosts such as step-free entrances, fixed grab bars or bath or shower chairs are reviewed and

confirmed by Airbnb agents. Guests can use 13 accessibility search features such as “guest entrances wider than 32 inches,” “accessible parking spots” and more to find a place that is right for them. To start planning your own magical, accessible travel experience, go to airbnb.com/adapted-category or scroll to the Adapted Category icon on the mobile app.

BECOME A HOST

Do you have a home adapted for travelers with accessibility needs? You should consider joining the growing Host community on Airbnb, creating more options for guests with access needs to choose from. You can find more information on how to get started at airbnb.com/hosting-guests-with-accessibility-needs

LET'S GET PHYSICALS:

Why People with Disabilities Get Shortchanged in Checkups, and How to Get the Most Out of Yours

BY JOHN BEER

When an insurance change forced T5 paraplegic Arthur Torrey to give up his outstanding primary care physician, he ended up with a new PCP who was much less impressive. “My exams seemed far less thorough in that they were more on the order of 95% talk, and he only looked at things I specifically said were bothering me,” says Torrey, a United Spinal Association member from Billerica, Massachusetts. “I stayed fully clothed. ... And he basically said, ‘Do you want to transfer [to an exam table] or not?’ And it’s like, ‘Well, do you need me to?’” The indifference leaves Torrey wondering if he’s getting an inferior exam because he is a wheelchair user.

His experience is a typical one for wheelchair users, like myself. After my multiple sclerosis progressed and I began using a wheelchair, my doctors stopped checking for testicular or prostate cancers. I know my skin wasn’t being checked for breakdown because I stayed in my wheelchair during checkups. Sure enough, my weakened skin sheared off during a transfer and I spent much of the summer in bed.

A study of wheelchair users found that 69.7% remained in their chairs during exams, which the National Council on Disability says “can generate inaccurate results or conceal physical evidence required for appropriate diagnosis and treatment.”

I’d always assumed that a physical is a physical, with a fairly standard checklist of procedures, but study after study shows that’s not the case for people with disabilities. So why are we not getting the same exams and health care as everyone else? And what recommendations do experienced accessibility advocates have for getting the best checkups?

The Scale of the Problem

When you can’t step on a doctor’s scale, you’re asked a simple pair of questions that speak volumes: “What do you think you weigh?” and “When were you last weighed?” When I ask these questions of other wheelchair users, I hear the “Ha!” of recognition, and then their answers are all over the board: “Good question”; “it was four years ago”; “over

10 years”; “it’s all just guesswork.” One respondent says she has to use the laundry scale down in a medical facility basement. Apparently, weight is important enough to be asked at every appointment, yet a whole lot of people with disabilities have no idea what theirs is.

“The purpose for [measuring weight] is to educate the doctor and [patient] on how they’re doing with managing their health,” says Laura VanPuymbrouck, who researches accessibility in medicine as an associate professor and physical therapist at Rush University Medical Center in Chicago. Large gains could raise risks of diabetes, heart disease and strokes, while significant losses could signal cancer. Further, people with disabilities have higher rates of obesity and are three times more likely to develop diabetes — both conditions where monitoring weight is important for management.

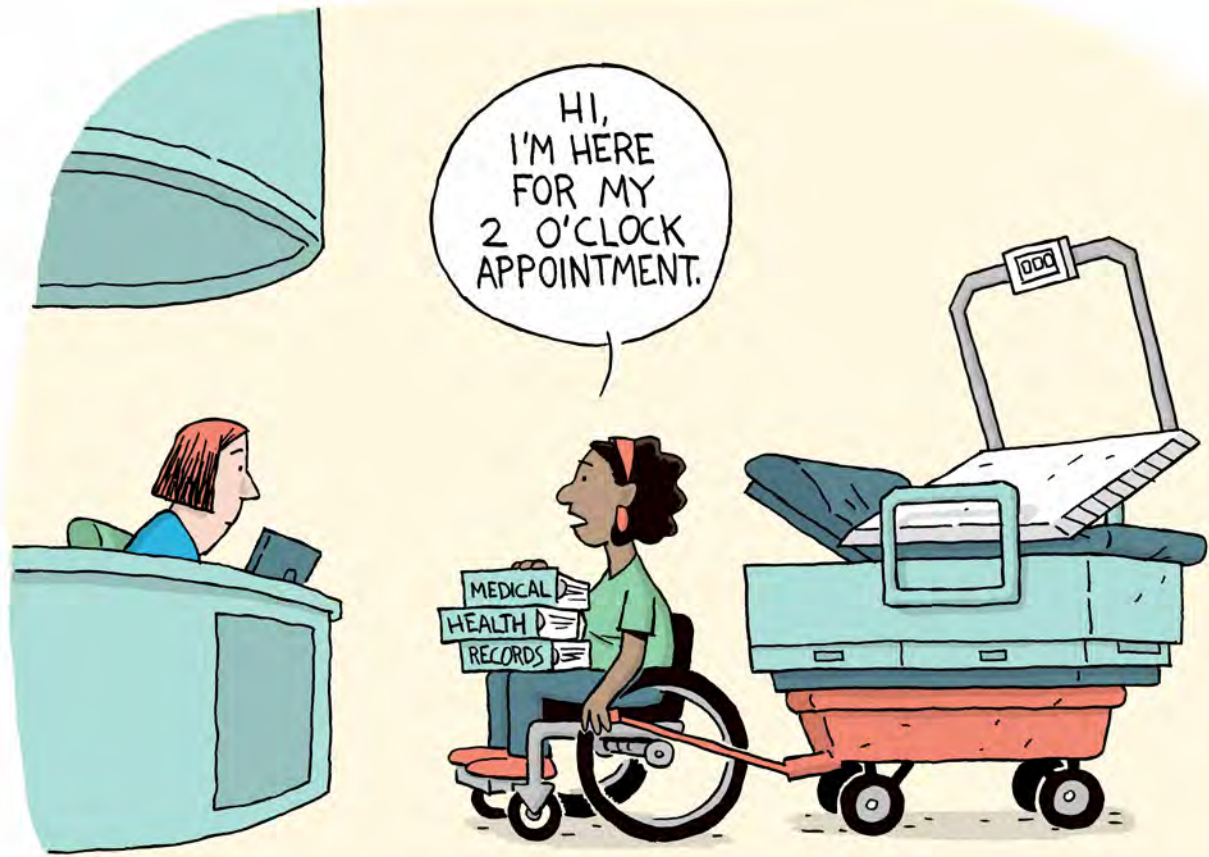
This state of “weightlessness” for the disability community indicates a lack of accessible medical diagnostic equipment: wheelchair-accessible weight scales, height-adjustable exam tables, mammography and imaging equipment, among other items. The National Council on Disability cites a “mountain of empirical evidence” proving that without accessible MDE in place, people with disabilities experience marked differences in care. And another survey found that less than half of administrators who purchase MDE even know that accessible versions exist.

