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\*Joe is a Coloplast product user who has received compensation to provide this information. Each person's situation is unique, so your experience may not be the same. Talk to your healthcare professional about which product might be right for you.

1. UTI risk factors defined by Kennelly M., et al. (2019), 10.1155/2019/2757862 Study supported by Coloplast.
2. Luja has close to no flow stops and complete bladder emptying is defined as <10mL, Landauro et al., 2023, N=42. Individual results may vary.

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## COVER STORY

# WHEELCHAIR REVOLUTION

What do you get when you add YouTube seed money, state-of-the-art manufacturing techniques and a consumer-first sales model? A wheelchair that could upend the mobility equipment industry. SETH MCBRIDE travels to Not a Wheelchair to see how the company plans to offer a custom manual wheelchair for \$1,000.

Photo by Kim Raff

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# BULLY PULPIT

By Ian Ruder



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## THE MIRACLE ON FLIGHT 3313

On Aug. 21, 2024, at 8:20 p.m., while seated in the first row of Southwest Flight 3313, I witnessed a miracle. This is my earnest attempt to document that miracle so the appropriate religious and scientific parties can study and learn from it. ...

Approximately three hours earlier, I was waiting to preboard at the appropriate gate in Denver International Airport. As a power chair user, I always arrive early to talk with the gate attendants and baggage crew to try and ensure my chair is handled properly. It has been broken so many times when flying, that prior to this trip I'd have considered it a small miracle if it arrived in one piece. After witnessing the miracle of Flight 3313, that seems blasphemous.

It had been a few years since I'd flown, and throughout that time I'd heard all the complaints about how air travel had changed for the worse: ruder passengers, more-callous airlines, poorly trained staff. I had prepared myself for all of them.

One common complaint I'd heard was that a growing number of travelers were "faking" disabilities to take advantage of preboarding. Earlier this year, the CEO of Frontier Airlines made headlines for calling out the "massive, rampant abuse." As an educated disability advocate, I scoffed at his statement.

Every disability doesn't come with an obvious signifier like my power chair. Hidden disabilities are real, and I'd like to think our society is advanced enough to accommodate them equally. With that in mind, I tried paying scant attention to the growing huddle of preboarders massing at the gate.

One particularly chatty woman seated beside me in an airport-issue wheelchair kept undermining my efforts. She was what Jerry Seinfeld would have called a "loud talker." Speaking just loud enough for everyone in a 10-foot vicinity to hear, she rattled off her litany of ailments and disabilities for upwards of 15 minutes.

She was still rambling when I headed down the jetway to board. Minutes later I watched as her husband and the gate attendant painstakingly helped her onto the plane. With her cane in one hand and her other arm bracing against the plane, she slowly made her way to her spot across the aisle and slightly behind me, and collapsed into the seat — bemoaning her pain the entire time.

I didn't think about her or any of the other preboarders again until we landed. A combination of low blood pressure and increased spasticity made the three-hour flight seem like an eternity. I did my best to zone out and push through, by turns dreaming about getting back in my wheelchair and praying it arrived in one piece.

Having long ago accepted the "first on, last off" tradeoff that comes with preboarding, I didn't flinch when the flight attendant announced that we had arrived and could begin deplaning. Zoned out with my headphones on, I almost missed the loud talker flashing by me — one of the first passengers to deplane. Without any assistance, she was up and out before I even realized what was happening. Her husband followed with her cane in tow. She had been cured!

I looked around, expecting to see other passengers marveling at her recovery, but they seemed oblivious. Even the flight staff looked nonchalant about the miracle we had just witnessed. Somewhere in the three-plus hours it took to fly from Denver to Portland, something stunning had happened. This proudly disabled woman had been healed, and no one seemed to care!

I wanted to talk to her about what happened, but by the time I got to baggage claim she was long gone. I pictured her running through the terminal, juggling her bags.

I've since resigned myself to never knowing exactly what transpired on Flight 3313. All I can do is wait for my next flight and hope it holds a miracle for me.



