

Joe Stone Cooking Arts & Crafts Disabled in Ukraine

# nm

## NEW MOBILITY



THE MEMBERSHIP PUBLICATION  
OF UNITED SPINAL ASSOCIATION

**Spiritual  
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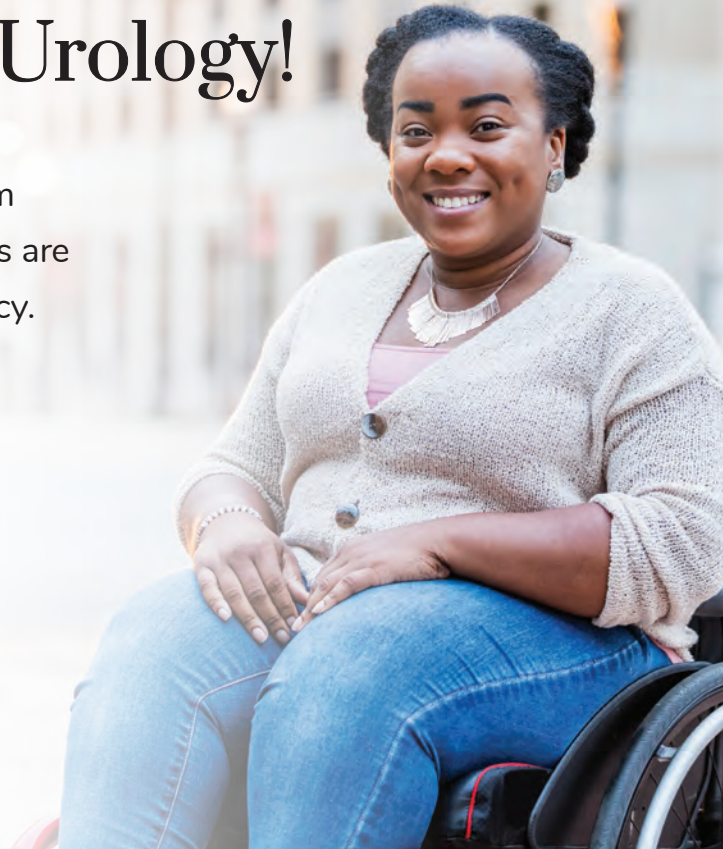
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## COVER STORY SPIRITUALITY

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# BULLY PULPIT

By Ian Ruder



**NEW MOBILITY IS THE  
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## GOODBYE BOWEL PROGRAM, HELLO COLOSTOMY (A FAREWELL TO BUTTS)

This spring, after almost 24 years of ever-lengthening mornings sitting on my shower chair, I put away the lube and gloves, and said farewell to bowel programs and hello to a colostomy.

The bowel programs that started as an effortless hour on my side in the hospital so many years ago had devolved into a grueling two-to-three-hour sludge every other morning. With the time and assistance I needed, the routine had become the anchor of my life — often determining my schedule and my emotions.

I'd learned to live with the long, monotonous mornings sitting in my room waiting for my bowels to respond and the scheduling complexities that came with them. But over time a more sinister problem emerged: hemorrhoids.

At some point in the last 10 years, my hemorrhoids went from being a rare, minor problem to the biggest burden in my life, one that constantly weighed on me. I turned my music up to drown out the sound of the dripping blood splattering on the floor, and I learned to look away from the sheets after transferring so I wouldn't have to see how much blood I lost.

One doctor suggested I was exaggerating how much blood I was losing and told me, "You know, women bleed every month." It took a hemorrhoid squirting blood directly into his eye to make him a believer. I still fired him.

In hopes of avoiding the dreaded "c" word, I talked with specialists and peers, scoured what little literature exists and made myself a regular in all the online forums. I tried everything: banding, sclerotherapy, cauterization, a whole new routine using a Peristeen and finally last year, a hemorrhoidectomy.

Sometimes a combination of the above would buy me six to 12 months in the clear, but the hemorrhoids always came back —

usually worse than before. My strength and energy levels yo-yoed, as I'd build up my endurance only to lose it again. I needed multiple rounds of iron infusions and a blood transfusion.

The hemorrhoidectomy had always been the last line of defense in my efforts to ward off a colostomy, as it is a more serious surgery with a lengthier recovery in exchange for longer-lasting results. Ten months post-op, it seemed to have delivered on all fronts. Then one morning this January, I heard the splatter. It grew steadier over the next two weeks. On a particularly bloody Valentine's Day, I decided I'd had enough.

The hemorrhoids had won. I called my surgeon and asked to schedule the colostomy as soon as possible.

By my count, I've probably endured around 4,500 bowel programs. If you figure an average of 2.5 hours for each one, I've spent somewhere in the ballpark of 11,000 hours waiting on my shower chair. That's over 450 full days of my life.

Sitting there one last time as I did the final preparations for the colostomy, I thought back to a series of posts I'd read years ago in a now-extinct forum for quads. In the main chain, one man detailed his struggle to treat his hemorrhoids and sought novel solutions and advice.

The people who responded shared nearly identical stories that all ended in colostomies. They encouraged the poster to bite the bullet and schedule surgery. I remember thinking I'd show them. I was confident I'd figure out how to beat the hemorrhoids.

There will always be a part of me that wonders what the last decade would have been like if I'd bitten the bullet back then. What if I had all that time back? What if I had avoided all the stress and damage I endured?

But for the most part, I'm ready to move on. I'm still adjusting to the realities of a colostomy, but I'm ready for something new.



# BEHIND THE STORIES

With Ian Ruder

It's not a stretch to imagine a different timeline in which **Josie Byzek** is using her seminary master's degree to pastor a disability- and LGBT-inclusive congregation. Thankfully for us, she instead stuck with **NEW MOBILITY**. After this issue, she is transitioning to an exciting new role as digital experience and content director for United Spinal Association. In her final feature as executive editor, she taps into her pastoral roots and captures an "action-oriented" brand of spirituality with the insightful and thoughtful style that has long made her a reader favorite. "Spirituality is a super-broad concept, but very specific to whoever you are talking to," she says. "For the people I spoke with, it's a lot more than just sitting around and meditating. It's the actions we take."



Our recent reader's survey made it clear: Many of you wanted a cover package on spirituality. Deciding whether to include **Bob Vogel's** psychedelics pitch as part of that package was less clear. Not because it wasn't an interesting pitch — it was — but because we weren't sure how it would fit. We made the right call. As always, Vogel has crafted a fun read full of colorful personalities and experiences that will hopefully expand the way you look at the intersection of psychedelics and spirituality. Although Vogel has been interested in the potential of psychedelics a long time, he is hesitant to delve in personally. He's still not sure psychedelics are for him but says, "Writing this, I learned more about what to do and what not to do. Now I feel like I can develop the tools so maybe they are an option down the line."

I got hold of **Esme Mazzeo** at 6 p.m. on a Friday to discuss her writing a cooking story for us. After a long workweek, cooking dinner was not on her mind. She explained that her Long Island kitchen is not very accessible, and she leaned more toward Lean Cuisine than gourmet cooking. "I really have to be in the mood to overcome a challenge," says Mazzeo. Still, interviewing cooks gave her some good ideas she'll look to employ when she eventually does have an accessible kitchen. It also helped her rethink her concept of accessible cooking. "You really have to mold your own definition based on your abilities and needs," she says.



## COLUMNISTS

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Please send queries, manuscripts or feedback to Ian Ruder: [iruder@unitedspinal.org](mailto: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](http://unitedspinal.org/ask-us); 120-34 Queens Blvd, Suite 320, Kew Gardens, NY 11415.

SHARE

“I love their ingenuity and ability to create what’s needed.”

MARCH-APRIL 2022

## Rural Life as a Wheelchair User

**Git'r Done:** I love their ingenuity and ability to create what’s needed. It may not be tested and approved, but it works and gets the job done.

**David Nisbet**  
Facebook

## An Angel Gone Too Soon

**Look at our Angel,** breathtakingly beautiful inside and out. She touched so many lives effortlessly, compassionately, and lovingly! She will be missed without a doubt, but she is now soaring beyond the universe in the astral realm with her mom, dancing up a storm. As our queen on her throne would say, “If you are alive and have a heartbeat, you have a purpose. Live your life passionately with purpose!” She definitely lived her life to the fullest with purpose. I love you, @autiangel, my twin flame for eternity.

**Angela Rockwood**  
@therealangelarockwood  
Instagram

**Editor:** Angela Rockwood costarred with Auti Angel in Push Girls.

## As Millions Flee, Disabled Ukrainians Forced to Fend for Themselves

**Sad:** I feel so sorry about others in Ukraine, but you don’t hear about people with disabilities and how they’re coping and what’s happening with them and how they are getting out — or if they’re getting out and if they are getting the assistance that they need.

**Simone Stevens**  
Facebook

**More Needs to be Done:** So far, I have not seen our governmental agencies or our administration supporting or coordinating with our disability-led organizations here in the U.S.

**Tom Olin**  
Newmobility.com

**We Can Help:** Thank you for shining a light on this. I have shared the article and GoFundMe page and hope others will as well. I can’t imagine being in that position with nowhere to turn.

**Maria**  
Newmobility.com

**Editor:** To learn more about efforts to assist disabled Ukrainians, see page 15.

## The Pleasure is Ours

**Thank You for Sharing:** I’m 4 1/2 years into my journey and haven’t found her yet. As a guy, I’ve found out that discovering what you can and cannot do in a sexual/physical sense can be psychologically devastating if you are not prepared for the possibilities. For example, not knowing that the “keep it up” message from your brain to Mr. Happy cannot get through to Mr. Happy is devastating to a guy because of how much we identify with performing for our lady friends. Newbies need to know that there are options to help with most everything. I really do miss the physical part, but it is the intimate, connective part that leaves one wanting.

**Thomas**  
Newmobility.com

**Editor:** To read all three essays in “The Pleasure is Ours,” visit newmobility.com. To read the first essay in the series, see page 36.



## Searching for Solutions to Spasticity

**A Mixed Bag:** Spasticity can be a pain in my daily routine as a C5-6 quadriplegic, but it’s also a big contributor to my independence. When I was first injured in 1995, I refused to take Baclofen or any other muscle relaxers. I wanted to understand how my body was firing off involuntarily.

How did the spasms trigger in hot or cold situations? Did food or sleep affect them? What about prolonged sitting? When I listened to my body, I was able to use my spasticity in a positive way. Eventually, I was able to trigger my spasms and use them to help me transfer, dress in my wheelchair, grab items like door handles, heavy objects and many other useful things.

I understand that every SCI is different, and I am lucky to be able to manage my spasticity. I also have days where I’m a complete wreck, and my spasticity is tiring and disruptive. And for some, spasticity is unbearable. I just hope that we teach newly injured people to be patient with their bodies instead of medicating them right away.

For me, the best remedy for a quality spastic day is drinking lots of water, eating nutritious foods rich with vitamins, stretching regularly and getting plenty of rest.

**Mark Fuglevand, @abilitease**  
Instagram



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## Adam Lane to Handcycle Across America in Support of the #StrongWheeled Together Campaign

On April 11, United Spinal member Adam Lane embarked from San Diego on a cross-country handcycling tour to bring awareness to the #StrongWheeled Together campaign. A member of United's Oklahoma chapter, Lane plans to visit up to 13 chapters across the country, attend Roll on Capitol Hill in Washington, D.C., and end his trip in New York City on June 25. The goal of #StrongWheeled Together is to highlight the SCI/D community's contributions to American society and our struggle for equality.



Adam Lane may be coming to a United Spinal chapter near you this summer as part of his cross-country handcycling tour.

Instead of handcycling the entire way on dangerous highways and freeways, Lane will cycle the distances between stops during extended stays in the cities where he visits chapters. "I hope this format will give me more time to connect directly with chapters and the general public," he says. "I think I will be more effective raising awareness and money for United Spinal."

Lane has an extensive background competing in triathlons but says he got the idea for the ride while training as a yoga instructor. "This has been in the back of my mind for 13 years. Then one day, I made the mistake of telling someone I was thinking about it. Once it was out there, it came together pretty quickly," he says. "I'm at the point now where I am both excited and terrified. Every time I talk about it, I get more fired up."

United Spinal will share updates on its website and social media channels. You can follow Lane's progress on Facebook and Instagram @2022handcyclearcrossamerica or adamklane.com.



## Accessible Travel Blitz

The new online *Accessible Journeys* magazine is full of articles and resources for disabled travelers. Funded by TravelAbility, the publication is edited by longtime New MOBILITY contributor Ashley Lyn Olson. "We need something to get the industry to start learning and changing, and the magazine should make them pay attention," she says. "It has been a fun challenge." Read the mag online at [bit.ly/3r3PkUx](http://bit.ly/3r3PkUx) and find out more at [travelability.net](http://travelability.net).



*Accessible Journeys* is packed with writing from leading accessible travel bloggers.





Jillian Mercado is one of the changemakers who posed for the All-Inclusive Photo Project.

Photo by Annie Leibovitz



Celebrity Cruises agrees the travel industry must pay more attention to disabled travelers. Toward this goal, it created the "All-Inclusive Photo Project," the world's first open-source photo library featuring ethnic, disabled, curvy and LGBTQ+ changemakers. "We invite our industry to join us in changing the face of travel," the company says on its website. The project revealed its first images on March 29, showcasing an all-star roster of photographers led by

Annie Leibovitz. Browse its catalog at [celebritycruises.com/about-us/celebrity-cares/all-inclusive-photo-project](http://celebritycruises.com/about-us/celebrity-cares/all-inclusive-photo-project).



### Win a Wheeliez All-Terrain Conversion Kit

Ramp up your summer with some off-road gear, courtesy of Wheeliez. The company will judge short essays and give away one of its all-terrain conversion kits to the winner. In 300 words or less, describe the exciting adventures you would embark on if you won the kit. Submit by June 15 to: [info@apsl.com.hk](mailto:info@apsl.com.hk)

### Expand Your Mindset

Do you want to be an advocate, but you're not sure how or where to get started? Luticha André Doucette put together a guide to help you understand your values and strengths and how to effect social change called *Cultivating an Intersectional Mindset: A 30 Day Guided Journal*. During an NM Live with Teal Sherer, she compared the process to planting and cultivating a seed: "This is a way for you to get that soil fertile so you can grow the seeds of change," she says. Buy the book at [Bit.ly/catconjournal](http://Bit.ly/catconjournal) and watch NM Live at [instagram.com/p/CbdWmvnL\\_2X](http://instagram.com/p/CbdWmvnL_2X).



### Queen of the Ice

The Seattle Kraken hockey team didn't make the playoffs in its inaugural season, but the team scored many goals off the ice. High atop that list is hiring the NHL's first intersectionality consultant, Chanel Keenan, a lifelong hockey diehard who uses a power wheelchair because of osteogenesis imperfecta. Sportsnet.ca documents her first year on the job and how she is changing the game. Read the story at [sptsnt.ca/38loNLL](http://sptsnt.ca/38loNLL)



"It's a really innovative role. ... Strictly through a disability and disabled-community lens, I feel like this is the first of its kind," Chanel Keenan told *SportsNet*.

## WATCH

AFTER YOU READ KELSEY PETERSON'S POWERFUL ESSAY ON EMBRACING HER POST-SCI SEXUALITY [PAGE 36], YOU WILL WANT TO SEE **MOVE ME**. IN THIS LONG-IN-THE-WORKS DOCUMENTARY, PETERSON TAKES VIEWERS EVEN DEEPER INTO HER LIFE AS SHE EXAMINES HER IDENTITY AND THE POSSIBILITIES FOR HER RECOVERY, BODY AND SPIRIT. THE MOVIE PREMIERED AT THE FULL FRAME DOCUMENTARY FILM FESTIVAL ON APRIL 7-10. FOR MORE INFO, VISIT [MOVEMEDOC.COM](http://MOVEMEDOC.COM).



## MEMBER BENEFITS

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United Spinal Association is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D) by providing programs and services that maximize independence and enable people to be active in their communities.