But, as *NEW MOBILITY* reported in April 2023, the lack of accessible MDE is only part of the problem. When you add in the hurdles of getting to and accessing medical facilities, and the fact that many doctors have little knowledge or training in providing care for people with disabilities, the common-sense expectation of equal care can feel more like a pipe dream.

Making Preventive Health Care Work for You

When our full health care needs are treated as an inconvenience, it becomes crucial for us to speak up and insist on complete exams, and to find the doctors and facilities capable of treating us. This requires plenty of phone calls to doctors, or to others with disabilities for their recommendations.

“Are [the doctors] willing to be a partner with you to collaborate and listen to you? Because quite honestly, people with disabilities are probably more expert in [what’s need-



ed],” VanPuymbrouck says. Ask physicians or their staff whether they have experience or understanding in working with people with disabilities. Don’t just tell them your needs, such as being seen on an exam table or requiring a lift or a scale; force them to document your needs and requests. This way all nurses and assistants and schedulers can see it on your chart. It must be written down as part of your official record. Make sure they know that this is not a matter of convenience or inconvenience, it is a critical requirement for your health, just as it is for everyone else.

Rosemary Ciotti has seen the issue from both sides. As an advanced practice nurse in Alexandria, Virginia, she treats people with SCI in their homes when they need accessible care. And as a wheelchair user due to lupus, she’s faced her own struggles getting routine health care, including injuries during transfers to exam tables, and putting off her own physicals after having bad experiences. Ciotti successfully sued for access to cancer treatment facilities at Washington Hospital Center, in Washington, D.C. It’s important, she says, to specifically tell prospective doctors about your level of disability and the exact accommodations required, down to the precise height of exam table you need. “My one recommendation is don’t surprise them,” she says. “Don’t go in there as a new patient in a wheelchair that they didn’t expect.

“If you get pushback, that’s not the doctor for you. ... Be

One study found that only 10%-44% of surveyed medical practices had accessible exam tables, and only 1%-11% had accessible scales.

aware of the cues that they really don’t want you as a patient,” Ciotti says. “Take them at their word — go shop for a doctor.”

What goes into a yearly exam depends on your age and personal risk factors, but usually includes many of the following: blood pressure, weight, cholesterol, and tests for bone density, blood sugar, and starting in your 40s, a colorectal test. For women, starting in your 20s, a clinical breast exam and Pap test, and starting in your 40s or 50s, a mammogram. For men, up to about age 40, a testicular exam, and starting in your 40s, a digital rectal exam and prostate-specific antigen test. Vaccinations should be updated. People with disabilities can have higher risks of diabetes, osteoporosis, heart disease and certain cancers, so the exam should ad-

dress those areas, as well as weight control and exercise.

As you age, a good primary care physician, preferably someone certified in internal medicine, should track the health of all your vital organs with twice-a-year blood tests – including a complete metabolic panel (with special attention paid to kidney function), a CBC (blood panel), complete lipid panel (for awareness of potential coronary artery disease), and other specific tests that match up with your medical record or conditions. If you have nonhealing or recurring pressure wounds on your lower extremities, ask for an ABI test (ankle-brachial index), to check for peripheral artery disease.

“It takes work. It’s not just, you go and accept whatever they tell you,” says June Isaacson Kailes, a disability policy consultant in Los Angeles who has published dozens of studies and books on accessible medicine, including a free resource guide for people with disabilities, *Making Preventive Healthcare Work for You*. Kailes, a wheelchair user with CP, has been working on the subject since the 1990s, and pours her knowledge into this easy-to-read workbook that teaches users to be assertive at doctor visits, because “being passive can be dangerous to your health.” Filled with resources, it’s a worthwhile download to save and reread before your next physical.

“The core value throughout the little book is you have got to take charge, because otherwise what you get might be potluck,” she says. “You’ve got to work for this to get something that’s of value and quality for you.”

Where’s Your List?

A couple of ideas that work well for me were echoed by the advocates contributing to this article. The first is bringing a friend or family member along as another set of ears and to take notes. It’s important, though, that your doctor addresses you and not your friend as some kind of surrogate for you.

Unsatisfied With Your Physical?

Speak to the doctor, clinical manager or ADA coordinator for the facility. “These facilities and these practitioners have an obligation ... to do the best they can do to try to accommodate you, even if they’re not aware of everything that they’re supposed to be doing,” says Mary Lou Breslin of Disability Rights Education and Defense Fund.

All providers have an internal complaint process. Write a letter to your provider with details about the appointment and the points where you did not receive equitable care. See examples of effective advocacy letters online.

Look up legal nonprofits in your area like DREDF in Berkeley, California; Disability Rights Texas; and Equip for Equality in Chicago.

United Spinal Helps Move the Needle

Thanks in part to the advocacy of United Spinal Association, the Department of Justice recently proposed rules establishing specific requirements and technical standards for the accessibility of medical diagnostic equipment like exam tables, x-ray machines, mammography equipment and weight scales purchased by state and local governments. The revised regulations are expected to be incorporated into Title II of the Americans with Disabilities Act, which requires state and local governments’ services, programs and activities to be accessible to people with disabilities.

Want to get involved? Join United Spinal’s Grassroots Advocacy Network and advocate for change! Visit unitedspinal.org/grassroots-advocacy-network or scan the code at right.



Also, in the weeks and days before an appointment, keep a list of issues and questions. I print a copy for everyone who will be in the room, including the doctor or other health care professionals, who often greet me with, “Where’s the list?” A list keeps the appointment focused and makes sure all my questions are addressed. Working through the list builds the partner dynamic I want and afterward it goes into my medical record.