# BEHIND THE STORIES

With Ian Ruder



## COLUMNISTS

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Longtime readers likely know **Sheri Denkensohn** from the Daily Dilemmas column she used to write, while our social media followers probably know her better as @happyonwheels — one of our most loyal supporters. She has always managed to find time for new endeavors despite a busy schedule doing disability consulting, motivational speaking and more. In this issue we are lucky enough to have her first foray into profile writing, a fun look behind the Broadway debut of actress Jenna Bainbridge. “In addition to learning a lot about writing a profile, I enjoyed interacting with Jenna and I learned a lot about the issues with accessibility and the challenges of being a wheelchair user on Broadway,” says Denkensohn.



As NEW MOBILITY’s unofficial aggregator of product stories, announcements and news, Director of Digital Content Strategy **Seth McBride** is continually scouring the internet and press releases for exciting new things to review. When a representative for Vapor Wheels mentioned his company was collaborating with the celebrity YouTubers behind JerryRigEverything and Not A Wheelchair, McBride took note. He stayed on the story and, thanks to his diligence, we have a first look at a potentially game-changing new wheelchair line. “More affordable wheelchairs are one of the most common things our

readers tell us they are looking for,” says McBride. “It was exciting to see someone who might have the ability to make them a reality trying a new approach.”

**Shannon Kelly** is probably the most fashionable and hip member of our small NEW MOBILITY team, so she was a perfect fit to tackle this month’s Day in the Life profile of interior designer Maegan Blau. “Maegan has a real vision for what she does, and it was cool to see all the different aspects of her job and how she fits them into a typical day,” says Kelly, who also writes our United Spinal section and helps keep communication between NM and United Spinal running smoothly. When Kelly isn’t writing for NEW MOBILITY, she is managing United Spinal’s social media and generating quality content for the organization’s website.



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.

JULY-AUGUST 2024

## My Search for the Best Treatment Option When My Shoulders Went South

Bravo! Great information. I'm a T2 complete para, injured in 1973, post-injury 51 years. Of course, my shoulders are completely whacked! I've had some shots, some PT, etc ... detached and retracted biceps muscle and previously had a brachial plexus in one shoulder. Lastly, dislocated one shoulder from a fall.

Doc said basically, "You need two complete shoulder replacements, and, I'm good at doing it, and can do it for you, but considering your situation you may be better off with what you have if you can tolerate the pain."

It's completely counterintuitive ... because our shoulder problems derive from overuse, but from the day of the above shoulder replacement convo with my doc, I have faithfully ridden my hand bike every single day. It started slowly and it was painful, but little by little I got better and stronger. I have built up every muscle I still have, and it seems to help protect my shoulder and has reduced my pain. I asked my doc, "Why is this working for me?" And he responded that there is less stress on the joint each time I am using it now because I have built up the muscle to protect it. I will be staying the course. There will be no long-term nursing home recovery for me.

**Glen Gregos**

*Newmobility.com*

I wish there had been some comment re: C7 and rotator cuff tears, not to mention preserving those absolutely necessary shoulders if a quad wants to maintain independence. In my 38th year of C7 quad-dom and basically full independence, I tore my left rotator cuff. A

"Anything that you can do to save your shoulders, do it."

year of PT later, things are better but I will never be close to what I had: no more turning myself in bed, in hospital bed for first time, pressure wounds for first time. I am scared to death of losing my right shoulder.

I can't even go into my two months in hospital due to excruciating pain which they didn't even diagnose as rotator cuff for weeks. Instead, I was just an older quad bound for a nursing home. I am a retired aerospace engineer, owned my home for years, drove my van all over this country, gave birth six years post-injury, raised him as a single mom. Now I'm an old quad the hospital couldn't be bothered with. In fact, they made me worse.

**Nancy Rhoads**

*Newmobility.com*

Avoiding shoulder problems for wheelers is easier today than before. You simply avoid manual wheelchairs as much as possible and get yourself a modern 4WD electric wheelchair. Manual dinosaur wheelchairs belong to the past. I bet in a few years no one will want manual wheelchairs.