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Membership in United Spinal Association is free and open to all individuals who are living with SCI/D, their family members, friends, and healthcare providers. Visit [unitedspinal.org](https://unitedspinal.org) or call 800/962-9629.

United Spinal has 75 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.



## NEWS FROM UNITED SPINAL



### NEW FOR ROLL ON CAPITOL HILL 2022

United Spinal Association's 2022 Roll on Capitol Hill will offer in-person and virtual participation options so advocates from every state can engage directly with federal policymakers on the SCI/D community's most pressing issues. The new hybrid format will expand the reach of United Spinal's signature event more than ever before.

For the event's first eight years, United Spinal brought wheelchair users and advocates to Washington, D.C., for training and meetings with legislators, but in 2020 the COVID-19 pandemic precluded an in-person gathering, and we were forced to cancel the event. The 2021 Roll on Capitol Hill took place entirely online, with a record 214 advocates logging on from 35 states plus the District of Columbia, paving the way for the integration of a permanent virtual option.

As United Spinal continues to grow our network of registered advocates, which already includes nearly 1,300 people representing more than 90% of congressional districts in all 50 states, we want to make sure that all our elected officials hear directly from their constituents affected by SCI/D. Our new hybrid format will allow us to reach more policymakers and deepen the understanding of the SCI/D experience with a larger coalition of potential allies on Capitol Hill.

At this year's Roll on Capitol Hill, we will focus on issues largely familiar to our community and urge lawmakers to take needed action:

- Access to quality SCI rehab has been slipping over time. We need greater funding for SCI Model Systems and federal regulations to ensure that newly-injured individuals with SCI receive the health care and services they need.
- Air travel poses serious risks for wheelchair users. We need to improve safety for travelers with disabilities and ensure that wheelchairs are not damaged by airlines.
- Employment issues continue to plague our community. At the height of the pandemic in 2020, the society at large recognized that home and community supports and personal care attendants are critical and saw how job loss can lead to dangerous health situations for members of our community. We must remind legislators of the importance of maintaining PCA support regardless of income level.
- Adaptive vehicles remain out of reach for many veterans. We are asking the Department of Veterans Affairs to increase support for automobile grants for disabled veterans to enable them to truly participate in their communities.
- Outdated and restrictive federal regulations prevent many community members from getting the wheelchair that's right for them. We need better access to life-changing equipment.

We are very much looking forward to welcoming all of our advocates to this year's Roll on Capitol Hill, and United Spinal will continue to push forward on policy and advocacy throughout 2022 and beyond.

You can visit United Spinal's Action Center for all the latest Roll on Capitol Hill and other policy priorities, [unitedspinal.org/action-center](https://unitedspinal.org/action-center).

— ALEX BENNEWITH AND STEVE LIEBERMAN

## SO LONG, JOSIE, AND THANKS FOR ALL THE FISH

**That's a headline Josie Byzek wouldn't let past**

**the editorial gates** — cliché, doesn't mean what people think it means, terrible SEO. But Josie isn't editing this piece — she's outta here, on to a big new job with our parent company: Digital Experience and Content Director of United Spinal Association.

It's hard to say goodbye to my colleague and friend of 22 years, but I know she'll continue to dispense heartfelt and insightful feedback from her new perch. She can't help it — and never could, really, even as an entry-level editor. When I advertised that assistant editor job in 2000, the candidates sent their writing clips via fax. As I pored over blanch-



ing pages of pixelated text, one technicolor voice refused to fade: Josie's. I wanted that brilliant mind for NM! — but I figured I should downplay my enthusiasm so she would work hard. I needn't have worried. After more than two decades of rising through the editorial ranks, she still sees the possibility of greater things around every corner, if we could only do this and this and this. ... Stay in touch, Josie. We still need your tenacity and voice, even if it's just a friendly call nudging us to reimagine a cliché headline or janky metaphor. We will always listen — and we'd be very foolish to forget about all the fish.

— JEAN DOBBS, NM PUBLISHER

**I'll never know exactly what it was** that convinced Josie to take a chance on me as a freelance writer 12 years ago when we met at an advocacy event in Washington, D.C., but I will be forever grateful. I am one of hundreds, if not thousands of people who have benefited from Josie's advocacy. Whether as an activist, an editor, a mother or friend, she uses her passion and conviction to help those around her and those in need. As the executive editor of *NEW MOBILITY*, she has been the meticulous and incisive overseer we needed, but more than that, she has been a reliable smiling face in Teams meetings and a true friend.

— IAN RUDER, EDITOR

**Josie and I first found our stride together** when we co-wrote a piece about a critical unmet need for emergency evacuation equipment soon after 9/11. It still has an impact today. Even though we sometimes disagreed on how to approach a story over the years, our iron-sharpening-iron dynamic always made it — and us — better. She has made her mark on *NEW MOBILITY* with her informed insight into advocacy issues,

her keen eye for disentangling complex stories, and her willingness to take on any challenge. Don't forget to take time to go fishing, Josie!

— TIM GILMER, EDITOR EMERITUS

**When I started working** regularly for *NEW MOBILITY*, Josie helped teach me the ins and outs of news writing and editing — how to cut through the clutter and superfluous words to get to what matters in a story, quickly. I'm sure she'll bring the same passion for language and precision editing to her new role, but we'll certainly miss it here. Best of luck, Josie!

— SETH MCBRIDE, SENIOR EDITOR

**I first met Josie in 2012** when she interviewed me for the YouTube All Stars cover story. She was so fun to chat with, encouraging and supportive. Fast forward almost 10 years, and Josie continues to empower me and those around her. Her passion and skill have shaped *NEW MOBILITY* into the publication it is today. I love you, Josie, and am so excited for your next chapter!

— TEAL SHERER, SOCIAL MEDIA MANAGER

**Although I've worked with Josie** at *NEW MOBILITY* for around two decades, it only feels like a few years — proof that time flies when you have a treasured friendship and working relationship. Josie is always there to take my calls when I'm struggling with an article or I want to share a funny story or poignant moment. I'm glad you will still be a phone call away and under the United Spinal roof. Wishing you all the best in your new endeavor.

— BOB VOGEL, SENIOR CORRESPONDENT

**I was instantly fond of Josie** working on our first project in 2013 about "How to Get an Accessible Hotel Room," but I played it cool to respect her poised yet hawk-like demeanor. Her ability to see the bigger picture naturally made her a dynamic editor, teacher and community leader. Josie's encouragement made me a better writer. She is a grounded visionary who has brought balance to and equality for this community. I wish her success, love, peace and joy.

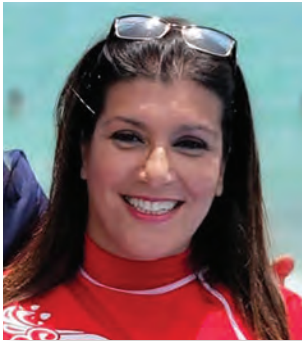
— ASHLEY LYN OLSON, CONTRIBUTOR

*Email Josie at [jbyzek@unitedspinal.org](mailto:jbyzek@unitedspinal.org).*

# HOW WE ROLL

ADAPTIVE RECREATION COORDINATOR

## Sabrina Cohen



Getting stuck in the sand at Miami Beach motivated Sabrina Cohen to shift her focus from SCI cure research to quality of life. A decade later she is on the precipice of changing the face of Florida beach access.

## Life's a Beach

In 2012, Sabrina Cohen was promoting her foundation, The Sabrina Cohen Foundation for Stem Cell Research, and traveling the country speaking about the virtues of stem cell research as the director of public relations for The Genetics Policy Institute. A broken foot took Cohen, a C6-7 quadriplegic, off the road while she was dealing with several donors who didn't fulfill their promises to her foundation.

Cohen and a colleague were discussing what to do with the foundation when she rolled her power chair onto Miami Beach to be close to the water and instantly got stuck. "Before that, I never consciously thought about going back to the beach, but I got stuck on that day — it took six guys to get me out — and in that moment I'm like, wow, we could do better," says Cohen, now 44.

Cohen decided to shift her foundation's focus from research to quality of life. The first goal? Improve beach access.

Within a week of being stuck in the sand, Cohen and a colleague arranged a meeting at Miami Beach City Hall where the commissioners challenged her to help them figure out how they could do better. That's how the idea for Sabrina's Adaptive Beach Days began.

While attending a concert, she bumped into a former high school classmate who ran an adaptive surfing program for children with autism. She shared her vision of bimonthly events



that would give people with physical disabilities an accessible beach experience, complete with food. He enthusiastically volunteered to be the program's director. She recruited volunteers from the local colleges to provide the boots on the ground and secured grants for equipment like beach chairs, tents and roll-out mats.

Cohen envisioned a truly integrated solution that went beyond providing a bunch of accessible equipment. She wanted to address the underlying issues that kept disabled people away from the beach. "How do you transfer people into [chairs]? How do you keep a power chair from getting overheated in the sun, so when people get back in their chairs, they don't get a burn?" says Cohen. "It was everything. I even have a team who comes out at 8 a.m. and sets up access decks, so there's a stage over the sand for power chair users or people who don't want to be in beach chairs to remain independent."

The results gave attendees options. You didn't have to use a beach chair if you didn't want to, and if you wanted to get into the water, there were plenty of people to help. Even with all this work, the beach days weren't her endgame; they were just a steppingstone to her ultimate goal: building an accessible beachside recreation facility.

"I had to put together all these little details because the city

**WHAT ARE YOU DOING WHEN YOU'RE NOT RUNNING THE SABRINA COHEN FOUNDATION?** I'm a realtor specializing in universal design and accessibility, and 60% of my clients are people with disabilities. I also love concerts, comedy shows and being on the water boating.

**WHAT'S YOUR IDEAL DATE?** On a first date, I like to meet at a restaurant or coffee shop just to break the ice and get to know someone.





The Sabrina Cohen Foundation offers wheelchair users a great day at the beach.

said to me, ‘Sabrina, we love the idea of a building, but create a proof of concept,’” says Cohen.

Holding twice-a-month pop-up beach days for the past six years proved the concept. In October 2017, the city allocated a piece of land needed to build the accessible beachside recreation and fitness center.

The City of Miami Beach Commission awarded The Sabrina Cohen Foundation, renamed in 2016, a \$2.5 million matching grant and promised public land to build the center. Designed pro-bono by sustainable architecture firm Kobi Karp, it will be a 27,000-square-foot, three-story, universally-designed fitness center, equipped with fitness and therapy spaces and a rooftop pool, in addition to providing full-service beachside and water activities.

“The intention of the center is to create access to the beach for 365 days, where if someone shows up on a Tuesday, they’re not denied,” she says. “We have everything they need.”

The foundation still needs to raise another \$8 million to make her vision a reality, but Cohen is undeterred. “We hope to break ground in the winter of this year and have already raised \$4.1 million,” she says. “We’re selling bricks at \$500 and \$1,000 apiece. Anyone can buy one and name it and literally be a part of the pathway that will lead to the center. It’s called The Pathway to Inclusion and we’re on our way, but we still need more support. I think it’s just a matter of time.”



**MOST ACCESSIBLE PLACE YOU’VE EVER BEEN?** Cruising is an accessible way to get around and less hectic than getting on a plane.

## Crushing It During COVID

Sabrina Cohen explains why the pandemic didn’t slow her progress and how she offered more accessible recreation opportunities despite lockdowns and social distancing.

“In 2020 we had to stop our beach program, but that also gave me the quiet time to put all the pieces together and strategize. Out of COVID, we started a wheelchair tennis program because we were looking for something safe to do outdoors. Plus, literally in March 2020, when we found out we couldn’t host the beach days, I moved to a virtual platform, so now the Sabrina Cohen Foundation provides fitness classes three days a week with an adaptive fitness coach. That’s going strong, and we will never take that away — we have people from all over the country logging in. I’d say, in a weird way, the pandemic actually helped, rather than hindered, us.”



Sabrina Cohen didn’t let a little thing like a world-wide pandemic keep her from improving the quality of life of fellow wheelchair users.

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# As Millions Flee, Disabled Ukrainians Forced to Fend for Themselves

by Seth McBride



The war came quickly to Uliana Pcholkin's doorstep. She and her husband, Vitalii, are manual wheelchair users who live in Bucha, a city just northwest of Kyiv, the capital of Ukraine. As Russian forces invaded Ukraine and advanced toward Kyiv, Bucha took heavy fire, and the Pcholkins were forced to shelter in place.

"Our house was under direct shelling from a tank, now the city is looted by Russian invaders. We have no chance to [be] rescued — we have nowhere to run!" Uliana posted on Facebook on March 7. "There is no communication in the city. Light, water, gas [are] missing. Temperature in apartment [is] on the edge of 10-12 degrees. There is no connection either. This post is uploaded under shelling, at risk of life, where [there's] at least a little bit of connection."

There are an estimated 2.7 million people with disabilities in Ukraine. Many now face brutal conditions brought on by the invasion, an unfolding humanitarian crisis, and international organizations' failure to account for the needs of disabled Ukrainians.

Yuliia Sachuk foresaw this crisis. She heads Fight for Right, a Ukrainian disability-rights nonprofit. "I started the process of finding support and coordinating our efforts to be prepared for a possible invasion months before the war, knowing that the situation of people with disabilities could be very difficult," she says. But she found little willingness to help among major national and international players.

As the war unfolds, Fight for Right is left scrambling to help disabled Ukrainians who face a multitude of dangers. There are immediate concerns for those whose towns and cities are hotspots, such as whether to stay at home or seek protection in a basement or bomb shelter.

If you stay put, you risk shelling and rocket attacks, freezing temper-

atures and lack of power and heating. But how do you seek shelter when safety is underground, and there are no lifts to get there? You can ask friends and strangers to carry you, but where will you go to the bathroom once there? Where will you sleep without risking pressure sores? How will you get back out to secure food? How will you take care of your most basic needs? The questions are innumerable and often unanswerable.

## EVACUATION EFFORTS

For many, the safest bet is to seek refuge in neighboring countries, as more than a million Ukrainians have already done. But accessible transportation options are limited. Tanya Herasymova, a manual wheelchair user who works for Fight for Right, evacuated her city of Kamianske in the east of Ukraine. She left by train with her mother, who also has a disability and uses crutches. There were no lifts or ramps, and everywhere they went, she needed people to help lift her on and off the train. They escaped on Feb. 25, just a day after Russia invaded, while tickets were still available. They eventually made it to Poland, but she says that many people with disabilities lack the resources or means to self-evacuate as she did. "They just stay [at] home and pray to God for peace," she told the BBC.

Anna Landre is coordinating evacuations with Fight for Right and the Partnership for Inclusive Disaster Strategies, a U.S.-based nonprofit that typically focuses on natural disasters. "We, as two small organizations, are simply not equipped to manage evacuations of people with disabilities in a conflict environment. Because of the lack of attention to this issue, we've stepped in."



Uliana and Vitalii Pcholkin at an art exhibition in 2019. Photo courtesy of UNDP Ukraine.

When she began helping Fight for Right, she reached out to major international organizations like the United Nations, the Red Cross, USAID and others, but was repeatedly told the organizations “lacked the ability to evacuate ‘personnel with those needs’ — in other words, people with disabilities,” she says.

Landre, Sachuk and a coalition of disability activists and organizations spread across North America and Europe are crowd-sourcing help for disabled Ukrainians in lieu of well-funded aid. There’s the case of Serhiy Kovalchuck, a manual wheelchair user who needed a new wheelchair as he was evacuating. A case manager in Germany found a wheelchair in Poland, and a driver from Finland delivered the chair to Kovalchuck.

According to Landre, as of March 10, their organizations received over 114 requests for evacuation help from disabled Ukrainians and successfully evacuated 90 individuals and their loved ones. “Our first, biggest need has been transportation — going from people’s houses to a border point — we have struggled to find accessible transportation, especially for people who need to be transported in their wheelchair,” she says.

Once people escape Ukraine, problems persist. “We’ve found that most existing aid and settlement resources are not inclusive. For example, one of our biggest problems is that buses from border points in Poland to refugee registration centers are not wheelchair accessible,” says Landre.