If your provider’s office isn’t fully accessible or lacks the proper equipment, you need to receive equal treatment, speak up. Kailes lectured her doctor for years about his exam table being dangerous to her and the nurses transferring her. And, eventually, he came through. “The nurse came out and said, ‘Look, finally! We’ve been begging him to do this too,’” she says. “People just don’t get it. ... Be in their face and keep bringing it up over and over.”

She urges us to educate our doctors about our disabilities and accessibility needs. “If someone says, ‘I don’t know what to buy,’ well, here are some features that are important and that you should apply when you buy equipment,” she says. ■

Resources

- *Making Preventative Healthcare Work for You* by June I. Kailes, jick.com/pubs/Preventivehc.pdf
- Medical Office & Equipment Accessibility Checklist from United Spinal Association, unitedspinal.org/checklist.pdf
- NEW MOBILITY, “Doctors Still Have no Idea how To Treat People With Disabilities,” newmobility.com/doctors-still-have-no-idea-how-to-treat-people-with-disabilities/

Nathalie McGloin

A Driving Force for Inclusion in Motorsports

BY CHERYL ANGELELLI



Photo by Rick Guest

AS NATHALIE MCGLOIN emerges from the staging area in her wheelchair and black racing suit with neon yellow and pink stripes, and her long chestnut hair securely fastened under her helmet, she clearly stands out from the field of racers. But as soon as she transfers into her adapted Porsche 987 Cayman S, she's just a race car driver like everyone else.

"I love the speed and freedom driving gives me. I'm able to do something without my wheelchair that feels completely normal," she says. "My disability doesn't matter

because I'm on the racetrack with nondisabled drivers and we are all doing the same thing at the same time. I don't have any disadvantage. I'm just another driver, and that is the way it should be."

McGloin, 40, from Northampton in the United Kingdom, has been recognized by the Guinness World Records as the first female quadriplegic driver to compete in a race. She was also the first female with a spinal cord injury in the U.K. to be granted a racing license in 2015 and a rally license in 2019. "I like being the first to

do things. I was also the first female wheelchair rugby player in the U.K.," she says. "It's a motivator to me to prove it can be done."

Race car driving wasn't even on McGloin's radar until long after she sustained a C6-7 SCI in a car accident at age 16 in 1999. "I'd been doing quad rugby for about 10 years, when I was introduced to a teammate who had a passion for cars and invited me to a track day. I absolutely fell in love with it," she says. "Before I knew it, I bought a car and was racing."

LIFE IN THE FAST LANE

McGloin's race car features automatic transmission and adapted radial hand-controls like those in U.S. cars. Cars in the U.K. typically use different hand controls than in the U.S., requiring a push forward to brake and a pull backward to accelerate, which is not ideal for a racing car because of a gap between brake and throttle. McGloin has good grip strength in her left hand, so her steering wheel is not modified other than being lighter weight. Because the Porsche 987 Cayman S is a road car, the door opens like a regular car, which makes transferring easier. She also has a seat insert that is molded to her body and placed inside the race seat.

"A lot of race car drivers will feel the car through their bum — obviously that's not going to happen for me. The seat [insert] gives me feedback higher up around my rib cage as to what the car is doing. And it gives me stability, so I rely on my seat insert quite heavily," she says.

The dangers of the sport are not lost on McGloin, who reaches race speeds around 140 mph. "The day before my first-ever race, I was testing [the track] when I got turn 1 wrong and ran into a gravel trap. Because of the speed, the car went up onto two wheels. I was millimeters away from rolling the car onto its roof," she says. "Not the best preparation ahead of my first race."

Besides demonstrating her driving skills and knowledge to obtain her race license, McGloin also had to show that, in the event of an emergency, she could exit the vehicle unaided and without a wheelchair in seven seconds or less. "I literally threw myself out of the car onto a mattress. Of course that would not be there in a real emergency, but if the car is on fire, I don't care if the ground is hard, I'm getting out of there," she says.

"This is my eighth year racing and still when I'm sitting in the car right before the start, I still think to myself, 'Oh my god, what are you doing? I'm about to do a car race,'" she says. "So I try to keep calm and focus on past

races when I felt like I was on top of my game. ... But once I get going and I'm on the track, I'm just thinking about racing."

To stay in race-ready shape, McGloin has a home gym where she works out three or four days a week doing cardio and strengthening her upper body. "I like having strong arms and being fit," she says. "On race day, I may only transfer in and out of the car once or twice, but if it's a test day, I might be transferring six times."

She also recently purchased a race simulator with hand controls, and works with a sports psychologist. "I am my own worst critic," she says. "If I don't perform well, I really beat myself up. That is where working with a psychologist is helping me get to a place where I can enjoy what I am doing without always having results to justify enjoyment."

Racing is also a family affair. McGloin met her husband and fellow racer, Andrew Bayliss, in the pit lane during a track day. "My first impression was she was a very driven person. We spoke every day online after that until we moved in together," says Bayliss. After years of dating, they married in 2021.

Bayliss was doing rally races, which motivated McGloin to also get a rally license. In rally races they are both in the car, with McGloin in the driver's seat and Bayliss in the passenger seat serving as the co-driver, providing route direction. "Nathalie's strength as a driver is she has brilliant awareness of other cars and good natural speed," says Bayliss.

"I love rally car driving because of the challenge of not being able to practice the [course] beforehand. Rally car driving is more tiring mentally, because it goes against everything you've learned to do driving a car on the road safely," says McGloin. The cars must be able to turn tightly into sharp curves since the roads are unknown to the drivers, and be able to slide on low-grip surfaces like gravel if they have gone into a corner carrying too much speed. Because of the harness and race

seat, she is completely secure, so lack of trunk muscles isn't an issue.

Racing is an expensive sport, but thanks to sponsors, McGloin competes in about seven circuit races a year, from March to October. In circuit racing, drivers navigate a combination of fast, sweeping straightaways and tight technical corners on slick tires, a tire type with smooth treads. The winner is the first driver to reach the checkered flag once the number of laps or the time limit has been completed. Most of McGloin's races last about 40 minutes.