**Leif Arild Fjellheim**

*Facebook*

## Ways To Help Prevent Shoulder Damage

Remember how much you hated being dependent on others immediately after SCI? After having worked so hard to regain independence, you will really hate losing it for at least eight weeks if you have rotator cuff surgery. Other advice: don't do strenuous repetitive activities that raise your arms above shoulder height ... like washing windows ... keep those elbows tucked into your waist when lifting stuff.

**Madonna Logosz**

*Facebook*



I'm 11 weeks post-rotator cuff repair surgery. Anything that you can do to save your shoulders, do it. If that means using a transfer board instead of transferring without it, having friends push you, using a power assist chair, I strongly encourage you to do it. Also use proper technique when reaching around to pick up things.

**Craig Rittase**

*Facebook*

## Quad Hands

Angie's essay covers something I always thought about, as I felt I was missing out on bonding with the children as my wife is able to. Remarkably, I discovered children, even if they cannot understand or express it, know and want to hug and share love with you just as much as you do with them. This gave me a lot of comfort over the years.

**damian.neville.9**

*Instagram*

## Gear Guide: Lifts

SureHands has the best implementation and design for personal lifts. You mentioned their wall-mounted lift with the Body Support System — it is superior to all others. After reading your article, I contacted SureHands suggesting the incorporation of the Body Support System with their Mobile Lifts.

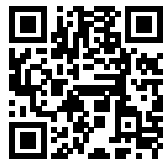
**Bruno Santos**

*Newmobility.com*



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1. Hollister data on file, ref-00814, July 2018

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Making a difference in the journey of life.

A vibrant beach scene under a blue sky with scattered clouds. In the foreground, a long, striped beach mat lies on the sand. Two women are walking away from the camera on the beach. In the background, a lifeguard stand is visible on the right, and several people are scattered across the beach near the water's edge. The ocean is a deep blue-green color.

# Welcome

TO ACCESSIBILITY  
FOR EVERYONE

In Greater Fort Lauderdale, we're excited about welcoming everyone under the sun and providing access for all, from beach wheelchairs and accessible pathways to the Hidden Disabilities Sunflower Program at FLL airport.



Learn more about local resources and plan your trip at [VisitLauderdale.com/Accessibility](https://www.VisitLauderdale.com/Accessibility).



By Shannon Kelly

## Get United Spinal Merch

Now you can look good and rep United Spinal with custom merchandise from the organization's new online store. All profits support United Spinal programs to empower wheelchair users. Be the first in line to check out exciting offerings that include shirts, mugs, totes and more.

Early shoppers can score a \$50 Amazon gift card. Just post a picture of yourself using or wearing your new United Spinal store purchase, tag the United Spinal account on Instagram, X or Facebook and you'll be entered to win. Find out more at [unitedspinal.org](http://unitedspinal.org).



Houck

## Virtual Roll on Capitol Hill

This June, 200 United Spinal Association advocates and allies attended the 12th annual Roll on Capitol Hill, participating in over 200 online meetings with federal representatives. They urged policymakers to reform wheelchair service and repair standards, expand access to care support, and maximize rehabilitation outcomes for wheelchair users.

"This was my second year doing Roll on Capitol Hill, and my first virtual experience was amazing," says Tyra Randle, an advocate and wheelchair user in Missouri. "For my state's representative to see me as a constituent and sympathize with our cause meant the world. They may not have been disabled themselves, but they knew someone with a disability they were close to. I felt like my voice was heard."

Photo by Ryann Mason

**"I felt like my voice was heard."**

The Roll on Capitol Hill brought progress, but the work is far from over. To be part of the change and take action, visit [unitedspinal.org/advocacy-program](http://unitedspinal.org/advocacy-program).

## Meet Member Greg Houck

C5-6 quad, Age 53 from Rio Rico, Arizona  
Hobby: Wheelchair Rugby

### Why did you join United Spinal?

I was introduced to United Spinal through my participation in the Pathways to Employment program. I then went on to work on several workgroups and am currently working on starting a United Spinal Chapter in Arizona.

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

Three products from Total Incontinence Management: 1) Hygienic Wash & Cream — great scent and works as a wound barrier; 2) Bed Underpads — great protection against accidents, especially at night; 3) Extra Large Premium Wipes — very gentle on the skin and one will clean a large area. I've been in a chair 38 years and I wish I'd had these products from the beginning.