Temporary and long-term accessible housing in neighboring countries is a major need. Disabled Ukrainians who leave their homes have no idea if or when they may return.

## SYSTEMIC ISSUES

Fight for Right also battles systemic issues, like clarifying emergency measures within Ukraine so that people with disabilities and their personal care assistants can move freely. Since the war started, men aged 18-60 have been banned from leaving the country. According to Fight for Right, there are exemptions, but the border patrol service lacks clear instructions about what documentation is needed to allow men in this age range out of the country.

Ukraine also has a significant population of people with disabilities, both children and adults, who live in institutions. The spotty information that activists have received about the conditions inside those institutions is grim.

“We are receiving reports from many angles, some of which are hard to verify, that there are targeted attacks on institutions and hospitals,” says Avery Horne, an external coordinator for Fight for Right, currently living in Ireland. “Humanitarian aid is vitally needed. We don’t know if these institutions have access to food, water, energy, and staffing. There have been reports that staff has been leaving and that there’s a grave situation occurring, especially in the institutions in the urban areas that are under direct attack.”

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Given the scale of the crisis, disability groups need the assistance of major international aid organizations, but so far, support is limited, at best.



In the meantime, disabled Ukrainians will keep helping each other however they can, coordinating with individuals and organizations in other countries that are willing to assist. If you'd like to directly support Fight for Right and its efforts to evacuate disabled Ukrainians, please visit the group's GoFundMe page at [gofund.me/5723f869](https://gofund.me/5723f869).

## United Spinal's Efforts to Help Ukrainians With Disabilities

Ever since Russia began its latest attack on Ukraine, United Spinal Association has been focused on understanding the facts on the ground and the needs of the disability community, both in Ukraine and among the refugees fleeing the invasion. United Spinal is now organizing with our partners to determine the best ways in which we can assist in this vast humanitarian effort.

### **We have identified three areas in which we can engage:**

**Immediate monetary aid:** Funding can be provided to Fight for Right through its GoFundMe campaign.

**Equipment and supplies:** There is a great need for accessible vehicles to transport people with physical disabilities. Equipment such as wheelchairs, ventilators and other disability-related supplies will surely be needed. Partners on the ground in Europe will need to identify physical locations to send these items as well as plan the logistics of a supply chain.

**Build support:** United Spinal and other U.S.-based disability organizations will work to raise awareness about the situation of the Ukrainian disability community and build support with federal policymakers and governmental officials to make sure that Ukraine's disability community receives the aid and support it needs right now and throughout this crisis.



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# Accessible Cooking FROM SCRATCH

By Esme Mazzeo

**W**hile preparing for a gender reveal party, Sara Gaver realized her cupcakes had a superpower. “We threw them on the floor, and they bounced like balls,” she says, blaming the amount of food coloring needed to turn her creations an exact shade of blue and pink. Since she couldn’t serve them, she purchased a new, unfrosted batch to decorate and pass off as her own.

Food coloring mishap aside, Gaver found success in the kitchen by confidently embracing the body she has, instead of worrying about what she is unable to do. With limited use of her hands — her joints and muscles are fused because of arthrogyriposis — she learned to rely on her mouth for cooking.

Her unique culinary technique caught the attention of Permobil, which asked her to star in a commercial for its Voice Assist app. One of the promotional photos shows her holding a spatula in her mouth to flip eggs.

Gaver jokes that she learned to cook when she started living independently and realized she couldn’t order takeout every night. But celebrated Philadelphia chef Eli Kulp got his first taste of the culinary world when he was 14. He washed dishes at a small, sit-down res-

taurant in his hometown of Mossyrock, Washington, transitioned to prep work and graduated from the Culinary Institute of America in 2005.

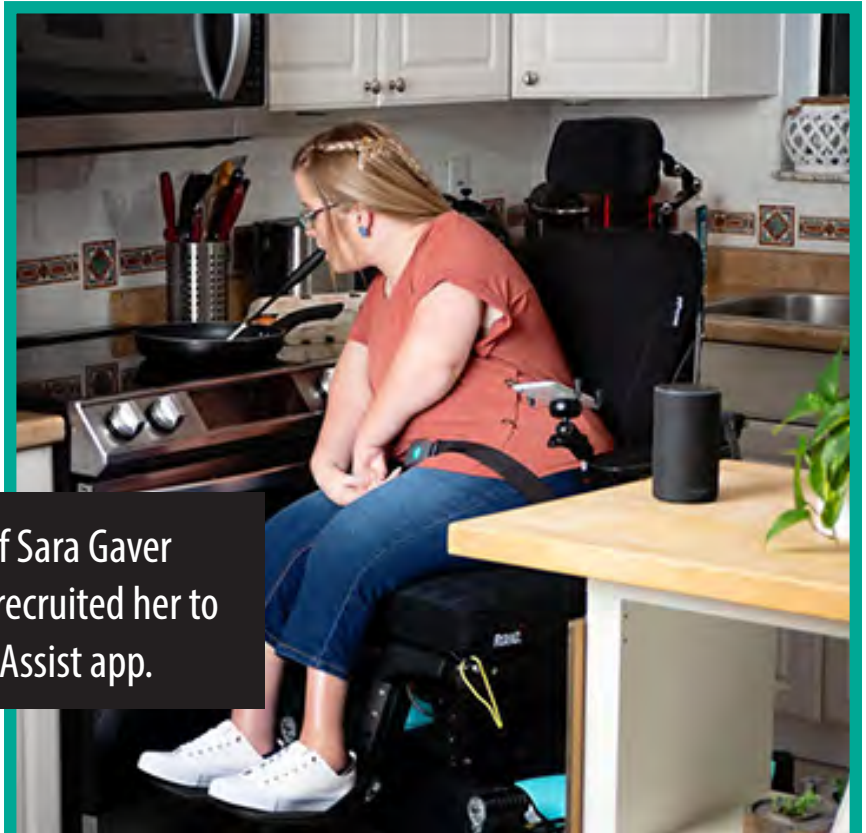
Kulp was paralyzed in an Amtrak crash in 2015 while traveling home to Philadelphia from New York, where he was launching his new restaurant, High Street on Hudson. The wreck damaged his spinal cord at C4-5, and he lost the ability to cook with his hands. Now a High Street Hospitality Group chef partner, he kicks off his weekly meal planning at a local farmers market. “I get the ideas running in my head, and we go home and start looking at each item. Then we say, ‘OK, we’re going to cook this with the lamb. We’re going to

add this. We’re going to roast this piece. We’re going to grill that.’”

## KITCHEN CONFIDENCE

Kulp’s advice for an inexperienced cook is straightforward — learn the necessary culinary terms to tell an assistant what you need. “If you have minimal ability to get in the kitchen or hold a knife or cut or chop or sauté or whatever, you have to rely on somebody to communicate that with, and you have to develop the language between the two of you,” he says.

Agreeing on a vocabulary is a great place to start, but eventually, you must get into the kitchen, and Kulp knows



When Permobil saw this photo of Sara Gaver flipping an egg on Instagram, it recruited her to star in a commercial for its Voice Assist app.



Star chef Eli Kulp shows off the peppers he grew in his rooftop garden.

this might be hard for some. “One of the challenges people with disabilities have is the fact that nothing’s going to come easy,” he says. “You just have to do it and get used to it, as painful and frustrating as the first few times might be.”

He recommends searching YouTube for inspiration. While there, you might come across Brent Poppen’s “Cooking with a Quadriplegic” videos.

A two-time Paralympian in wheelchair rugby and tennis, Poppen now works as a rehab counselor at Children’s Hospital in Fresno, California. Paralyzed in a wrestling accident as a

teenager, he dedicates his life to showing newly injured children that using a wheelchair is not the limitation they might perceive it to be. “They don’t always believe it until somebody like me is able to represent it to them and show them,” he says.

It became important to Poppen to cook well to prove to the children that they could do things they or their families may have thought they’d never do again. “So, if the kids could cook a meal for themselves, then they could wash the dishes. If they could wash the dishes, they could do the laundry. If they could

do the laundry, they could go to school.”

Poppen makes it clear that he’s a quadriplegic in his video titles so that anyone watching can understand his limitations. He calls cooking a brick in the “wall of independence” wheelchair users need to build and suggests people who feel afraid to get into the kitchen start with simple foods they enjoy eating.

“Simple” is key there. Even the biggest fan of pasta isn’t going to enjoy making fresh linguini if they haven’t honed the skill they need to make it an enjoyable experience. A box of dried pasta is fine to start with.

## TIPS, TRICKS AND TOOLS

Most kitchens aren't wheelchair accessible. So, once you have the confidence to try cooking, you'll need as many tricks as possible to help turn your kitchen into a more accessible space.

Gaver compensates for her kitchen's small size and general inaccessibility by choosing her tools well. She relies on her mouth stick and seeks out lightweight appliances she can grip with her teeth. "I picked a few appliances that I really like, like the Crockpot, the coffee pot — because I live off of coffee — and the microwave," she says. "I placed a little table outside the kitchen with those tools on it at a level that I could reach so that I could do a few things here and there just to kind of build up my skills."

Her pots have long handles, and she uses a "12-in-one chopper" to slice or dice ingredients into her desired shapes. She also buys groceries online and gets pre-cut items whenever possible.

Poppen enjoys cooking, and he and his wife love to entertain, so a friend built him a prep area that's lower than a standard countertop, with space underneath for his feet. He also has another clever hack ready.

"Have your friends over," he says. "Open a bottle of wine and make an event out of cooking the meal. That way, your guests can help with the prep tasks that are hardest for you to do. It's important not to over-complicate the meal just because you have sous chefs available, but it will add a unique twist to the typical dinner party."



**Brent Poppen uses a hair tie to bind two fingers together so he can hold and control knives better.**

## ACCESSIBLE COOKING HOPES

Poppen loves to make cooking an all-day affair. "My favorite dishes to make are the dishes that take a couple hours to simmer on the stove," he says. "Whether it's a homemade marinara or a sausage and vegetable soup, I like something I can start and tinker with and taste throughout the morning or throughout the day. It makes the house smell good, and it'll be ready to eat a couple hours later."

Gaver is an artist and loves the different colors of a good vegetable stir-fry with teriyaki sauce. "The different colors are so fun to play with in the kitchen and then stirring them around in the pot," she says. "It's one of those only meals that I literally can do everything and I don't need any assistance with any part of it, so it's one of my favorite things to make."

As far as what's on the menu for the future of accessible cooking, Kulp hopes that people with disabilities continue to

get exposure to professional kitchens. He'd like to see building developers create residential kitchens that have "a universal design where they take into account people that may be in wheelchairs," because getting into kitchens is such a big step for wheelchair users right now.

Poppen would love to collaborate on an easier-to-hold knife since currently, he binds two of his fin-

gers together with a hair tie so he can hold the handle. He'd also love motorized oven racks to help him get food out of the oven easier.

Gaver wants buttons on the front of her appliances like the big ones on her stove and would also like motorized shelves to make reaching her utensils easier. But even without these tools, she says cooking "gives me my space to have a little bit of creativity, but also be able just to have that time to do something for myself. A lot of times, those of us with disabilities feel like there's a lot of things we can't do, so cooking gives me that little bit of motivation and empowerment to take care of myself."

We all deserve that boost of confidence. So, the next time you find yourself with an empty stomach and an open mind, pull up that YouTube video, open that cookbook, root through those cabinets, and give cooking a try. **MI**

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# ARTISTS

## Their & Crafts

BY AARON BROVERMAN

### MEET THE METAL MAN

Today Jeremy Hannaford is a successful welder with his own business, Jeremy's Gimp Art and Welding. But in 2009, five years after he sustained a C6 spinal cord injury in a motocross accident, the flooring store he worked for closed, and he couldn't buy his mom a birthday present.

He decided to weld her a metal daisy as a gift, even though welding didn't go well the first time he attempted it post-injury. His dad had recently acquired a welder, and Hannaford tried it out. "It was terrible," says Hannaford. Using the welder required pulling a trigger, which proved difficult with his quad hands. "My positioning was totally off, so I'm leaning way over in my chair trying to hold onto this thing and not fall out. I did a couple of little welds, and they looked like boogers all over the place."

He felt defeated.

But having to come up with something for mom's birthday makes desperate men do desperate things. So, Hannaford tried again. This time, he rolled under the table and put his elbows up, which provided enough stability for him to hold the welding gun with both hands. With his dad's help, he pulled off some decent welds — cutting the flower out, grinding it clean and



"What a nondisabled person does with their two hands and feet, I have to figure out with two nonworking hands," says Hannaford.

putting it all together.

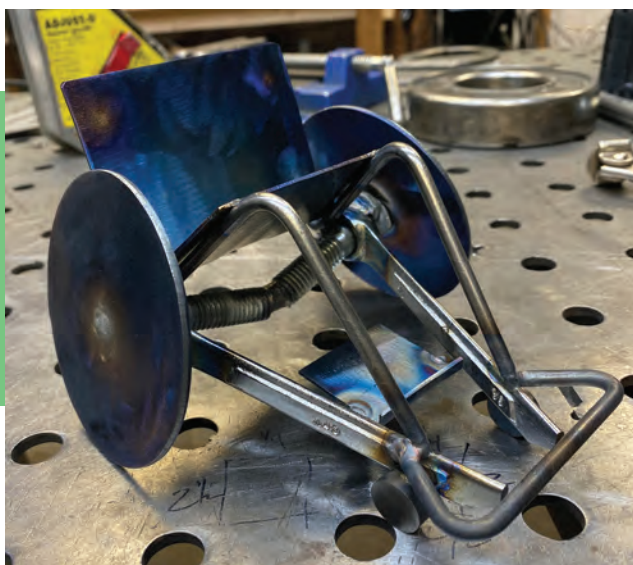
"Mom absolutely loved it," he says. "We have a close, big family, so everybody else who saw it was super impressed that I used the function I have to make something my mom could buy at the store. It motivated me to start messing around with junk metal."

Messing around quickly became something more, and today Hannaford's business plan is built on turning junk metal into art for paying customers. Among his many creations

are wheelchair rugby and handcycle trophy toppers, name signs, shooting targets, BBQ tool hangers and furniture. The Bremerton, Washington, man even made a didgeridoo holder in the shape of Mount Rainier, the tallest mountain in his state. While he has always had a knack for drawing, when it comes to metalwork, he is completely self-taught, learning through countless welding videos on YouTube and good, old-fashioned trial and error.

"Right now, I have a fixture table, so I can put clamps inside of it and clamp down the pieces of metal I'm going to weld. Whether I'm using a TIG welder or a MIG welder, I'm able to take two pieces of metal and burn them together," he says. "I'm probably one of very few TIG welders in the world that's a quadriplegic."





Hannaford draws inspiration from all over, including his passion for wheelchair rugby.

TIG, or tungsten inert gas, welding uses an electric-powered torch with a non-combustible tungsten electrode to create an arc between the base metal and the electrode. The torch pumps inert argon gas to protect the electrode while melting filler metal into the line it burns. That filler becomes part of the final project as the metal surfaces fuse together. A MIG, or metal inert gas, torch uses a feed wire instead of filler metal.

Typically, a TIG torch is powered with a pedal near the welder's feet, but Hannaford's is attached to the top of his welding table. He holds the torch in his right hand, the filler metal in his other hand and uses his left elbow to push the pedal.

"What a nondisabled person does with their two hands and feet, I have to figure out with two nonworking hands," he says. Using old car parts and tools to create the ideas people have in mind is a slow, methodical process, but Hannaford is eternally grateful that his skill and passion allow him to make a living on his own terms. "[The creations] are definitely not



big moneymakers. But they keep me busy, and people love art, so it kind of works out," he says.

## FOOD FOR SUGGESTIVE THOUGHT

When Gina Schuh began posting her "Eat Me Collection" of paintings on Instagram, she received outraged comments along with compliments. The series depicts neon-colored food like strawberries, hot dogs and tacos dripping with goo and eaten or handled in sexually suggestive ways. She took the comments as a sign to keep creating and challenging the status quo.