There are no separate classes or events for females or drivers with disabilities in motorsports, meaning McGloin's main competitors are mostly nondisabled men. And that is how she prefers it, she says, "because of the inclusivity of our sport and because we don't discriminate. Men and women compete together, disabled and nondisabled compete together. I think we have almost a bigger role to play for disabled people in society in showing that we are classified in the same way as nondisabled people."

PAVING THE WAY FOR OTHERS

Among her biggest accomplishments, McGloin lists winning her first race in 2018 and starting Spinal Track, a charity she founded with Bayliss in 2016. Spinal Track lets disabled people experience the thrill of track or rally racing in adapted race cars. "So many people reach out to me about how they can get into the sport," she says. "I wanted to give people the same opportunity I had, so Spinal Track gives them a chance to give it a go ... to see if they really enjoy it and want to take it further."

In the beginning McGloin and Bayliss funded the free track days out of their own pocket. They even purchased a used adapted race car from a paraplegic driver who was selling it to buy another. Just as their personal funds began to run out, donations started coming in, including a sizeable contribution from Stanley Black & Decker.

“They saw what we were doing and wanted to be a part of it. All the donations we get go entirely into the charity,” she says. “We now have three track cars with hand controls and left foot accelerators, and four adapted rally cars for driving on dirt. We run 10 track days and 10 rally days, so we have 100 drivers a year participating.”

Spinal Track caters to as many disabilities as possible. To be eligible to participate, you must have a valid driver’s license and adequate tricep strength. “The need for triceps is due to the steering. When strapped into a racing seat with a harness, steering is different. Past the 12 o’clock position on the wheel, it becomes pure tricep function. In a road car, those with little or no tricep function can sit high and lean forward to use biceps and shoulders to do the steering past 12 o’clock,” says McGloin.

“Incredible,” is the word Richard Brindley, 53, used to describe his Spinal Track experience. A huge motorsports fan with a passion for cars, Brindley, a C6 quadriplegic, was delighted at the chance to experience driving an adapted race car at speeds over 100 mph. “What is great is you have a professional driving instructor in the car with you, which gives you a level of confidence, and they push you to test yourself and fully experience what the car can do, and that was amazing,” he says.

Spinal Track is also about building community. “The bond I have with the people I meet through my charity is really strong,” says McGloin. “Before racing, wheelchair rugby was a family I called home. When I left that sport, I felt lost without my disabled community. Through Spinal Track’s community events, I have found a new family. These people give me support, they give me strength, they give me life.”

From 2018 to present, McGloin has served as the president of the Federation Internationale de l’Automobile’s Commission on Disability and Accessibility. The FIA is the sole international governing body of motorsports, and McGloin its



McGloin after winning her first race.

youngest-ever commission president.

Under her leadership, the commission has changed legislation to make it easier and safer for people with disabilities to get into motorsports, and set up grants to help drivers with disabilities get access to the highest level of safety equipment so they can race in the safest possible environment. McGloin has also called for fundamental widespread changes within the world of motorsports, like making the competition license application process more inclusive and making venues and circuits more accessible.

“I understand I am hugely privileged to do what I do. Not everyone has the ability to be able to afford to go racing, but there are so many different aspects to racing that people can be involved with, like mechanics, marshals, journalists, spectators, whatever,” she says. “I want to make sure all the doors are open ... and that anyone with a disability who wants to get into motor-sport has the opportunity.”



Photo by Rob Overy

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FUNDING AN EXPENSIVE VEHICLE

Sticker shock doesn't begin to describe the emotions that come with finding out the accessible van you need may cost a small fortune. We can save the bigger discussion about how broken the system is for another time, because when you get out of rehab or are ready to be out and about, the only question that matters is "How do I pay for this?"

Fortunately, there are a number of resources and options that may spare you mortgaging your home for a new set of wheels. Before you commit \$60-\$100k to a new vehicle, though, see if there are any used options locally. Your local mobility dealer likely resells trade-ins, and many people list used vans on Craigslist and Facebook Marketplace at significant discounts.

"The first thing you need to do is research your options," says Vicky Aubry, a T10 para who has worked for adapted vehicle dealers for over 30 years. To protect your investment, she urges everyone to consult with an expert at an adapted dealership, even if you aren't buying from it. "Knowledge is power and adapted dealers often know of financing options and other information, like whether parts are still available for older models," she says.



After 23 years as a C5-6 quad, Casey Moore knew what van and controls he needed to return to work and maximize his independence, but he also knew the price tag was likely out of his range. That's where vocational rehab came in.

"I told my voc rehab counselor I had a job opportunity but I needed to be able to drive independently as a C5-6 quad," he says. "It took a couple of years, but voc rehab ended up paying 100% of the cost of my new van and ... adaptive controls — that's around \$130,000 I would never have been able to afford."

Whether you opt for voc rehab, the Department of Veterans Affairs, or community support, there are more ways than ever to meet what may seem like an unpayable bill (see below). With a coordinated effort and a little luck, you should be able to lighten that sticker shock and eventually drive home your ticket to more independence.

MEMBER TIPS

“

If you're buying a used adapted van, make sure to get the conversion checked as rigorously as the vehicle. For the cost of one to two hours of labor, a knowledgeable inspector can save you from buying a lemon or a vehicle that you won't be able to get parts for.

”

— Vicky Aubry, Portland, Oregon



UNITED SPINAL RESOURCE CENTER MOST FREQUENTLY ASKED QUESTION

HOW DO I PAY FOR THE ACCESSIBLE MINIVAN THAT I NEED?

This is one of the most common questions we receive in the resource center. Look for a used vehicle for more savings. Check in with your local mobility dealer to learn what's available in your area. Visit the National Mobility Equipment Dealers Association website to find a dealer near you. Networking with other members of your local disability community, including local United Spinal Association chapters and centers for independent living, can help you learn about available options. Start local.

Many vehicle manufacturers offer mobility assistance reimbursement for accessible vehicles, typically about \$1,000.

If your vehicle will be used for employment, your local vocational rehabilitation agency may provide funding for vehicle modifications. These VR agencies may have stipulations on the age of the vehicle. Before investing in any vehicle, check with your VR to learn about their criteria. If you're a veteran, you may be eligible for an automobile allowance from Veterans Affairs.

Contact the assistive technology program in your state to learn about local funding options such as alternative loans for people with disabilities. These low interest loans can be used for vehicles and vehicle modifications in many cases.