"Why can a nondisabled woman post sexually suggestive content of themselves, maybe topless, and I can't paint a cantaloupe with someone poking a finger in it without somebody getting offended? We've got to ask ourselves why that is," says Schuh, a C5-6 quadriplegic from Mesa, Arizona.

It wasn't just Instagram followers getting offended. A printer she'd already paid \$1,000 refused to print her work because they said it was pornographic and embarrassing. Plus, her sister's neighbor, an artist herself, admitted to Schuh that her art makes her uncomfortable.

"Part of me is cool with that," she says. "I'm like, 'You have to ask yourself why you're uncomfortable with my cantaloupe.' Besides, I want my art to make people feel things. Other people are excited by it, and they love it. As an artist, it couldn't be more of a compliment for it to be controversial."

Schuh wants a conversation about why so many people still have trouble wrapping their minds around the concept



Schuh's art ranges from the erotic "XXXtra White Chocolate" (above), to the more mundane "Almond" (left).



“My life is very colorful, and I want that to be portrayed in my artwork,” says Schuh.



Sendelbach derives great pleasure from crafting her unique creations.

that disabled people have sex. She also knows that sex sells, and tackling such subject matter helps her popularity and grow an Instagram following.

Not bad for someone who took up painting during the COVID-19 pandemic. “I realized that my writing looked pretty nice since I was taking a lot of notes for school. When I wasn’t taking notes, I was doodling, and my doodles looked good, so I thought I’d give painting my first serious try since before my injury,” says Schuh.

She discovered she doesn’t need adaptive equipment to get back to a professional standard. Instead, she adjusted her artistic technique to her post-injury capabilities.

“I used to do a lot of landscapes before I was injured, but now I don’t do so many because they take me three times as long. I also work a lot smaller than I used to because it’s easier for me to rotate the canvas,” she says. “Thankfully, I have a steady hand, so I just thread the brush through my fingers. I want to get into pinstripping wheelchairs in the future.”

If you look closely, you can see her paintings consist of several lines and deft use of negative space. The other elements that stand out are the extremely bright colors.

“Every artist wants their art to represent them. I’d like to think I’m a vibrant, outgoing, bright person. My life is very colorful, and I want that to be portrayed in my artwork,” she says. “People ask me where the inspiration for the Eat Me Collection comes from. Well, duh, it’s my two favorite things — sex and food.”

## CRAFTY TREASURE MAKER

Carol Sendelbach is passionate about crafting. Since developing complex regional pain syndrome from surgery complications, she has tapped into that passion to find happiness and deal with the pain that comes from her disability.

She takes orders from her website — [thestylishdragon.com](http://thestylishdragon.com) — or her Facebook Page, The Stylish Dragon Treasures. “I’m a

workaholic who can’t sit and watch TV without doing something,” says the Auburn, California, woman. “That’s what brings me joy.” Her fiancée built a desk that’s high enough for her wheelchair to fit under and supplied her with rolling tables she could move in and out of the way to make it easier to do her crafts when she’s able.

So, what does she make? The answer is anything that’s currently trending in the crafting world that she can pull off, including decorated acrylic shot glasses, resin-wrapped pens, pen stands and tools for other crafters who decorate pens.

“I’ve sold over 200 of my Pen Twist ‘n’ Stands that help other crafters decorate these pens. It’s hugely popular in the crafting world,” she says. “I belong to a lot of crafting groups, so I see what people are doing, and if I’m interested in it, I try it by studying a lot of YouTube videos.”

She also credits her business coach with helping her capitalize on those projects that are most likely to sell. As a result, Sendelbach has a small source of income and an important outlet to take her mind off her pain.

“Creatively and mentally, crafting takes me out of the moment as far as my pain and concentrating on what I cannot do,” she says. “It allows me to put a bubble around my pain because I want to get what I’m doing done.”

## RESOURCES

- Jeremy Hannaford’s Gimp Art and Welding, [facebook.com/JEREMYSGIMPART](https://facebook.com/JEREMYSGIMPART)
- Follow Jeremy on Instagram, [@jeremysgimpart](https://instagram.com/@jeremysgimpart)
- Inside Gina’s Head: The Homepage of Painter Gina Schuh, [insideginashead.com](https://insideginashead.com)
- Follow Gina on Instagram, [@insideginashead](https://instagram.com/@insideginashead)
- The Stylish Dragon: Carol Sendelbach’s Online Store, [thestylishdragon.com/links](https://thestylishdragon.com/links)
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*Spiritual connection can be found anywhere, whether in a church, synagogue, at the top of a ravine or in a Facebook post. These four wheelchair users share where they find it, how they recognize it, and how it sustains them.*

BY JOSIE BYZEK

# *a spirit runs through us*

## **If All Works Out**

Traveling through New Zealand was like moving through a dream, says Ashley Lyn Olson, a T12 para. She explored the island's national parks in 2020 for her website, [wheelchairtraveling.com](http://wheelchairtraveling.com), and missed the start of the pandemic. "I was oblivious to COVID," she says. "I was so happy to be there I wasn't paying attention to the news."

The day before she left, she picked a random lake to explore in her rented car. This serendipitous choice led to danger and a profound spiritual experience.

After an hour bouncing along a one-way rutted dirt road, Olson reached her destination, and it was lovely. "As I left the lake, the road curved down and to the right. There were no tracks, only slick rocks, and I didn't have 4-wheel drive," she says. The car slid back and forth, and she struggled to avoid the deep ditches on both sides of the road.

Eventually, she hit the left-side ditch, lost control, and rolled to the bottom of the ravine. "I remember flying in the air and feeling very calm, thinking, 'OK, this is happening.' Then I blacked out momentarily and came to with the car still rolling and the passenger window above my head."

Once she stopped, she did an inventory. She

seemed uninjured, the car still worked, and the airbag didn't deploy. There was no cell reception, and she was alone. "I screamed for help a couple of times just for kicks but knew I had to get myself out of there."

After a harrowing search for a way out of the ravine, Olson left her chair and vehicle behind and crawled up using the deeply rooted grass as a rope. On the summit, "I said a little prayer of gratitude, looked up and saw two hawks circling above me. I think of my dad when I see hawks, so I knew I would be OK."

She realized no one could see her through the road-side brush, so she crawled toward the road. She saw a shed and a barn and knew that someone would eventually find her even if she had to spend the night. Thankfully it didn't come to that.

"I was almost at the road when I heard a car, so I screamed, 'Help! Help!' and waved my bag in the air. The car stopped, and four people came running over. I didn't want them to worry I was injured since I was crawling through a meadow, so I yelled, 'I'm OK! I'm paralyzed, but I've been paralyzed for 20 years, and that's why I'm on the ground!'" With their assistance, she made it back to her hotel and



*all*



Olson

*“I think about the dirt, worms, drops of water, our sun, solar system, and the universe. Life is unfathomably infinite, and we must appreciate all of it to really see it.”*

saw a doctor the next day before catching her flight.

Olson was filled with joy and trust that everything would work out after what could have been a terrifying ordeal. She credits her wide-ranging approach to spirituality that includes a life-long connection with nature,

Eastern mindfulness philosophy, Christ’s love and even quantum physics, among other influences, for her positive reaction to a dangerous situation.

“The strongest thing that someone can do sometimes is not do anything. Be completely still,” says Olson. “Just be silent and see what comes up. Don’t get stressed about it. If you have to go to the bathroom or a test is around the corner or a job, see these thoughts, accept them and allow them to pass and to float away. Whatever you’re in is what is meant to be. There is a purpose for all.”

Olson stresses she is not advocating to accept platitudes like “this, too, shall pass” at face value. She heard that a lot from well-wishers after becoming paralyzed at age 14. “I knew I was *going to be* OK, but I wasn’t OK at that moment, so these words provided no comfort or insight.” But years later, while hospitalized due to pressure sore surgery, she read *A New Earth* by Eckhart Tolle, and realized this phrase means that *everything* will pass, bad *and* good. This resonated. “Reflecting on these words lying in a hospital bed, not able to do anything but think, opened me up to a new level of appreciating life.”

Understanding this fundamental truth about the nature of change helped her focus on positive moments. “I chose to see the good, no matter how small or seemingly insignificant,” she says. Eventually, that difficult period in her life did, indeed, pass. “Oddly, though I was ready to go home, a part of me was also sad to leave. I saw the good in the experience of being hospitalized.”

It sounds paradoxical but knowing even deep joy is transitory allows Olson to feel it more intensely. A flower may cause her to spontaneously laugh with pleasure and meditate on all that must happen to make that one plant grow. “I think about the dirt, worms, drops of water, our sun, solar system,

and the universe. We are spinning on a rock of fire and water surrounded by countless other galaxies filled with forever-evolving rocks. Life is unfathomably infinite, and we must appreciate *all* of it to really see it.”

## Holy Coincidences

Sure, it’s kind of funny now, but back when Aaron Broverman was in college, he passed as being able-bodied enough to participate in a Birthright Israel tour. That’s a free trip for Jews between 18 and 26 who want to connect with their roots in the Holy Land. There’s a Birthright for disabled Jews as well, but Broverman, a journalist with cerebral palsy, didn’t know that. And he didn’t want to miss his shot at using his cub reporter skills to get to better understand Israel’s relationship with Palestine.

First, Broverman had to prove his Jewish credentials, which was easy. “People can go even if they think they’re Jewish but are not quite sure, so they want to know how are *you* Jewish,” he says. Then he had to demonstrate he could walk independently. “So, I dropped my forearm crutches and walked to the end of the room, and they were satisfied.”

He made it to Israel and thought he was doing well keeping up with his nondisabled peers when he realized an Israeli soldier about his age was nonchalantly tagging along with him. The next day one of the Birthright leaders pointed out that he was the last person to get everywhere, and they needed to keep things moving.

“Are you kicking me out?” he asked. “No, no, it’s totally fine,” they said.

“They were saying, ‘You’re too disabled,’ without saying it. They got a guy, Isaac, and he became my buddy for the rest of the trip. He was the Aaron minder, and he pushed me around in my manual chair that fit under the bus. I should have been on



Broverman

the disabled trip, but I was proud I snuck through. I didn't crack the case of peace in the Middle East, but it was a really cool experience."

The trip brought Broverman closer to his religion, although he calls himself a liberal Jew who only observes high holidays. "The thing I like about Judaism is that it seems founded on debate. It is self-aware enough to realize it doesn't have all the answers. Jews are much more into keeping their circle small and special rather than, 'let's get as many people as possible to believe what we believe.' I like that way better," he says. "It's not a weapon to be used against people. It's a very Jewish thing to think, 'Ehhh, maybe you're right. I don't believe what you believe, but I'm not going to fight about it.' It's a much more peaceful thing than, 'No, you're wrong!'"

Recently Broverman moved his young family from Toronto, Ontario, to nearby Waterloo, so his toddler son, Wells, would be close to his wife's parents. "There's a Jewish community here, but it's really small. During the pandemic, they had Zoom-style meetings, and I introduced myself to them. Being a dad changes what I think because now that I have a kid, do I want to introduce him to Judaism? If so, how much? My wife's an atheist, so if he's introduced to any religion, it's going to be mine."

So, what does he believe? "I pay attention to what people call coincidences, and I don't think of them as coincidences. They are little, small moments that I take as symbols — 'oh, that's of God. It wouldn't have happened without some divine intervention.' I don't think of God as a dude in a robe in the cloud. I think of God as positive energy pushing you toward good things in your life," he says. Broverman notices that often when bad things happen, they tend to lead to something down the line that he'll get a lesson from, or perhaps to something good that wouldn't have materialized if the bad thing hadn't happened first.

"Even though we have free will, there's a force guiding us in a generally positive direction," he says. "It's having faith that there's something more out there, that we're not just going to die, and it's lights out. Maybe that's naïve, but I'd rather than thinking your life means nothing."

*"I don't think of God as a dude in a robe in the cloud. I think of God as positive energy pushing you toward good things in your life."*

## Those Moments of Joy

Shameka Andrews is a busy woman. She's a community outreach coordinator for the Self-Advocacy Association of New York State and a volunteer for what seems like a myriad of other projects, including her state's Ms. Wheelchair program. She stays grounded by taking time each day to create and post a gratitude list she calls "Today's Favs," like so:

- Remembering to stay hydrated
- Working on getting rid of inflammation
- Stress Less Workshop
- Boneless ribs
- Home delivery

*"It brings me joy when I'm able to notice the simple things and the different ways that God moves in my life."*

Photo by Colleen Ingerto



Coming upon Andrews' list in a newsfeed is a nice break from the doomscrolling so many of us engage in. Yes, remembering to drink a glass of cool water is restorative. And truly, home delivery has saved us all during these pandemic-cursed days.

Andrews' list evolved from a gratitude journal she kept when she was in her early 20s and lived in her parent's inaccessible home, located in an inaccessible neighborhood.

"The year I decided to move out of that neighborhood was one of the hardest," says Andrews, 43, who has spina bifida. "I moved into a residential community with nine other people of various ages, which was a challenge in and of itself — 20-somethings and 50-somethings in the same house." She also enrolled in college and got her first job.

Today, Andrews lives in an apartment in downtown Albany, New York. She reconnected with the spiritual discipline of practicing gratitude when she turned 40. She'd joined a daily celebration Facebook group and decided to celebrate her birthday for 40 days. "It turned into a year," she says. As part of that celebration, "I looked at how I go about my day and noticed that I tend to shift my attitude or energy depending on who was around me, and I was allowing negative energy to affect me. My favs list is how I snapped out of that."

She loosely structures her list around the five senses: things seen, tasted, heard, smelled or touched. "It just brings me joy when I'm able to notice the simple things and the different ways that God moves in my life," she says.

Perhaps gratitude comes naturally to Andrews since she understands spirituality is not about a place or specific activity. "I can have a spiritual experience in a church or sitting in my living room barefoot listening to Bon Jovi," she says. "It's all about the energy of the activity, and how it affects me is my spiritual connection to God, the universe, love, whatever it is you want to call it."

She especially finds God in moments of joy. "And they can look like many things ... getting an unexpected check in the mail or watching birds outside my window appear every morning. Seeing those little birds makes me forget I'm in a big, huge city." That joy bubbles up when she sees a rainbow or children playing in a park and distracts her from becoming weighed down by violence happening somewhere in the world or shootings closer to home or discrimination she may face. "Those moments are when I can realize there is beauty under all the things we might perceive as ugly in the world."

Don't mistake Andrews' positivity for naivete — she knows who she is, what she believes and plots her own spiritual course. "I've had a few experiences in religious settings where healing circles and similar things made me feel 'less than' at the time because the outcome that people in the room wanted didn't happen," she says. She's learned she doesn't need to adopt anyone else's views of spirituality, religion or success. "It's OK for me to have my own path and live my own life. I know what my relationship with God is and the messages I get from him daily, and I don't need anybody else's approval."

Andrews attends a Unity church, where many in the LGBTQ community find a spiritual home. "I like the Unity tradition because it has different views than the stricter Bible readings found in many other Christian denominations," she says. For

example, the Unity tradition teaches that if God is omnipresent, then that means God is within each of us as well, and that bit of the divine seeks to be expressed.

Perhaps this underpins Andrews' recognition that people will believe whatever they believe, and it's not for her to change their mind. "There are better ways to use my energy. I just want to live my life and be an example of a person that is living with a disability," she says. "I don't need anybody's approval of what that looks like."

## We Are One in the Spirit

When our editor emeritus Tim Gilmer was 14, he began acting out. He and his friends ran around in their small hometown of Wasco, California, breaking windows and generally being menaces. Eventually, their moms roped them into taking a confirmation class at their church in hopes of taming them. Which is how young Gilmer found himself plopped in the pews on Maundy Thursday, a ceremony commemorating Jesus' Last Supper.