Many individuals have found success paying for their vehicles by coordinating fund drives through their church congregations or local service clubs, while others have used crowdfunding platforms. Fully explore and compare any crowdfunding platform under consideration to learn about any tax implications or impact on public benefits.

Help Hope Live is a nonprofit organization that offers fundraising assistance for people with complex medical conditions. Help Hope Live offers advantages, like support from a team of coordinators, press support, social media campaigns, tax-deductible donations and more.

Make sure to visit United Spinal's listing of available grants for people with disabilities — see Best of Web Resources — to learn about funding offered by various organizations. The grants are categorized by area of focus, each with its own eligibility criteria.

— JANE WIERBICKY

RESOURCES

BEST NEW MOBILITY ARTICLES

Basics of Buying an Adaptive Van:

newmobility.com/buying-adaptive-vans

Tim Gilmer covers various funding sources, including VR, VA, nonprofits, and local resources, that can help you pay for an accessible van.

Tips for Buying a Used Wheelchair Van:

newmobility.com/tips-for-buying-a-used-wheelchair-van

NM's longtime Motorvation columnist, Mike Collins, guides you through the process of purchasing a used wheelchair-accessible van as an alternative to expensive new options.

Affordable Vans and Cars:

newmobility.com/affordable-accessible-vehicles

More help on ways to reduce the financial barriers associated with purchasing accessible vehicles, especially wheelchair vans.

BEST OF THE WEB RESOURCES

Help Hope Live

helphopelive.org

This national nonprofit goes beyond simply hosting a crowdfunding campaign, with personalized support, the ability to make tax-free donations and more.

United Spinal Resource Center: Available Grants For People With A Disability

askus-resource-center.unitedspinal.org/index.php?pg=kb.page&id=2971

A thorough listing of SCI and disability-related grants that may help with fundraising for a new vehicle.

Videos via SpinalPedia.com

How to Fundraise for a Wheelchair Van by The Chronic Health Advocate: youtube.com/watch?v=AOEpFHUJjck

How to Get a Free Wheelchair Van by Low Income Relief: youtube.com/watch?v=3Eot4O9YsqU

“

We started with our local community board and got awarded \$17,000 through their unmet-needs fund. We found \$2,500 in rebates, including one that was tied to using Help Hope Live. We'd already tried GoFundMe and had almost raised enough, but went ahead to secure the rebate. Help Hope Live proved to be really helpful and we had a short but successful campaign. We ended up raising almost \$42,000.

”

— Katie Muench, Aurora, Colorado





FUNCTIONAL FITNESS

By Ben Clark

HOW TO MAKE YOUR TRANSFERS EASIER

Q: *I'm a C6 quad and I can do simple transfers independently using a sliding board. That's fine at home, but I hate having to lug a board around when I go anywhere. Similarly, I drive a ramp-equipped van, but I'd love to be able to transfer into a car independently to make rentals and transport easier when I'm traveling. What are some things I can do to get stronger with my transfers?*

A: As a C7 quadriplegic, I understand how important transfers are for independence, especially when away from home. There is a variety of exercises that can enhance your upper body strength and make transfers easier, or maybe even reduce your need for a sliding board.

But before I explain exercises and fitness strategies, I think it's important to make all your transfers as easy as possible. There are no medals for doing difficult transfers, and we want to keep our muscles, joints and ligaments as healthy as possible for as long as possible. If that involves using a sliding board some of the time, then I recommend using one when you can.

For those times when a sliding board doesn't make sense, learning to transfer without one will require new techniques, balance and use of your muscles. When you're ready to start practicing technique, please check out "Mastering Everyday Wheelchair Transfers" on newmobility.com.

Strength Matters

Once you have your technique down, there's no doubt that increased strength is helpful not just to make transfers easier but also to protect the shoulders. Let's look at a few exercises that can help.

• **Lying shoulder squeezes** are an exer-

cise where you lie face down and retract or squeeze your shoulder blades together. By engaging the muscles between your shoulder blades, this exercise helps improve posture, enhances shoulder stability and can alleviate upper back and neck discomfort. It's particularly beneficial for keeping your shoulders stable through your transfers and reducing the risk of injury. If lying face down is too difficult, you can lean over your lap while seated

shoulders in a controlled upward motion, as if trying to touch them to your ears. Shoulder shrugs are an excellent way to build strength in your upper back muscles and stabilize the shoulders. If you have limited grip, Active Hands gloves can help secure a dumbbell, and wrist weights work too. This exercise can also be done with a resistance band tied under your footplate. Do this exercise three times per week, performing the movements in



Author Ben Clark, a C7 quad and founder of the Adapt to Perform YouTube channel, performs dumbbell shoulder shrugs. They are an effective way to strengthen upper back muscles that can help keep you stable during transfers.

in your wheelchair or even do shoulder squeezes while seated in an upright position. Do 20 squeezes every day, holding each squeeze for 10-15 seconds or as long as you can.

• **Dumbbell shoulder shrugs** are a simple yet effective strength-training exercise that is a step up from the previous exercise. To perform dumbbell shoulder shrugs, you typically sit upright with a dumbbell in each hand, then lift your

three sets of 10, with two minutes' rest between each set.

• **Straight arm rows** help transfers in a number of ways, including working muscles of the upper back and providing static strength-building for the triceps. Even when you're not actively extending your triceps in a transfer, the muscle still keeps the elbow stable. The stronger the triceps, the easier the movement. To perform a straight arm row, you secure a



Straight arm rows strengthen both the stabilizing muscles of the back and the triceps, which provide lift during transfers. They can be performed with resistance bands, a cable machine or, if you bend over your lap, with dumbbells or wrist weights.

resistance band in front of you at shoulder height, holding onto the band — or wrapping it around your wrist — and extending your arm in front of you. Then pull the band toward your hip while keeping your arm straight. If you have balance issues, you can do one arm at a time. This exercise can also be done with a cable machine if you have access to one. Do this exercise three times per week, performing the movements in three sets of 10, with two minutes' rest between each set.

You can easily find dumbbells and resistance bands in most stores that supply fitness equipment, online marketplaces and even secondhand stores. You don't need heavy or expensive equipment to get started and make a big difference.