"I was a terrible Bible student, and I was surprised during the confirmation ceremony when this peaceful feeling came over me. I wasn't expecting it," he says. "It was an extreme calm, a feeling that everything was right, and I was where I was supposed to be." He didn't have that feeling again until he was 25, five years after the 1965 airplane crash that took his friend's life and caused his T11 paraplegia. He had become filled with bitterness, and before he realized it, he was deep into an addiction-fueled paranoid psychosis. Trapped in his parents' home, he had nothing and couldn't imagine a future. He felt God was distant and indifferent to his suffering — if God existed at all.

Finally, desperate, he let it all go and pleaded for relief.

"I broke down and cried and



*"The older I get, the more I think we are connected, all of us, in a spiritual way. But some of us are not aware of it. I know I wasn't for a long time. Just how that shared spirituality works is beyond me to understand."*



prayed and begged God to help me. I felt totally lost and thought I was dying or maybe had already died, maybe even trapped in a hell of my own making,” says Gilmer. “All of a sudden, this calm washed over me, the same calm as when I was 14 but hadn’t felt since then. It felt like God was telling me everything would be OK. I could only attribute it to the Holy Spirit, and for me, it came from Jesus; his presence was with me. That helped me get through that terrible time, and it has always stayed with me.”

He feels that presence in times of profound joy as well, like when he and his wife, Sam, adopted their daughter. “When we brought her home, just one day old, we were overjoyed because the adoptive mom who couldn’t care for or provide for her baby had chosen us to raise her as our own. That was tremendous joy when she came into our lives, and we thought God was part of that process.”

A peaceful joy will also come over him sometimes when he is in a special place in nature, like the ancient redwoods or seeing a formation of geese flying over. “A lot of it has to do with nature for me, I connect it to God’s creation. It’s not just this wonderful place in the forest or birds chattering. This is what God created, and he wants us to enjoy it and take care of it. That fills me with joy.”

It’s not about being devout, as Gilmer doesn’t think that label fits him. It’s about recognizing how all creation is interconnected — including you and me. “The older I get, the more I think we are connected, all of us, in a spiritual way. But some of us are not aware of it. I know I wasn’t for a long time. Just how that

shared spirituality works is beyond me to understand.”

In college he was attracted to the essays of Ralph Waldo Emerson and the idea of the Over-Soul — that every individual is eternally connected with every other living thing in the universe, and also to nature. Now he likes to focus on a calligraphic work of art hanging on his wall created and given to him by the wife of his pastor, using the words of Teresa of Avila: “Yours are the only hands with which He can do His work. Yours are the only eyes through which His compassion can shine forth upon a troubled world.”

Gilmer has honored this interconnection by organizing a local church group and others to establish a Habitat for Humanity chapter in their area. These days he is involved with his church’s latest project, an international mission to address the need for better health care in a poor nation. “Right now, I’m helping write a fundraising brochure to help build a hospital in Sierra Leone. “My pastor, my friend, asked me if I could take something he had written and maybe make it better. It fills me with joy and gratitude just to be involved.” They will use the materials to raise money from both inside and outside the church to accomplish its goal.

Following Jesus and belonging to a church is Gilmer’s path, but it’s not for everyone. He recognizes there are many roads to spirituality but cautions against getting lost in relativity – or the idea that there’s no absolute truth. “If there’s one thing that’s absolute to me, it’s that God is Love,” he says. “And if we lose that, I don’t think I want to even be here.”

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# Spirituality, Psychedelics & SCI

BY BOB VOGEL

**T**hree years after becoming a C5 quadriplegic, Karl Lewis felt lost and out of touch. “I felt the SCI took away my complete identity,” he says. “All of a sudden, I was consumed by ‘I can’t do this.’ I was focused on what I had lost; specifically, the freedom to do all the activities that provide that dopamine-feedback reward you get out of living.”

In his quest to rediscover his pre-injury excitement and joy, Lewis investigated psychedelics. He experimented with psilocybin and LSD and found the mind-expanding benefits he’d hoped for and more side effects than he wanted. “They reframed my mindset and helped me appreciate and find joy and excitement in things I was already doing,” he says. “However, the length of the trip and the adverse side effects were way too much — too much spasticity and difficulty with body temperature.”

Seeking something with the same benefits but fewer draw-

backs, Lewis turned to the hallucinogenic tryptamine DMT, short for N-dimethyltryptamine. “When I exhaled after the third hit of DMT, I was blasted through a multi-colored tunnel and laid out on an altar in a huge dome, covered with geometric figures and outlines of Zeus and Poseidon. There was a higher being in control. I was just there — no thoughts, no internal dialogue. I shifted through more tunnels, which led to multiple experiences ranging from walking in the gentle surf on a beach to looking up from my own grave. In the last experience, several female humanoid creatures gave me a big hug, and the trip was over. I was back in my body.”

The psychic journey seemed several lifetimes long to Lewis, yet only 12 minutes elapsed. It left him feeling grateful and more aware. “The trip gave me a profound sense of introspection that was so spiritual,” says Lewis, now 37. “I thought if

# guide to psychedelics

**Ayahuasca:** A hallucinogenic drink made from plants native to South America that produce a psychedelic experience lasting four to six hours. It has a slow come-up, peaks and plateaus, and slow comedown.

**DMT (N-dimethyltryptamine):** This naturally occurring hallucinogen can be found in plants and animals and reproduced synthetically. It has a rapid onset, intense effects and a relatively short duration.

**Ibogaine:** This potent psychedelic is made from the root of the African iboga shrub. Experiences are described as intense and can last up to 12 hours. It is frequently used as a one-time detox for a range of drugs, from opiates to tobacco and alcohol.

**LSD (lysergic acid diethylamide):** This synthetic hallucinogen is made from a substance found in ergot, a fungus that infects rye. Effects begin within 20-90 minutes and last up to 15 hours.

**Microdosing:** Taking a very low, sub-hallucinogenic dose of a psychedelic drug (like LSD) may improve mood, induce physical and mental stimulation, and encourage creative thinking without producing full hallucinations.

**Psilocybin:** This naturally occurring psychedelic compound found in certain species of mushrooms comes in natural and capsule forms. Effects kick in about half an hour after taking and last approximately four to six hours.

Getty Images

this is anything like what true believers gain from going to a church, I get it. I can see why people seek out religion.”

For thousands of years, indigenous cultures have incorporated the psychedelic powers of plant medicines in their religious practices to find spiritual connections, healing and guidance. Since the 2000s, there has been a resurgence of research into these substances by the scientific community, studying everything from their ability to help with depression and trauma to chronic pain to acceptance and comfort with death in terminal cancer patients.

This research, along with a growth of popular literature and culture investigating the possible benefits of psychedelics, is softening long-held stigmas and resulting in more people following Lewis's tracks. In addition to increased spirituality, self-reflection and inner knowledge, psychedelics offer many benefits with extra appeal for people living with SCI/D trying to accept and reframe a new, often physically-limiting reality.

To find out more, I interviewed psychonauts with varying levels of SCI and experiences with different drugs about what drew them to psychedelics and what they experienced.

## A New Way to Adjust

Like Lewis, Jason Holdahl struggled to adjust after a diving accident made him a C6-7 quad. “About eight years after my injury, I was going through a lot of emotional pain from the frustration of being paralyzed, and I was taking this out on my family and drinking more than I should,” says Holdahl, now 46.

As part of his search for ways to change his mindset, Holdahl read

Michael Singer's *The Untethered Soul*. Singer's book offers a step-by-step guide to help readers understand their emotions and actions and change for the better. “I read it, and it seemed like psilocybin would put me on a spiritual path to ease this pain,” he says. He hadn't tried psychedelics before his injury 13 years ago, so he started slowly with microdosing (see sidebar). “Spiritually, psilocybin removed my ego and enabled my spirit and heart to control my thoughts,” he says. “The journey gives you lessons, whether you want them or not, and unlike reading a concept or lesson in a book that may stay with you for a week or two and fade, this knowledge becomes part of you.”

His experience with psychedelics catapulted him into being present in the moment and helped him not get bogged down with trivial things. “I'm much more present and in the moment for my kids, my family, and my life,” he says. He also credits the experiences with removing his interest in drinking alcohol. He has only done psilocybin four times since his initial trip. “I try it when I come upon an idea or a concept from a self-help book about processing emotions or healing that I want to explore in-depth.”

Both Holdahl and Lewis warn that psilocybin use can produce severe muscle spasms, including muscle-tightening spasms around the ribcage to the point where breathing becomes difficult, especially for a quad. “When I do psilocybin, I plan ahead and lie down on a surface that protects my skin, which makes breathing easier,” says Holdahl. “The spasticity is so much that it causes me to heat up, so I have a fan blowing on me and



Jason Holdahl credits psilocybin for his spiritual awakening.

a tub of cool water in case I get too hot.” For Lewis, the spasms and overheating created so much discomfort and potential danger that they outweighed the benefits of psilocybin.

## A Trip-worthy Cocktail

Dave Moore used psychedelics recreationally in his teens but found the spasms to be too painful when he tried after his SCI. Moore, 60, and now in his 41st year as a T3 para, reembarked on his psychedelic journey while working to process rage caused by childhood trauma and the many impacts of SCI on his daily life. “I was in service of my ego and needed to prove to the world I could work within the ‘norm,’” he says.

In 2015 he traveled 30 miles down a river to a Peruvian village in the Amazon rainforest for a shaman-guided series of journeys while taking ayahuasca. Ayahuasca is a hallucinogenic drink made from native plants that produce a psychedelic experience lasting four to six hours. It has a slow come-up, peaks and plateaus, and slow comedown. “For me, a longer trip gives me time to integrate the experience,” says Moore. He explains that, like other psychedelics, ayahuasca causes spasticity, but not as much as psilocybin.

Moore participated in a three-night ceremony with a group of other people, sitting on the floor of a yurt. “They give you a cup of ayahuasca, which is about an ounce of bitter-tasting liquid, sort of a dandelion taste,” he says. “You sit there, and the shaman starts singing the Icaro medicine song. When the ayahuasca took hold, it felt like there was a massive tree in the middle and we were all lying in the roots of the tree, fully held, fully nurtured.”

The ayahuasca took Moore through traumatic events in his life — whether he wanted to visit them or not — in a way that was so real it was as if he was re-living it. He found the experience more beneficial than his time with western therapists. “If you are open to doing it, you can get about 20 years of psychotherapy in about half an hour of an ayahuasca trip, but it is extremely intense,” he says. “When the journey was over, my trauma never came back. The ayahuasca and ceremonies helped me find my place in the universal field and that I am part of the universe, just as we all are.”

Since his Peru trip, Moore has participated in two more ayahuasca ceremonies. “After the third time, I felt that the drug had enabled me to complete the psychological and spiritual work I needed, and for now, I don’t see a reason to do more,” he says.

Ayahuasca is a regular part of Scot Hollonbeck’s life since he discovered its benefits on his own 2016 trip to Peru. After a long career as a wheelchair athlete, he felt something was miss-

ing as he approached his mid-40s. “When I retired, the need for something more and the need to reconnect with nature became louder, and football games and booze and work wouldn’t silence it or fill the void,” says Hollonbeck, now 51 and in his 37th year as a T10-11 para.

He started working with a shaman in 2013, and after partaking in various ceremonies, practicing holotropic breathing and a vision fasting, he booked the retreat to Peru. “My first experience with ayahuasca was hands down the most amazing experience of this lifetime, without a doubt,” he says. “I had a realization that I’m not this body, and I’m not these thoughts — I’m a spiritual being. I’d never defined myself first and foremost as a spiritual entity. I came away from the experience with the understanding that it’s all OK; I don’t have to be tied to anything in life. If something is bugging me, I now see it is a choice whether I let it bother me or not.”

He points out that, like all psychedelics, not all experiences are bliss. “I’ve had experiences when the ayahuasca came on, and I freaked out,” he says. “I felt I was going to die. Some people have total 100% bliss, and others have terrifying experiences.”

Still, the benefits keep Hollonbeck coming back. He schedules the ceremonies four times a year, usually around the solstices and equinoxes. “Each time I take ayahuasca, I find it to be a profound spiritual experience. It is a reset for the brain, like defragging the hard drive, and each experience teaches me something new about myself and connections with the universe.”

## A Solution to Pain

As the facilitator and cofounder of Flor De la Vida Retreat, Pete Aviles offers guidance in various psychedelic plant medicines, sound healing and breathwork. A T11-12 paraplegic, Aviles realized he had grown addicted to prescription opiates about seven years after his accident. Instead of relieving the pain, they were making it worse. While searching for detox options, he saw a documentary called *Right of Passage* about ibogaine (see Resources), a psychedelic made from the root bark of the African iboga shrub that enabled people to break free from ad-



Dave Moore says ayahuasca helped him process childhood and SCI trauma.



diction in one 10-hour psychedelic journey.

Aviles already had considerable experience with recreational psychedelics and decided to travel to Mexico to do a session with an iboga facilitator. Before being accepted for a journey, he was required to undergo a physical, including bloodwork and EKG, because iboga is extremely taxing on the body. "The entire 10-hour iboga journey was very intense and forced me to face memories that I had repressed and didn't want to deal with," he says. "The medicine taught me some brutally hard lessons, which seemed appropriate as part of a detoxing package."

The comedown from the trip was quite rough because he was detoxing. "The next day, I was brought to tears, as if I had just ended a terrible relationship, the relationship with opiates," he says. "I wasn't sick — no withdrawal — I had no craving, no post-opiate depression. It vanished in one 10-hour session. I haven't had an interest in opiates in 10 years." Since the experience, his pain has diminished, and there is no longer any emotion around it. "Psychedelics changed the way I dealt with my injury by changing my relationship with pain, enabling me to detox from opiates and discover a spiritual connection to everything and everybody," he says.

At Flor De la Vida Retreat in Mexico, his guidance includes addressing DMT-containing substances. Aviles cautions that DMT is one of the psychedelics that takes you furthest into the experience. It can be a positive and touching experience but can also be scary and unsettling, with a way of waking up old traumas. He also says it can cause intense spasms in people with SCI. Like ibogaine, it is important to have a check-up for general health and potential heart or breathing issues before trying it.

## Proceed with Caution

Despite the surge in interest, researchers have yet to include people with SCI in significant trials of psychedelics, so much of our knowledge of benefits and dangers for people with SCI is limited. Anecdotal evidence suggests the substances work similarly on people with SCI/D but can cause a range of physical side effects not experienced by nondisabled people. The side effects appear to change or intensify with higher level of injury and can include severe increases in spasticity, overheating and the possibility of autonomic dysreflexia.

"Everybody is different when it comes to psychedelics," says Holdahl. He adds that some people are more prone to a 'bad trip' when the psychedelic brings something



Pete Aviles is the cofounder of Flor De la Vida Retreat.

"Psychedelics changed the way I dealt with my injury by changing my relationship with pain, enabling me to detox from opiates and discover a spiritual connection to everything and everybody."

up they don't know how to deal with. A bad trip can be terrifying but breathing techniques and a developed ability to let go and not fight may help ease it. "I think it is very important to do the reading and develop the tools before trying psychedelics," he says.

Lewis recalls a mixed experience he had in college when he ate some magic mushrooms and drove his powerchair across campus to a party. "The

first two hours were wonderful, my acute awareness of people looking at me and my power chair, and self-imposed 'physical barrier around my chair' and my social anxiety melted away," he says. "Little things became miraculous, like a glass of cold water — the texture, temperature and taste were absolutely amazing."

Then the trip became too intense. Lights and music became overwhelming. He got motion sick while driving his chair back to the dorms and stopped every 20 feet to throw up. Once safely in his

dorm room, he watched concert footage and began to recover. "I was coming down around dawn and starting to overheat, so I went outside," he says. "The sunrise was the most beautiful thing I had ever seen."

Psychedelics are not for everybody. Most of the people I spoke with suggest if you are curious, try microdosing something like psilocybin. Starting with a full dose and realizing it is not for you can be terrifying, as there is no way to stop it, and your only hope is to ride it out. As Lewis puts it, "Do not try to jump in with a [huge] dose with anything. You have to have respect for these substances and what they bring. Done right, they can bring a great understanding of oneself, and one's position in the world."