Balance, Coordination and Flexibility

Balance, coordination and flexibility are essential aspects of successful transfers. Strengthening these skills can significantly enhance your ability to transfer safely and independently. Here are some specific exercises and practices to help you improve in this area.

- **Balance Practice:** Start by sitting upright in your wheelchair without using the backrest, or on a flat surface like a bed. Initially, you might need assistance or cushions for support. Gradually decrease the support until you can comfortably sit unsupported.

- **Weight Shifts:** While sitting without

a backrest, practice shifting your weight from side to side and forward and backward while maintaining your balance. This mimics the movements required during transfers.

- **Yoga:** Many yoga poses and stretches can be adapted for wheelchair users. Yoga is an excellent way to improve flexibility, balance and strength while remaining seated in your wheelchair.

- **Stretching:** Perform stretches that target the muscles in your arms and shoulders. Reach one arm across your chest and gently pull it with the opposite hand to stretch the back of the shoulder. Repeat on the other side. Put your hands on your wheels behind your hips and squeeze your elbows together. This will stretch the front of your shoulders and your chest.

Practice your stretching and balance every day if you can. Yoga can be done a few times a week. You can find videos on my YouTube channel, Adapt To Perform Yoga, at youtube.com/@AdaptToPerform.

Fit Into Your Routine

With all of these practices, consistency is key. A great aid for consistency is linking exercises with things you already do. For example, do your lying shoulder squeezes before getting out of bed in the morning; do your stretches while your coffee is brewing; do your dumbbell exercises before you have lunch, etc. Linking exercises with your already-established routine

helps you remember that it's time to do them and increases your likelihood of being consistent.

Remember, progress takes time, so be patient with yourself. Gradual increases in strength and stability will help you become more independent in your transfers. Always prioritize safety, and if you experience any discomfort or pain, consult with a health care professional. Your determination and commitment will certainly pay off, making travel and daily life more accessible and enjoyable. Keep pushing forward!

WORKOUT VIDEOS

RESISTANCE BAND SHOULDER WORKOUT FOR WHEELCHAIR USERS

— youtu.be/4c08zjNgi-A

This video provides an effective resistance band workout specifically tailored to enhance shoulder strength, offering a practical and accessible means for you to improve your transfer abilities.

RELAXING WHEELCHAIR YOGA

— youtu.be/igx56VulVnc

Explore the practical benefits of yoga for wheelchair users — including more range of motion and reduced risk of injury while transferring — in this 10-minute video.



PRODUCTS

By Michael Franz

CURAPROX SAMBA ROBOTIC TOOTHBRUSH

For those of us with limited or no hand function, keeping our teeth clean and healthy can be problematic. So, I was intrigued when the Swiss brand Curaprox rolled out its new Samba Robotic Toothbrush, designed specifically for people with limited dexterity.

Over 22 years as a C5-6 quadriplegic, I've devised a pretty effective routine to compensate for my limited tenodesis grip, and wondered if the Samba could match or improve on my results. I also wanted to see how good an option the Samba is for users who rely on caregivers or need more assistance than I do.

How It Works

The Samba uses a brush head that is essentially a mouthguard lined with bristles that brush the front and back of the teeth simultaneously. The 12,900 bristles cover the entire surface of the teeth. On the bottom of the brush head are two additional sets of bristles that more resemble traditional manual toothbrush heads. These clean the flat surfaces of the molars opposite of where the mouthguard is brushing. For example, while the mouthguard portion of the brush head cleans the top teeth, the additional bristles clean the upper surfaces of the bottom molars.

Driven by two pistons that push the brush head rapidly back and forth, the Samba runs in 30-second intervals and shuts off automatically, allowing the user to flip the toothbrush over and brush the other set of teeth.



Since the Samba cleans the front and back of the teeth at once, it's recommended you brush for only 30 seconds on a side.

My Trial

I used the Samba as a replacement for my regular electric toothbrush for three weeks. Before I started, I had a number of questions and concerns. My biggest concern was that the

motor would be too powerful. Aside from discomfort or possibly damaging my gums, I worried the Samba might create a mess of toothpaste and saliva, complicating my routine instead of making it more efficient.

Thankfully, none of these concerns panned out. Although it took a few days to get used to a gyrating mouthguard brushing my teeth, my gums got irritated only once, and the Samba never made me choke as I feared it could. Using toothpaste in the mouthguard was also much tidier than expected. I squirt some in the front of the mouthguard and on each side near the molars, and the device does a good job preventing and containing messes.

As a replacement for my regular brush, the Samba performs well. My teeth feel as clean after using it as they do with my toothbrush. One shortcoming is that I can't brush a specific area the way I can with a regular toothbrush. If there is a piece of food stuck and the Samba misses it, I would still need to get it with a



The author tested the toothbrush for three weeks.

regular toothbrush or dental floss. Similarly, if I want to brush my tongue, I'll need another device.

Ironically, the biggest problem I have with the Samba is that it is difficult to use as a person with limited hand and arm mobility. While the Samba advertises itself as being designed for people with limited dexterity, it doesn't feel like designers fully considered what would allow people like me to use the toothbrush independently.

Over three weeks of tinkering and trying new approaches, I was never able to complete the process of brushing my teeth independently with the Samba. Holding the Samba in the correct position with my limited grip is difficult but doable, although adding an adaptive grip would likely be better for many users. More problematic is turning the Samba on and off.

To use the Samba properly, you insert the mouthguard in your mouth and press the power button, a small circle on front of the handle. The button is hard to hit — I had to hold the handle with one hand while awkwardly trying to depress the button with the other. When the Samba is upside down and I can't see or feel the button, pressing it is impossible. If the Samba had a time-delay setting or even a switch that could be activated by biting the mouthguard, it would be much easier for someone of my ability-level to use.

The Verdict

Although the Samba does well cleaning my teeth, I find it to be less accessible than my current toothbrush setup. I can see how the Samba's unique approach would make brushing easier for some with limited dexterity, but, for the many reasons listed above, it doesn't feel like a great solution for users with quad hands or similar function who want to brush independently.

If you are able to brush your teeth independently with a regular toothbrush or existing adaptive devices,

I don't think it is worth the effort learning how to effectively use the Samba. In my opinion, the best use for the Samba would be for someone who requires the assistance of a caregiver to brush their teeth. The Samba cleans teeth well, and for someone with a caregiver who does a poor job brushing teeth, the Samba would eliminate human error. With a few

design changes, however, the Samba could also be a more practical option for other with limited arm and hand function.