"Prior to doing psychedelics, I was so fixated on being independent I would never let people help me, to the extreme point where I would rather struggle for five minutes trying to do something rather than let a friend or co-worker step in and do it in about 10-seconds," he says. "Psychedelic experience enabled me to let go of that. I no longer have to prove to others how independent I am."

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## Resources

- Flor De la Vida Retreat, [flordelavidaretreat.com](http://flordelavidaretreat.com)
- Holotropic Breathwork Benefits and Risks, [verywellmind.com/holotropic-breathwork-4175431](http://verywellmind.com/holotropic-breathwork-4175431)
- Ibogaine – Rite of Passage, [youtube.com/watch?v=vt0E8N4FRFY](https://www.youtube.com/watch?v=vt0E8N4FRFY)
- Ibogaine Treatment Study, [pubmed.ncbi.nlm.nih.gov/28402682](https://pubmed.ncbi.nlm.nih.gov/28402682)

"I had a realization that I'm not this body, and I'm not these thoughts — I'm a spiritual being," says Scot Hollonbeck.

# How Rediscovering My Sexuality Taught Me to Accept My Post-Disability Self

BY KELSEY PETERSON

We're all born with an essence that we carry into the world, pieces of our spirit that are innately us. For me, I came with a passionate, look-harder, reach-higher, take-the-little-blue-pill-and-see-what-happens kind of spirit — a curious and daring nature.

Fortunately, my exploratory spirit was grounded in a strong foundation of love in a household that I trusted. There wasn't that common glaze of shame that many of us have endured and absorbed throughout our lives, especially as sexual beings. Somehow, thankfully, I grew up largely unscathed by any trauma which could have dampened parts of my curious nature. I was lucky, and more so, privileged. Only since my injury have I realized that something as vital as my sense of self, personal power and sexual prowess could be quickly squashed, not only by the loss of my body and my independence but also by feeling unseen.

I suppose I was an early bloomer. I started exploring when I was probably in second grade. Well, let's be honest, I was playing "doctor" with friends before that and got busted with my friend Nikki once — her mom caught us giggling and diddling in the closet. But what I remember most was my mom talking about it with me on the way home and how kind she was about the whole thing. She made it abundantly clear that she didn't want me to feel bad about anything. There was no shame, fear or manipulation. I remember her reassuring me that it was OK, that there was nothing wrong with it. I felt so loved in that moment.

As I got older and more curious, I had a great time exploring. This form of self-exploration was fun and exciting. I was the master of my pleasure. It

was eye-opening, healthy and built my confidence and identity as an independent, empowered young woman. By the time I was 27, I'd relished a liberating and fun sex life for over 10 years. I'd been clocking orgasms and connection through physical intimacy for even longer. I loved my sex life. And as a dancer and yoga teacher, sensuality, movement and my body itself were a huge part of who I was and how I interacted with my world. My body was a sacred and sovereign place to return to when I needed to retreat from my mind and translate my thoughts or things that the outside world delivered, good or bad.

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## MORE ON NEWMOBILITY.COM

For two more recent essays on sexuality, see [newmobility.com/the-pleasure-is-all-theirs-3-essays-on-sex-after-sci](http://newmobility.com/the-pleasure-is-all-theirs-3-essays-on-sex-after-sci).

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Then on July 4, 2012, I was injured. My sacred and sovereign flesh felt as if it was torn from me. I immediately felt detached from it after I dove into the water that night. As a C6 quadriplegic, I was forced to let go of my former reality and explore a new body, a new world, a new home within myself — one in which I can't move, let alone feel, in the same way. All the while, I was learning to fight against a culture that puts me, as a person with a disability, at the bottom of the totem pole when it comes to definitions of sexiness.

Beyond the trauma of my accident, I was suddenly met with an onslaught of disability microaggressions. These stressors of feeling unseen — from inaccessibility to invisibility to inequality and beyond — collectively brought forth their own traumas. And I felt my

curiosity, my trust in life and my sexuality not just slipping away but disappearing into a deafening, silent abyss. I still felt that fire of my sex drive exactly the same as before — but pleasure, orgasm and sexiness seemed out of reach.

Suddenly, I wanted to be shamelessly checked out again. Objectification became something I missed. I yearned to feel lusted after and be obnoxiously gawked at again. How shallow was I that, ironically, after years of pushing back against annoying and insulting objectification, I now somehow missed it? Now, this separation of body from self became hurtful and insulting in a totally different way. Instead of being uncomfortably stared at out of lust or admiration, I was stared at out of sheer human curiosity — or worse yet, pity — or I was skimmed over in the crowd and casually disregarded. After my injury, I felt assaulted by ableism regularly. And it all made me question my sense of identity.

There was so much to understand and unwrap when it came to ableism, including my own internalized attitudes and the culture that had shaped my ideas of self-worth, sexiness and sexuality. Because now I was the one in a wheelchair, and my preconceived notions and misconceptions of what it meant to be sexual in a disabled body were their own form of self-inflicted daily assaults. I could no longer live and thrive, sexually or otherwise, within the constraints of an able-bodied existence. I needed to change the narrative on my disability and get curious again with my still-sacred form. There was a level of self-acceptance that needed to happen, and it was a bigger leap than I had ever taken on any dance floor.

For the longest time, I just didn't



Photo by Noah Forbes

know how to get there. For five long years, I didn't have sex. I was too afraid and wounded. And I felt more vulnerable to judgement — or any other form of harm for that matter — than ever before. It was as if I was there for the taking, emotionally and physically, if I were to put myself in that position. And even though I so badly wanted to, there were too many questions and even more fears caging me from my beloved curiosity.

And then, on a weekend to go visit an old friend, it finally happened. I lost my quadginty. I felt cared for and safe, desired and sexy. It was wonderfully strange — I immediately felt this renewed sense of empowerment. So many questions were answered. I didn't get some of the answers I wanted, but I didn't expect those answers anyway. I knew I wouldn't feel him inside me the same way, and I knew I wouldn't climax. But it was more than I expected. Sex was still fun and pleasurable. It felt good in a completely sensual and exciting new way, and we all know how

**“It finally happened. I lost my quadginty. I felt cared for and safe, desired and sexy. It was wonderfully strange — I immediately felt this renewed sense of empowerment.”**

erotic new can be. Did I suddenly have a leg up on all the able-bodied normies?

This was revolutionary. This was an awakening.

Post-injury/disabled sex brought me back to life in many ways — I wouldn't dare tell him that, but it was true. The whole experience gave me back some of that much-needed sense of prowess and empowerment ... and possibility! It reignited something in me that I had lost and so gravely missed. Something that was traumatized and hiding away,

protecting itself in a place that felt safe. This was one of the first steps toward owning my sexuality again — not just thinking I'm sexy and merely accepting my body but knowing I'm sexy and loving my body.

I've been slowly but steadily relearning to see my body without the harmful narrative, without shame or judgment, and without confining ties to the able-bodied sex I'd been having. I'm discovering what feels good in this body, finding new pathways to pleasure, without feeling like it should be something else, like I should be someone else. I'm trading in comparison for discovery, which sometimes feels impossible, but nonetheless, vital. It's all wild and scary and weird, but it's also completely liberating, this return to trust, to play, to myself. ■

*This piece was originally published as Return to the Home Within on Unite 2 Fight Paralysis' blog on December 7, 2021. It ran as a personal companion piece to U2FP's podcast, episode 56: “The Science of Orgasm.”*

# JOE STONE TAKES BACK THE SKIES

BY AARON BROVERMAN

**Y**ou never know what a paragliding flight will be like until you're in the air. That's what Joe Stone loves about flying. There are so many variables you can't see, from thermals to turbulence to gusts of wind, that you're forced to be completely in the moment.

"As you're flying, you're painting this image in your head of what the air is like. You're feeling it. You're reacting to it," he says. "You're having to do things with quick timing to respond to whatever is being thrown at you."

Some flights only last a few minutes. Others stretch for hours. Sometimes you get lucky. "When you're circling around on a thermal and a bird is looking at you as you're doing the exact same thing it's doing, that connection with nature and the environment is pretty unmatched," he says.

Those feelings of being present and connecting with the natural world and like-minded people have drawn Stone to adventure sports his entire life. As the director of mission for Teton Adaptive Sports, a nonprofit based in Jackson Hole, Wyoming, that provides inclusive outdoor recreation opportunities, Stone makes sure people with disabilities of all backgrounds can access those same experiences.

## A NEW DIRECTION

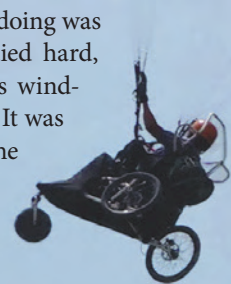
How he got there is a story that wanders as much as the rivers around Jackson. It starts with speed flying, a particularly risky type of paragliding in which you fly as fast and low to

the ground as possible. It's an adrenaline mainline, and it was Stone's passion throughout his early 20s. Then, in 2010, he hit the side of Montana's Mount Jumbo and broke his C6 and 7 vertebrae and sustained a host of other injuries.

Stone knew that what he was doing was risky. He played hard and partied hard, and one of his biggest fears was winding up with a spinal cord injury. It was a fear rooted in ignorance since he figured that his life would be over if he couldn't walk. While in the hospital, he saw *Murderball*, the Academy Award-nominated documentary about the U.S. wheelchair rugby team, and realized that if those guys had figured out how to lead fulfilling and active lives as quads, he could too. "When I was first injured, I didn't know anything about spinal cord injuries or whether life would even be worth living, so the first stage, especially in the first year, was just about figuring out what I could do," says Stone.

He set a goal to handcycle the Going to the Sun Road, a 50-mile stretch of highway that climbs 2,500 feet up Logan Pass in Montana's Glacier National Park. It was ambitious, to say the least. He didn't know if he could do it — he didn't even have a handcycle yet. But it gave him a goal to work toward.

One day before his first SCI anniversary, he rode the Going to the Sun Road with a group of friends. The 12-mile climb up Logan Pass took him eight and a half hours, but the hardest part was riding the last flat miles back to camp after the climb. The high of the summit and the adrenaline of the descent had worn off, and he was exhausted. It wasn't fun anymore. He didn't want to be there. He gutted through.



Joe Stone recently traveled to Tanzania with the nonprofit Peace for Conservation to deliver donated handcycles and wheelchairs.



Stone and his friends pulled back into camp just as the sun was setting. That trip and the process of working toward it changed Stone's whole outlook on living with paralysis. It gave him the confidence that whatever he wanted to do with his life was open if he was willing to do things differently, accept help from others and put in the work. And he'd just proved he knew how to work.

### FINDING PURPOSE IN FAILURE

Not long after the Going to the Sun ride, Stone set another goal: to become the first quad to complete a triathlon. He was one year out from his accident, had never done a triathlon, and had never been in a racing chair. He didn't

have the right equipment and didn't have the money to buy it. But he threw himself at it, confident he'd figure it out.

While learning about everything from racing chair techniques to adaptive wetsuits, Stone started a filmmaking project. He partnered with a close friend, Kevin May, to make a documentary, *It's Raining, So What*, about the Ironman journey. "My intention then was, if I could help one person who's laid up in the hospital dealing with a new spinal cord injury, the way *Murderball* helped me, then it's a success," Stone says.

During his Ironman training, he started posting regularly on social media, sharing everything from getting dumped into the water while rafting to how-to videos about trans-



ferring into a car or stretching out his muscle spasms. The intent behind Stone's various public-facing projects — the documentary, the social media and a newly-developed career as a public speaker — was to help other people with SCI move forward with their own lives.

In 2013, Stone competed in Ironman Florida. He completed the 2.4-mile open water swim two minutes beyond the cut-off time, but Ironman races have strict time limits, and Stone wasn't allowed to finish the race. At the end of *It's*

*Raining, So What*, Stone says that moment "felt like the biggest failure of my life."

The silver lining came later that night when he helped cheer on the race's last finishers, including a woman with Ehlers-Danlos syndrome who willed herself through 17 hours to finish less than a minute before the final time cut. Seeing the collective energy at the finish line and reflecting on all the support he'd received taught him some important lessons: "It's not all about me, and it's not about the path I want to go on and what I want to accomplish. It's about communities. It's about bringing people together."

### FOUNDATION LIFE

In the first years after he was injured, Stone benefitted from several adaptive sports foundations, but he still felt like there was a need not being addressed. He and May started the Joe Stone Foundation to bring adaptive sports into the broader outdoor recreation community. "One of the things that really bothered me when I was first injured was suddenly, I was separate from all the guys I used to fly with. What the hell? I break my neck, and suddenly I'm funneled into adapted sports? It's like any knowledge and experience I already had didn't matter," says Stone. "The Joe Stone Foundation is about bridging that divide."

The foundation began partnering with events like Whydaho Rendezvous, an annual mountain bike festival held in Idaho's Teton Valley every Labor Day Weekend, and organizations like Teton Adaptive to provide equipment, instruction and camping logistics so that bikers of all abilities could play together.

The successful partnerships proved Stone's hunch. "People with disabilities wanted to be at events where it wasn't just for people with disabilities. It was a lot easier to join an already existing event and make it accessible and inclusive than to create a whole new one," he says.



One of Stone's passions is getting other people with SCIs into the sky.



## *It's Raining, So What*

“There were times where the teenaged son of the dad who uses a wheelchair would go off and join an advanced downhill clinic, and his dad would go off and do a group ride, a downhill ride, or whatever it was to further his skills. And then they’d meet up after and have lunch. That’s kind of the dream — to have an event and a community that just supports everyone.”

### BACK IN THE AIR

After his accident, Stone didn’t immediately try to get back into flying since in 2010, there weren’t many resources for learning how to paraglide as a wheelchair user. Plus, he didn’t feel it was fair to his family to dive right back into an activity that had left him paralyzed. He kept an open mind and tried as many different activities as possible, hoping to find something that would grab him, like paragliding.

Despite trying swimming, quad rugby, triathlon, off-road handcycling, white water rafting and anything else he could find, the flying itch never left. Years later, he’d still dream of being back up in the air. Then, while he was training for the Ironman, a guy named Chris Santacroce reached out via Facebook about an organization he ran called Project Airtime, a Utah nonprofit that provides inclusive flying opportunities.

After a few months of hemming and hawing, he made the trek to Utah in 2014. On his first flight, he fell back in love.

“When I got out there and started learning with them, it turned out to be way easier and way more inclusive than I ever could have expected,” says Stone. “Once my eyes were

This feature-length documentary chronicles Stone’s early years after his paragliding accident, including the Going to the Sun ride and his Ironman attempt.

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[vimeo.com/ondemand/itsrainingsowhat](https://vimeo.com/ondemand/itsrainingsowhat)



open to how possible it was for someone in our situation, it was game on.”

He says the hardest part was telling his parents. But they eventually got on board after realizing that Stone wasn't the same person he was when he got hurt and that he had a different approach to the sport now. He says rather than flying “filled with ego,” he's learned how to enjoy the process, listen to his mentors and let his skills develop naturally rather than continually push his limits.

With his background, progress happened fast. He went from tandem flights to solo adventures in just a few sessions. Soon he was starting Project Airtime programs in Montana, Wyoming and Idaho and helping others create versions of the program in their cities. “My role with Project Airtime is both being a pilot and an advocate for it. And when the right people show up who want to bring a chapter to their area, I just help facilitate that by answering emails, sourcing the gear and providing some training,” he says.



“My favorite thing about Project Airtime is how organically we allow it to grow. It's never forced,” says Stone. “Chris Santacrocce was the guy who taught me that thing of ‘if you show up, you'll go flying,’ and that's helped me in my own personal growth and with my peer-mentorship. I could spend all day reaching out to people, but at the end of the day, if you show up, we'll make things happen — and that's what Project Airtime is all about.”

## FROM DIRTBAG TO DIRECTOR

Stone wasn't getting paid for anything to do with adaptive recreation until about a year ago. He was surviving on public speaking, and everything he did through The Joe Stone Foundation was completely volunteer.

“I got really good advice that I didn't take from the original founder of Teton Adaptive, who said, ‘Hey, I think what you're doing with The Joe Stone Foun-

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ation is really cool. Just so you know, at a certain point, you're going to have to start paying yourself because otherwise, you're going to get burnt out."

Stone brushed it off at the time, but that's what happened. He got pulled in many different directions and didn't know how to say no. He became overwhelmed.

That's why, in 2018, he took a break from all of it.

"I loaded everything into a storage unit and left with my truck and my camper, spending two years chasing warm air for paragliding," says Stone. "I had a few select speaking gigs that I flew to from time to time and activist things with ADAPT in Washington, D.C., but it was all real minimal. That allowed me to analyze what I got burnt out on and pull in the things I was passionate about, like creating adaptive recreation opportunities or being involved in disability civil rights."

Meanwhile, Teton Adaptive courted him for a full-time role, but the timing was always wrong. It wasn't until COVID hit in March 2020, when all Stone's speaking gigs dried up and his girlfriend announced she was moving to Jackson for a physiotherapy job, that Stone and Teton Adaptive were finally on the same wavelength.

Stone is now director of mission at Teton Adaptive, where he leads fundraising initiatives and finds businesses the organization can partner with to develop new

In addition to his more high-octane adventures, Stone also has a passion for wildlife photography.



## Joe Stone's Favorite Spots for Accessible Outdoor Adventures

**1. Jackson, Wyoming** – "I might be a bit biased because it's where I live, but I do think it's a unique area. You can go white-water rafting or you can get on flatwater, and both of those can be guided. You can also rent some adaptive paddling equipment to go out on the lakes with friends and family. You can rent a handcycle meant for paved paths through Wheel Wranglers, who will deliver the equipment. There are a lot of unique opportunities for families. Not to mention Yellowstone National Park, Grand Teton National Park and tons of wildlife."

**2. Salt Lake City, Utah** – "You've got the headquarters of Project Airtime right there. There's also the National Ability Center, Wasatch Adaptive Sports and the University of Utah, all with adaptive recreation opportunities. On top of that, there's an indoor skydiving place and the outdoor Skydive Utah, which are both open to taking people with disabilities. There's also a great art museum, aquarium and food. It's also really affordable and has a great music scene."

**3. National Parks** – "They are always super fun. It's just about figuring out how you'll get on the trails and what things you can do — so some are better than others. Yellowstone is pretty great, and if you have an off-road handcycle, Channel Islands is cool off the coast of California. The people contracted to do the boat rides were super helpful to me. It's a little challenging, so you will work hard for it with a lot of climbing, but it's really cool. Death Valley is also cool. National Parks are rad, and there are opportunities at all of them."



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adaptive recreational opportunities. “What’s made getting hired really nice is that all the other areas that burnt me out more on a volunteer basis, like being involved in panels and the nitty-gritty details of taking time out to

Stone has found his community, and he’s working with Teton Adaptive to make sure it’s as welcoming and supportive to as many people as possible.

help others establish an adaptive mountain bike program, are now part of my job,” he says. “What has helped me grow is being able to learn from everybody else’s perspectives. You’re never going to hit it out of the park with every single person. But we’re trying.”

Stone has simple advice for anyone who wants to get involved in outdoor recreation but isn’t sure how to start. “Get out, try new things, find groups of people who can help you do it, and be open to the help,” he says. “Stay curious, stay open-minded and show up.” M

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# AWARD NOMINATIONS ARE NOW OPEN!

As a part of its **#StrongWheeled Together** campaign, United Spinal Association will be hosting a member awards event in November to recognize leaders and emerging talent from the SCI/D community. The categories are: 1) Visual Arts; 2) Performing Arts; 3) Sports and Recreation; 4) Entrepreneurship and Innovation; 5) Youth Leadership.

We are looking for enthusiastic, up-and-coming individuals living with spinal cord injuries or disorders who are passionate about advancing their abilities to reach new levels of success.



If you believe that you or someone you know is a great representative of our **#StrongWheeled** community and has what it takes to reach that next level of success, fill out the nominee submission form here:

[unitedspinal.org/strong-wheeled-together/nomination-form/](https://unitedspinal.org/strong-wheeled-together/nomination-form/)

Deadline for submission: June 1, 2022

# Surviving CANCER

Cancer is an unforgiving opponent and it definitely doesn't pull any punches for wheelchair users. From early detection, to treatment, to recovery, wheelchair users face unique obstacles that can make an already difficult fight seem overwhelming.

Sadly, there's no "easy button" to guarantee a quick and painless battle, but with the right preparation you can reduce the challenge and bolster your odds at a successful outcome. This story shares tips, resources, humor and strategies from three wheelchair users who are currently battling or have beaten cancer.

## *No Book for This*

Gary Karp has a long resume as an architect, emergency management planner, internationally recognized public speaker, corporate trainer and the author of three books. On the heels of completing 35 radiation treatments over seven weeks, he can add throat cancer survivor to that list.

While you might think writing *Life on Wheels: The A-to-Z Guide to Living with Mobility Issues* would have prepared Karp, a T12 para, for his battle with cancer, his experience reveals a more disheartening truth.

"I have come across no resources specific to cancer and being a wheelchair user," he says. "I have not encountered another person in the course of this experience who also is paralyzed. Cancer treatment providers just don't have a lot of experience with it."

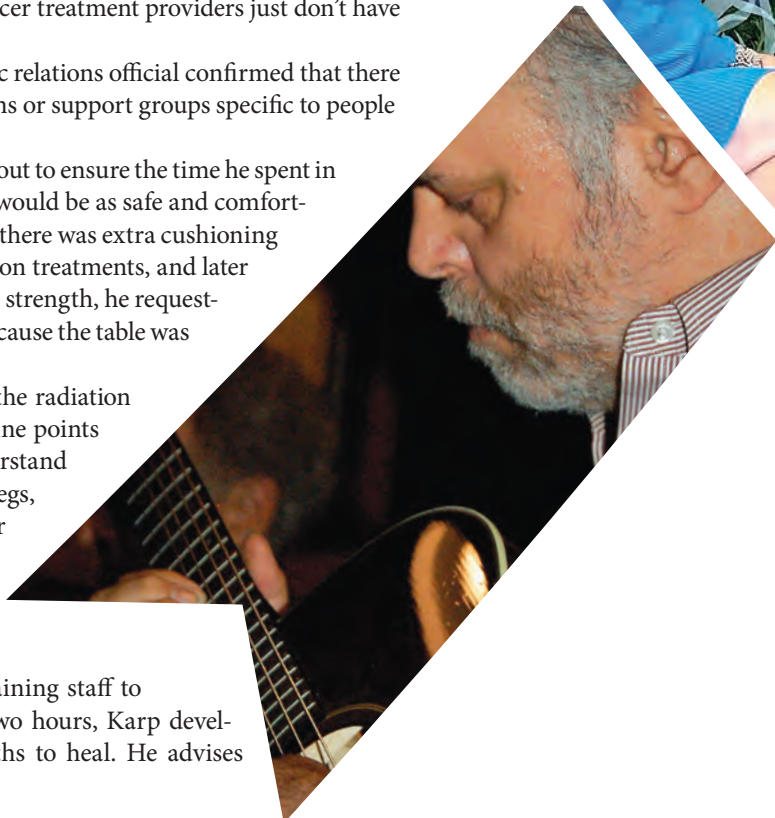
An American Cancer Society public relations official confirmed that there are no guidelines for treating physicians or support groups specific to people with disabilities.

Knowing this, Karp proactively set out to ensure the time he spent in the hospital and receiving treatments would be as safe and comfortable for him as possible. He made sure there was extra cushioning on the tables where he received radiation treatments, and later in the process, as he lost some physical strength, he requested assistance making a safe transfer because the table was several inches higher than his seat.

"I had to train the techs who did the radiation treatment on some really important fine points about the transfer. People don't understand that when you don't have use of your legs, you basically are balancing on your butt," he says. "Being upright is critical. As soon as I land, I need to be upright. If not, I feel like I'm falling forward, and that's panic mode."

Despite all his precautions and training staff to switch him from side to side every two hours, Karp developed a pressure sore that took months to heal. He advises

BY STEVE  
WRIGHT



those with SCI to be hypervigilant about protecting their skin during treatments.

The radiation treatment also affected Karp's ability to swallow, necessitating that he get a feeding tube. "My doctor was right up front about it, and I'm glad he was because I'd be dead without it," he says. "I still primarily get my nutrition through a feeding tube even after the CAT scan shows I've beaten this."

Other side effects impacted his taste buds, spurred massive weight loss and left him weakened — a difficult thing for someone who is "rabid about my independence." Karp typically drives himself, but says there were times when he needed to get a ride to treatment.

Karp, 67, advises those with SCI/D to plan on feeling foggy-headed even when out of a cancer center and recovering at home. He was not advised of the severity of pain he would feel or the impact of pain medications. For the first time in his life, he felt some insecurity about his ability to function at home.

"On the positive side, the nature of the disability experience is we are adaptive beings," he says. "We learn to advocate for ourselves. That couldn't be more important for someone going through cancer treatment. There are so many choices to make, so many individual paths, and so many products and strategies that each person has to keep learning."

### ***Therapeutic Education***

Karen Roy is a brand ambassador for Numotion and a passionate advocate for wheelchair users and people with disabilities. The 53-year-old uses a wheelchair as a result of a gunshot wound while being robbed 34 years ago. She was diagnosed with bladder cancer in the fall of 2021.

She caught her cancer in the early stages but faces a long treatment regimen. She travels more than four hours from her home in Baton Rouge, Louisiana, to Houston, for treatment at the University of Texas MD Anderson Cancer Center. Roy receives a version of the tuberculosis vaccine that is injected into the bladder to break through the cancer cells.



The side effects from Karp's cancer treatments hit him hard and led to some feelings of insecurity.

***"The doctors and staff said they never had a manual wheelchair user who had a double mastectomy."***

The treatments take two hours and are done every six weeks.

Roy has found her doctors uniformly respectful of her disability but wishes they were more proactive in considering unique risk factors and concerns for people with disabilities. "My one criticism would be that nobody is bringing ways to mitigate my known risk factors, which include the fact that I will continue to have to perform intermittent catheterization and likely continue to have recurrent urinary tract infections," she says.

While undergoing treatment, she has expanded her advocacy to educating people about catheters and bladder cancer. "People with spinal cord injuries that do intermittent catheterization get irritations and increased incidence of UTIs that put us at higher risk for cancer," she says. "I catheterized with products that turned out to

have a carcinogen in them." She's referring to Di(2-ethylhexyl)phthalate (DEHP), which is commonly used in plastics to make them flexible and requires a consumer warning label under Proposition 65 in California because it "can cause cancer and birth defects or other reproductive harm."

Roy's activism and open sharing about her cancer journey are her coping devices. She suggests joining SCI/D groups on Facebook and other social media platforms and connecting with survivors and people fighting your specific cancer.

"Staying focused on the gratitude for all the beautiful people in my life, work I am passionate about, and the ability to advocate for improved safety of catheters [is also important]. If I can help someone else prevent bladder cancer, this journey has meaning," she says. "Take friends and family with you to treatment when possible. Reconnecting with the people I love has been the silver lining of my bladder cancer diagnosis. Work on keeping a positive attitude. Take care of your mental health as well as your physical health."

### ***"What am I supposed to do as a wheelchair user?"***

In November 2011, Meg Paulsen had just begun dating the man who would become her husband when he discovered a



lump in her breast. She had no family history of cancer and had her annual mammogram in May.

Fortunately, the cancer was “the slowest growing, least aggressive type.” Still, Paulsen, who was born with spina bifida, had four lumpectomies on one side, and one on the other. “My oncologist said, we’re probably going to be doing these continually because it seems like your tissue is creating pre-cancerous stuff,” says Paulsen, now 56.

“They say the worst thing about having cancer is knowing that you have it,” she says. “And I totally agree, because it is a stressor.” Paulsen opted for a double mastectomy. “Long story short, I got my implants, did all the cosmetic tattooing — I don’t ever have to wear a bra again,” she says, noting a sense of humor is key to recovering.

As a lifelong advocate for people with disabilities, Paulsen was shocked at how unprepared the medical professionals she dealt with were when she peppered them with questions about her recovery as a manual chair user.

“After the double mastectomy, they said you can’t use your arms for three months. I said, ‘What am I supposed to do as a wheelchair user?’” recalls Paulsen. “They said they never had a manual wheelchair user who had a double mastectomy.”

Their lack of experience almost cost Paulsen severely. “Because I wasn’t allowed to use my arms, they were trying to see if my mom, who was probably around 70, could transfer me



Paulsen found a proactive approach to educating nurses and doctors was needed before and after surgery.

out of the bed into the wheelchair,” she says. “She dropped me and that was horrid because I still had open wounds.”

Paulsen took it upon herself to educate the “professionals.” She explained all the areas she envisioned needing help and made sure the hospital provided them, including a Hoyer lift for transfers and visiting nurses to change dressings and manage drains.

Having the right equipment and services was key, as was having supportive friends and family. Her partner’s family had a lot of experience helping others recover. His mom is an RN and she even moved in to support Paulsen at home.

Paulsen was worried the post-surgery inactivity might lead to muscle atrophy, but credits her athletic background and solid pre-surgery preparation with helping her stay strong. “I had built up a lot of upper body strength and I had PT people coming in and helping me figure out how to re-acclimate myself to moving,” she says.

Paulsen calls herself “very lucky” for being able to catch her cancer before it spread and treat it without chemo or radiation. The whole process has opened her eyes to the disparities facing wheelchair users battling cancer. She is disturbed that hundreds of millions of dollars are raised for cancer research and treatment each year, but there are virtually no resources for people with disabilities — including accessible mobile mammogram trucks. “More women are succumbing to cancer because of their inability to get early detection, but nothing is being done to increase mobile and other screening opportunities for people with disabilities,” she says.

Her advice as a survivor?

“You’ve got to advocate for yourself,” she says. “You’ve got to push, and if you’re feeling that something is wrong, don’t let your medical people talk you out of it . . . just keep advocating, keep bugging, and fight for your right to live.”

MM



Roy has kept her spirits up during treatment by devoting her time to advocacy and education.



# IN THE MEDIA

By Teal Sherer

## SO YOU WANT TO START A PODCAST?

Starting a podcast can be rewarding and fun. Podcasts allow wheelchair users to share their perspectives and quash the stigmas around disability. They can be straightforward and inexpensive to produce, and with a good microphone and simple setup, they can be recorded almost anywhere. They also have the potential to reach a lot of people and make a positive impact. The creators of three disability-centric podcasts — *Sit the F\*ck Down*, *From the Throne*, and *Disability After Dark* — share how they got started, what they've learned and what keeps them going.

### **Sit the F\*ck Down**

**How it started:** In October of 2020, Christina Chambers and Liv Bender lived less than a mile down the street from each other in Phoenix, Arizona. Both have transverse myelitis, a rare inflammatory disease that injures the spinal cord, and as the COVID-19 pandemic raged, they decided to quarantine together. "We were drunk talking one day and had a heart-to-heart moment where we said we were so lucky to have each other," says Chambers. "As women, we can talk to each other, share our stories, and be open and candid about what it is to be a disabled woman in today's world." They knew there was a community of female wheelchair users on social media who might also benefit from these conversations.

Thus, *Sit the F\*ck Down* was born — a show where they discuss topics like dating, sex, travel, mental health and disability representation. They also have guests



Liv Bender (left) and Christina Chambers quarantined together during the pandemic and decided to start a podcast.

— like U.S. Paralympian Kaitlyn Verfuert and Grammy award-winning guitarist Eric Howk. They even spoke with a disability devotee. "We just want it to be candid, and like every other conversation we've ever had," says Chambers.

**Behind the podcast:** "We almost didn't release our first episode because it wasn't perfect, but we knew that they would get better over time," says Chambers. She and Bender researched "how to make a podcast" online and watched YouTube videos. "We split up the tasks," says Chambers. "I became the social media person, and since Liv is more analytical and is an audiologist, she handled the sound and uploading."