The Curaprox Samba Robotic Toothbrush is available for \$299 and comes with a 60-day money-back guarantee. Replacement brush heads are available in packs of two for \$79. For more information, visit Curaprox.

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Arkansas Children's AcuteCare Rehabilitation Program, Little Rock, AR; 501/725-6428

Baptist Health Rehabilitation Institute Little Rock, AR; 501/202-7000

ARIZONA

Barrow Neurological Institute at Saint Joseph's Hospital and Medical Center, Phoenix, AZ; 602/406-3747

Encompass Health Rehab Hospital of East Valley, Mesa, AZ; 480/567-0350

CALIFORNIA

Sharp Rehabilitation Center, San Diego, CA; 858/939-6709

Sutter Rehabilitation Institute, Roseville, CA; 916/878-2588

PAM Health Specialty Hospital of Denver, Denver, CO; 303/264-6900

COLORADO

Craig Hospital, Englewood, CO; 303/789-8800

Post-Acute Medical Specialty of Denver, Denver, CO; 303/264-6800

CONNECTICUT

Gaylord Specialty Healthcare, Wallingford, CT; 203/284-2800

Hospital for Special Care, New Britain, CT; 860/827-2761

Hartford Healthcare Rehabilitation Network, Newington, CT; 860/972-0990

Mount Sinai Rehabilitation Hospital - a Trinity Health of New England, Hartford, CT; 860/714-3500

DISTRICT OF COLUMBIA

Medstar National Rehabilitation Hospital - SCI Program, Washington, DC; 202/877-1000

FLORIDA

Brooks Rehabilitation Hospital, Jacksonville, FL; 904/345-7600

Encompass Health Rehabilitation Hospital of Sunrise, Sunrise, FL; 954/749-0300

Pincrest Rehabilitation Hospital at Delray Medical Center, Delray Beach, FL; 561/498-4440

GEORGIA

Atrium Health Navicent Rehabilitation Hospital, Macon, GA; 478/201-6500

Emory University Hospital Center for Rehabilitation Medicine, Atlanta, GA; 404/712-7593

Rehabilitation Hospital Navicent Health, Macon, GA; 478/201-6500

Shepherd Center - Southeastern Regional SCI Model System, Atlanta, GA; 404/350-7645

HAWAII

Rehabilitation Hospital of the Pacific, Honolulu, HI; 808/531-3511

ILLINOIS

Shirley Ryan Ability Lab, Chicago, IL; 312/230-1000

The Spinal Cord Injury Program of Marianjoy Rehabilitation Hospital, part of Northwestern Medicine, Springfield, IL; 217/788-3302

INDIANA

Rehabilitation Hospital of Indiana, Indianapolis, IN; 317/329-2000

KANSAS

Mid America Rehabilitation Hospital, Overland Park, KS; 913/491-2400

KENTUCKY

Cardinal Hill Rehabilitation Hospital, Lexington, KY; 859/254-5701

Frazier Rehabilitation Institute, Louisville, KY; 502/582-7490

Gateway Rehabilitation Hospital Florence, KY; 859/426-2400

LOUISIANA

The Gilda Trautman Newman Rehabilitation Center, New Orleans, LA; 504/899-9511

Touro Rehabilitation Center- Spinal Cord Injury Rehabilitation, New Orleans, LA; 504/897-8560

MASSACHUSETTS

Spaulding New England Regional Spinal Cord Injury Center, Charlestown, MA; 617/952-5000

MARYLAND

Adventist Rehabilitation Hospital of Maryland, Rockville, MD; 240/864-6132

International Center for Spinal Cord Injury at Kennedy Krieger Institute, Baltimore, MD; 888/554-2080

Medstar Good Samaritan Hospital Spinal Cord Rehabilitation Program, Baltimore, MD; 443/444-8000

University of Maryland Rehabilitation and Orthopaedic Institute, Baltimore, MD; 410/448-2500

MICHIGAN

Mary Freebed Rehabilitation Hospital, Grand Rapids, MI; 800/528-8989

MATRX Health & Fitness, Macomb, MI; 586/232-3644

DMC Rehabilitation Institute of Michigan, Detroit, MI; 313/745-1055

Special Tree Rehabilitation System, Romulus, MI; 800/648-6885

MINNESOTA

EA Therapeutic Health Rehabilitation, Rochester, MN; 507/259-7570

Essentia Health Miller-Dwan Rehabilitation Services, Duluth, MN; 218/727-8762

MISSOURI

Ability KC, Kansas City, MO; 816/751-7812

SSM Select Rehabilitation Hospital, Bridgeton, MO; 314/768-5200

NORTH CAROLINA

UNC Hospitals Rehabilitation Therapies, Chapel Hill, NC; 919/966-4131

Vidant Medical Center, Greenville, NC; 252/975-4100

Wake Forest University Baptist Inpatient Rehabilitation Program, Winston-Salem, NC; 336/716-2011

WakeMed Rehab Hospital, Raleigh, NC; 919/350-8861

NEBRASKA

Madonna Rehabilitation Hospital SCI Rehabilitation Program, Lincoln, NE; 402/489-7102

QLI - Spinal Cord Injury Program, Omaha, NE; 402/573-3700

NEW JERSEY

HMH JFK Johnson Rehabilitation Institute, Edison, NJ; 732/321-7070

Kessler Institute for Rehabilitation, West Orange, NJ; 973/252-6367

NEVADA

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

NEW YORK

Garnet Health Medical Center, Middletown, NY; 845/333-1000

Helen Hayes Hospital, West Haverstraw, NY; 845/786-4000

Rusk Rehabilitation at NYU Langone Medical Center, New York, NY; 212/263-6012

St. Charles Hospital Rehabilitation Center, Port Jefferson, NY; 631/474-6011

St. Mary's Hospital for Children, Bayside, NY; 718/281-8987

Strong Memorial Hospital of the University of Rochester, Rochester, NY; 585/275-2100