To make *Sit the F\*ck Down* sound more professional, Chambers and Bender built a studio in the spare bedroom of Chambers' apartment. "We bought microphones and super cheap sound-proofing stuff on Amazon. We put a rug down, got some couches and filled the

room with fluffy things," says Chambers. **Why they do it:** Chambers was surprised to get thank-you messages from nondisabled people who appreciate how educational and insightful their show is. "This is our way of giving back to our community because we felt so underrepresented in the media and news outlets, and just in conversations that happen every single day," says Chambers. "This is our way of being brought to the table."

### **Advice for aspiring podcasters:**

Chambers says to do your research and avoid overspending on equipment. "Do what you're passionate about, release the first one, and it will get better, and you'll get more confident in your podcasting abilities as time goes on," she says.

**Where to listen:** *Sit the F\*ck Down* is available on Apple Podcasts and Spotify.

### **From the Throne**

**How it started:** In *From the Throne*, Jessie Chin, Francesca "Frenchy Minaj" Kellise,

and Antwan Tolliver share their perspectives on topics like dating, sex, parenthood, race and health. The three New York City friends are wheelchair users due to spinal cord injuries and share a passion for good conversation and educating others about disability. “People with disabilities are not represented in a positive way,” says Chin. “So, we wanted to showcase that. Just because you have a disability, that doesn’t mean life doesn’t go on. You can still have a productive life.”

Episodes often feature a guest with a different disability, and the crew allows the conversations to roll wherever the guest takes them. In episode 7, they chat with the host of the podcast *Blind But Now I See*, who goes by the name “cnote,” about what it is like to be visually impaired. “Our show is for people with disabilities, but it is also for everyone,” says Chin. “It’s all about bridging that gap. If we really want to make change, we have to talk to people that are nondisabled too. We have to find a common ground.”

**Behind the podcast:** Chin, Kellise and Tolliver record *From the Throne* in New York City and have a video version of each episode on their YouTube channel. “A lot of the studios are not accessible because the buildings are old,” says Chin. “That was the trouble at first, trying to find the right one for us.”

**Why they do it:** “If the podcast ends tomorrow, I did my part by the number of people it’s helped and touched,” says Chin. “My purpose is to help people; I don’t need a dime out of it.”

**Advice for aspiring podcasters:** Chin encourages people to be their authentic selves. “It’s important to show individuality within the disability community,” he says.

**Where to listen:** *From the Throne* is available on Apple Podcasts, Spotify, and YouTube.



Antwan Tolliver, Francesca “Frenchy Minaj” Kellise and Jessie Chin are committed to helping educate listeners about the reality of living with a disability.

## Disability After Dark

**How it started:** Andrew Gurza has been recording *Disability After Dark* from his bedroom in Toronto, Canada, since 2016 and has released close to 400 episodes. For the first year of his podcast, Gurza, who has cerebral palsy, focused solely on disability and sex but then pivoted to telling a wider variety of disability stories. In one of his favorite episodes, number 65, he interviews his mom about what it was like raising him — a disabled son who also came out as queer in his teens. Gurza also does bonus episodes like *Great Flix and Joysticks*, where he reviews TV shows and movies about disability.

Recently, Gurza started a podcast network, *Cripple and Co.*, to mentor people who want to create their own podcast. “I think there needs to be different voices in the disability space,” he says. “If I can use my platform to help others make a show that is disability-centric and is their voice, then I want to do that.” For those interested in working with Gurza, his email is [disabilityafterdarkpod@gmail.com](mailto:disabilityafterdarkpod@gmail.com).

**Behind the podcast:** Gurza coordinates guest interviews, records, edits, uploads and promotes each episode. To help support his work, Gurza uses Patreon, a plat-

form that lets people financially contribute to content creators. “I just said, if you like what I’m doing, throw me some dollars,” says Gurza. “It will help me do two things. It will help me survive as a disabled person making content. And I’m going to use the money to get a nice mic and a proper setup.” Gurza currently receives close to \$500 a month from his supporters.

**Why he does it:** Listeners tell Gurza that the podcast makes them feel less alone. “To know that something I make in my bedroom is giving people something they are craving is still very mind-boggling to me,” says Gurza.

**Advice for aspiring podcasters:**

“Don’t go into it looking for podcast fame. Just do it because it’s something you like to do and because you know the content you are making is important. Just have fun with it.”

**Where to listen:** *Disability After Dark* is available on Apple Podcasts, Spotify, Google Play and Stitcher.



Andrew Gurza receives around \$500 a month from his fans via Patreon.

Photo by Alice Xue Photography



# PRODUCTS

By Michael Franz

## OPEN SESAME MODEL 133 AUTOMATIC DOOR OPENING SYSTEM

A college student by day and DJ and songwriter by night, Anna Pannell doesn't have time for unexpected obstacles like doors she can't open. That's why Pannell, a C1-2 quadriplegic, installed Open Sesame's Model 133 automatic door opening system on two doors in her home, allowing her to open them with her voice.

"I don't have to have anybody open the door for me — I can just do it myself without asking. I can open the door for my family," she says.

I met with Pannell at her home in Ypsilanti, Michigan, to check out the voice-activated Open Sesame door opening system. She has one installed on her front door and one on a door that leads from her bedroom outside.

### Specs and Tech

The Model 133 is the residential version of Open Sesame's automatic door opener line. It is a relatively small piece of hardware measuring just over 14 inches wide and 4 inches tall and weighing 10 pounds. The Model 133 comes standard with a remote control that you can hold or mount to a wheelchair, an electric door strike that automatically unlatches the door, a low-voltage wiring kit and a backup battery system to ensure operation of the door opener when the power goes out.

Open Sesame offers many accessories to allow users of varying abilities to open doors independently. Pannell uses Open Sesame's new wireless Voice Interface, which is compatible with Amazon Alexa, for her setup. The Voice Interface is a small device that plugs into a power outlet near the door with the Open Sesame system installed and transmits voice commands, commands from the Alexa app and commands from eye-gaze programs.

Pannell has an Amazon Echo Dot connected to her power chair battery and mounted on her armrest that allows her to open doors from inside or outside her house as long as she has a solid Wi-Fi connection. All she has to do is say, "Hey Alexa, front door power on." The door is programmed to respond to this command by opening and staying open for 60 seconds before closing automatically. The time the door remains open is customizable, and the Open Sesame can detect obstructions and stop the door from closing if it



Open Sesame's Model 133 residential door opener allows wheelchair users like Anna Pannell to open doors using voice control.

meets resistance. Pannell has found the opener to be reliable — more so than Alexa. "Sometimes [Alexa] can be stubborn. You have to repeat yourself a thousand times for it to recognize what you are saying."

You can install the Open Sesame door opening system on both inward and outward opening doors, as well as specialty doors like French doors and storm doors. Problems can arise if there is not enough room above the door, if the

door frame is too deep to accommodate the arm that opens the door, or if the door is mostly made of glass. For these reasons, it is important to have any doors in question professionally evaluated before purchasing the system. Installation takes about two and a half hours and involves electrical work, so hiring a professional is recommended.

### My Take

After seeing the Open Sesame in action, I would recommend it to anybody looking for an automatic door opener, whether they need voice activation or not. I am in the planning stages of building a new house, and I intend to use the Open Sesame system on my doors. The hardware is much smaller and looks better than the door openers currently in my house. The opener responded quickly to Alexa's voice commands and the Alexa app. The only glitches I observed involved Alexa not hearing or misunderstanding a voice command, but anyone who uses Alexa knows this is a common problem.



For those concerned about the security of having a voice-activated door opener, the Open Sesame system works well with the smart deadbolt products available on the market. A smart deadbolt requires anyone attempting to open the door to know a code to unlock it, adding another layer of protection for those concerned that someone could learn the voice command to unlock the door.

The Open Sesame Model 133 retails for around \$2,400, plus an additional \$175 for the Voice Interface module. Professional installation varies by installer, but it cost Pannell \$300 from Assistive Technology of Michigan. Some insurances that pay for home modifications may cover the cost of the Open Sesame System. Veterans Affairs insurance has covered the cost for injured veterans. For Michigan residents injured in automobile accidents, the no-fault insurance system covers the cost of Open Sesame. Grants are also available through many organizations to help cover the cost of purchasing and installing the system. For more information, visit [opensesamedoor.com](http://opensesamedoor.com).

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# OUTDOOR TRACKS

By Kary Wright

## AN ANNIVERSARY IN THE MOUNTAINS

Last September was my 25th wedding anniversary. With the way things have gone the last couple of years, Terry and I hadn't made any big plans for the occasion. "Let's go to the mountains for our anniversary," she said, out of the blue.

Terry and I missed seeing the mountains, which have been one of our favorite destinations for years. We were even married there. Never one to turn down an adventure, I jumped at the opportunity.

For me, the fun starts as soon as there are plans made. Number-1-Organizer (Terry) did a great job of booking rooms, pawing the dogs off at our daughter's place, and making a to-do list. Half the fun of an adventure for me is the anticipation; I'm like a kid, and it makes me glad that growing up is optional.

One fly-in-the-ointment was my power chair. At seven years old, with about 5,000 miles on it, she was ripped, bent, had bald tires, weak batteries and missing bolts, was noisy and generally a wreck. She would only pack me around for a mile or so before the batteries died.

I had a new chair on order, but there was no indication of a timeframe to get it, especially with the pandemic. The mountain area we were going to had miles of paved trails, and running the trails was one of our favorite rites-of-summer. I'd prepared to be a stationary sightseer

on this trip, consoling myself with the fact we would be in the mountains.

### New Gear, New Goals

A day before the great adventure I received a call from the medical shop. "Your new chair is ready. Can I drop it off this morning?" said the nice medical-shop-lady.

"You bet! Wow, we go to the mountains tomorrow! That'll be great!"

The hamster in my head was running on its wheel full speed now. I was going to be in the mountains with a new chair with new batteries and miles of paved trails.

Now that I could tackle some trails, I suggested Terry bring her e-bike. As she charged it up, I got to thinking. "Maybe we can charge the GoPro, too. I'd like to play with it," I said. Sometimes the winter seems a bit long, and at these times I fondly remember the summer adventures. It is nice to have pictures and videos to look back on.

We assembled all the multitudes of quadriplegic-weekend-necessities and piled them next to the van. My chair arrived, and after a quick fitting session, I took it for a test-ride around the farm. It was fast, powerful, and stable ... perfect.

I read the manual for the GoPro and realized it is voice activated. I tested some of the commands in my office.

"GoPro video mode" switched to video and "GoPro start recording" did just that — it worked.

One of the frustrating things while taking pictures is that the good shots pass me by as I try to fiddle-fart with my paws to hit teeny-tiny buttons on cameras. Voice control helps immensely with this. The camera also has automatic stabilization, fixing the camera shake I was so annoyed about with previous action-cameras.

### Creating Memories

As it turns out, our friends Jim and Sheila were camping at our favorite campground, about 7 miles from our hotel. My favorite trail is paved and winds through beautiful mountain meadows. I remember wheeling this trail with our first dog about 25 years ago. She loved this trail and would trot beside me all day long when she was young. The years flew by, and soon her walks were short and slow. Now we're on our third dog that enjoys this trail.

The morning brought a great forecast, with lots of sun and warm weather. In September you never know what you'll get in the mountains, so it's good to check the forecast, as it changes quickly. Terry expertly organized my backpack and her bicycle-storage saddlebags, ensuring our survival for several months should we get stranded on our 7-mile trip. We had food, water, tools, cameras, my battery charger, the kitchen sink, etc. all on board.

I started recording as we exited our



hotel's underground parking. We were on our way. We turned left and followed the road for a half-mile until the start of the trail, and then turned onto it.

The smell of the mountain pine forest was incredible. The sun was up and showing its power as it beamed on us. I couldn't help but smile, it was so beautiful. We zig-zagged down the switch-backs through the trees. The first mile was a steep downhill run. My new chair worked great. There was no tendency to turn downhill on side-hills, even at high speed. My old wheelchairs were a handful to keep on the trail when at full speed, and I would often find myself doing some fancy stickhandling in those situations.

We crossed a river where my

A new power chair and a hands-free GoPro gave Kary Wright more freedom to enjoy his favorite trails while riding alongside his wife.

grandmother used to fish as a young mother. We scoured the ridge across the valley where my mother remembered watching grizzly bears in the spring, when she went to school here. There were flowers blooming everywhere, and fuzzy-looking honeybees searching them for pollen.

Terry's e-bike was amazing, and she could easily hit 25 mph even uphill, a vast improvement over the motorless bike she had before. We zig-zagged through tall pine trees, across open meadows full of flowers, and bushes

starting to turn colors. There was a hint of fall in the air and the faint aroma of fermenting leaves. In what seemed like no time we were entering the campground.

As I write this, I'm reviewing the footage, and taking a virtual wheel down my favorite trail. I glance out my office window at the blizzard outside and smile as I escape back to that summer day, zooming down a mountain trail once again. Thanks to the video we shot, I can escape to the mountains any time.

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[www.unitedspinal.org/pathways-to-employment/](http://www.unitedspinal.org/pathways-to-employment/)

### Meet New Member Tom Ufert

Age 57, from Crowley, Texas  
C5-6 incomplete spinal cord injury  
Author, personal private advocate,  
founder of the USA Unity Party



**What is the one disability-related product you couldn't live without?** My power wheelchair! It's my primary mode of mobility and, thanks to its numerous features, I can raise the seat to perform many activities of daily living. My overall quality of life would be severely diminished without my chair.

**If you could change one thing in the world to improve quality of life for wheelchair users, what would it be?** The primary thing I'd change are the perceptions of "non-physically challenged" people about wheelchair users. Wheelchair users aren't to be pitied or felt sorry for. Changing perceptions about life in a chair would make a positive difference in the life of wheelchair users.

*Meet other members or join United Spinal at [unitedspinal.org](http://unitedspinal.org)*



**SPINOUTS** ZEN AND THE CONTENT OF NM

Spirituality is nothing new to New MOBILITY. Over our 33 years we've covered different religions, physical and sensual practices like yoga and tantra and much more. One of the stand-out stories is Richard Louis Bruno's November 1999 feature on Buddhism. Bruno, a leading researcher on post-polio syndrome, took readers through The Four Noble Truths and suggested that Buddhism "provides the ideal method for living with a disability." Two years later, Barry Corbet shared a great conversation with Phil Simmons, the author of "Learning to Fall," that revisited some of the same topics and outlined an empowering approach to embracing the unknown and living in the present. Read the latter at [newmobility.com/faith-and-mystery](http://newmobility.com/faith-and-mystery).



SPECIAL GUEST

**Luticha André Doucette**

**WHAT TO WATCH FOR ON NEWMOBILITY.COM**

We hope you are enjoying all the web-first content we've been posting, and we've got lots more quality content headed your way this spring.

**Gear Guide: Wheels** — We'll help you make sense of all the different wheels on the market so you can choose the best option for your needs.

**Autonomous Vehicles** — Self-driving cars are coming. We look at what their arrival could mean for wheelchair users and what we'd like to see in their design.

**Best/Worst: Restaurants** — New York City's Contento is winning rave reviews for its forward-looking blend of haute cuisine and truly accessible environs. Seth McBride breaks down what makes the restaurant so special.

**NM Live** — Teal Sherer's YouTube series has a new home on Instagram. Don't miss her insightful and fun chats with disability community members. Follow @NewMobilityMag for access to previous NM Lives, including a great conversation about intersectionality with Luticha Doucette.

And of course, we'll have plenty of updates and posts on breaking news and new products. Stay on top of all of our content via Instagram, Facebook and Twitter.

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\*To learn more about the Villa, visit [magicalvacationhomes.com](http://magicalvacationhomes.com) and search with property code RVH 431M. Reunion Resorts features Three Signature Golf Courses, Six Restaurants, a Water Park and much more. Visit [reunionresort.com](http://reunionresort.com)

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