Sunnyview Rehabilitation Hospital, Schenectady, NY; 518/382-4560

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

OHIO

Metrohealth Rehabilitation Institute of Ohio, Cleveland, OH; 216/778-3483

The Ohio State Wexner Medical Center, Columbus, OH; 614/293-8000

Summa Rehabilitation Hospital, Akron, OH; 330/572-7300

OKLAHOMA

Valir Rehabilitation Hospital, Oklahoma City, OK; 405/609-3600

OREGON

Legacy Good Samaritan Hospital Rehabilitation Institute of Oregon, Portland, OR; 503/413-7151

PENNSYLVANIA

Allied Services Integrated Health System Spinal Cord Injury Program, Scranton, PA; 570/348-1360

Encompass Health Rehabilitation

Hospital of Altoona, Altoona, PA; 814/944-3535

Encompass Health Rehabilitation Hospital of Harmarville, Pittsburgh, PA; 412/828-1300

Good Shepherd Rehabilitation Hospital, Allentown, PA; 610/776-3100

Magee Rehabilitation Hospital - Jefferson Health The Regional Spinal Cord Injury Center of the Delaware Valley, Philadelphia; 215/587-3000

Jefferson Moss-Magee Rehabilitation Hospital - Center City, Philadelphia, PA; 215/587-3000

Moss Rehabilitation Hospital, Elkins Park, PA; 215/663-6000

Reading Hospital Rehabilitation at Wyomissing, Wyomissing, PA; 484/628-8000

Spinal Cord Program at The Children's Institute, Pittsburgh, PA; 412/420-2400

UPMC Rehabilitation Institute at Mercy, Pittsburgh, PA; 800/533-8762

SOUTH CAROLINA

Roper Rehabilitation Hospital, Charleston, SC 843/724-2800

TENNESSEE

Regional One Health Rehabilitation Hospital, Memphis, TN; 901/545-7100

Vanderbilt Stallworth Rehabilitation Hospital, Nashville, TN; 615/963-4051

TEXAS

Baylor Scott & White Institute for Rehabilitation, Frisco, TX; 469/888-5100

Texas Rehabilitation Hospital of Fort Worth, Fort Worth, TX; 817/820-3400

TIRR Memorial Hermann Hospital, Houston, TX; 713/799-5000

TIRR Memorial Hermann Hospital - Outpatient, Houston, TX; 800/447-3422

TIRR Memorial Hermann Hospital The Woodlands, The Woodlands, TX; 713/897-2300

UTAH

Neuro Specialty Rehabilitation Unit at McKay-Dee Hospital, Ogden, UT; 801/387-2800

Neuro Specialty Rehabilitation Unit at Utah Valley Hospital, Provo, UT; 801/357-7850

Neuro Specialty Rehabilitation Unit at Intermountain Medical, Salt Lake City, UT; 801/507-1261

Neuro Specialty Rehabilitation Unit at St. George, Saint George, UT; 435/251-6250

University of Utah Craig H Neilsen Rehabilitation Hospital, Salt Lake City, UT; 801/646-8000

VIRGINIA

Sentara Norfolk General Hospital, Norfolk, VA; 757/388-3000

Sheltering Arms Institute, Richmond, VA; 804/764-1000

WASHINGTON

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

WISCONSIN

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

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

Organizational Members

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

High Rollers Adaptive Sports Foundation, Las Vegas, NV; 702/372-9622

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

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

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

Project Walk New Jersey Mt. Laurel, NJ; (856/439-6772

Push to Walk Oakland, NJ; 201/644-7567

TRYAbility Neurorecovery Center Downers Grove, IL, (331) 775-2813

Interested in becoming a hospital or organizational member?

Please contact Matt Castelluccio at mcastelluccio@unitedspinal.org



It's FREE to join, and member benefits include New Mobility!

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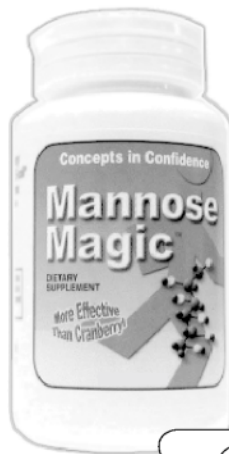
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**Every 2nd Wednesday of
the Month • 7-8pm EST**

ROLLING INTO PARENTHOOD

Being a parent with a mobility disability brings on a whole new set of challenges! All parents with disabilities and their partners currently raising children are welcome. This group is a safe place to share valuable information, advice, support and resources with your peers. The group's facilitators are Matt Castelluccio, a dad with a spinal cord injury of twin 10-year-old boys; Lesly St. Louis, a dad with spina bifida of a 5-month-old daughter; and Erin Gilder, a mom with a spinal cord injury of two teenage boys aged 16 and 18.



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Cape May farmhouse near beach. First floor entirely wheelchair accessible. Sleeps eight. Visit www.beautifullyaccessible.com for more info and reservations.

Ocean-front condo, wheelchair friendly, sleeps six, pool, boardwalk to beach. Rents daily, weekly, monthly. St. Simons Is., GA. bmmk4@frontier.com 419-569-6114.

New Zealand Accessible Vehicle Hire. New Zealand disability vehicles, hand control cars, left foot accelerator cars for hire. Explore New Zealand – we make it easy! We are happy to pass on our former clients' recommendations of accessible activities and accommodation. See www.freedom-mobility.co.nz

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www.unitedspinal.org/pathways-to-employment/



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www.facebook.com/newmobility

LAST WORD

MEMEWATCH



Meme by @life_keeps_rolling

Learn more about how to — and how not to — interact with disabled people in United Spinal's updated *Disability Etiquette Guide*: unitedspinal.org/top-10-disability-etiquette

SEE IT FIRST ON NEWMOBILITY.COM

Medicare Approves Exoskeletons for Personal Use

Exoskeletons have long seemed out of reach for most wheelchair users, but times may be changing. Cheryl Angelelli reports on two companies that had exoskeletons approved by Medicare for home use, potentially offering new access to the many benefits of standing and walking.



Help for Training Your Caregivers

Finding caregivers keeps getting harder, and finding ones who already have knowledge of SCI is almost impossible. A free online training course from the Kessler Foundation aims to help your caregivers get up to speed faster so you can get on with your life.

Reframing Inspiration

Many in the disability community are tired of being thought of as inspirational for going about their daily lives. An encounter with a parent near his son's school made Seth McBride wonder whether we've become too rigid when talking about the "I" word.

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