### If you could change one thing in the world, what would it be?

We need to change the minimal standards of the ADA to improve parking, transportation, parks, restaurants, stores, etc. Mandate compliance, or these places should face fines/closure.

## New Group for Semi-Ambulatory, Part-Time Wheelchair Users

United Spinal's newest peer support group, Walking Rollers, is a space for semi-ambulatory, part-time wheelchair users. The group will be facilitated by Rob Henry, a board member for United Spinal Association of Michigan who coordinates the chapter's peer mentor program.

He was diagnosed with Guillain-Barre syndrome in January 2019 and paralyzed from the neck down. Through physical therapy he regained the ability to walk for short distances, but uses a power wheelchair as his main method of mobility.

Henry hopes the group can show participants that they don't have to feel guilty about the stigma that surrounds ambulatory wheelchair users. "I know at times people will look at somebody who can stand up from a wheelchair and rudely say 'Why do you use a wheelchair if you can walk?' I know I've gotten funny looks before," says Henry. "I hope this group shows that there are many others out there like them, and helps them navigate the world in an easier way."

Join Walking Rollers on the fourth Monday of every month at [unitedspinal.org/events/walking-rollers](https://unitedspinal.org/events/walking-rollers).



## Celebrating the 25th Anniversary of the *Olmstead* Decision

The landmark *Olmstead v. L.C.* Supreme Court decision turned 25 in June. It was the first time the Americans with Disabilities Act was used to protect the rights of people with disabilities to receive care in our communities rather than in institutions.

At the Department of Justice's *Olmstead* celebration, United Spinal member Garret Frey shared with an audience how the historic ruling meant he could grow up in his parent's home after being paralyzed at age 4 in a motorcycle accident. "I am fortunate to have always lived within my home, and I have been blessed to have the support of my family and many great friends," said Frey, an advocate and member of United Spinal's Iowa chapter. He explained that living in his home would be impossible without the caregivers who help him throughout the day. "They are my hands," he said.

At the time of the decision, his family was locked in a 12-year court battle to get young Frey community services. Because of *Olmstead*, they won their case and he was able to get the supports he needed to stay with his family.

Recently Frey settled a successful complaint against the state of Iowa with the Office of Civil Rights. He had needed his daily hours increased so he could remain in his home.

"My life and my family's life have positively changed," he said to the audience. "I now have 24/7 care coverage along with respite services. I was also able to recruit and pay caregivers a livable wage."

He receives nursing care twice a week, with overnight and daytime coverage. "These supports have helped me live a more productive, active and independent life," he said.

Frey's story is a powerful reminder that the struggle for community services continues and *Olmstead* remains a potent tool in that fight.



# ROADMAPS

By Rebekah Taussig and Hannah Soyer

## NAVIGATING MY RELATIONSHIP WITH MY PARENTS

**Dear Rebekah and Hannah,**

*I feel super fortunate to have a family that has supported me at every turn since I was paralyzed, but after seven years, I'm worried they may be cramping my style. My mom does all my care and my dad does most of the driving me around. I don't have the money to hire enough staff to replace them, but I need some breathing room. How can I carve out some independence without hurting our relationships?*  
*Needing Space*

**Dear Needing Space,**

The line between parents and their children can be complicated in lots of families, but disability is one layer that can make those boundaries even blurrier and more difficult to define and hold. I'm not in the position of needing to rely on my parents for daily care, so I know my relationship with independence differs from yours. Even so, as I read your words, I found myself flashing back to the many times I've been forced to rely heavily on my parents. I've moved back into their home three times as an adult — once at 23 after a divorce, once at 29 when my roommate situation shifted, once at 36 when the home I'd been living in with my partner and our baby became inhospitable to us, and our whole family moved back into my childhood bedroom. Each time, my current living situation ended before I could find a new accessible, affordable place to live. Each time, the hunt for a new home felt impossible. Each time, I felt the confusing tension between deep gratitude for my parents' help and resentment that I needed it at all.

We're often in that position, aren't we? The world as it's been built has not prioritized spaces where we can thrive. Finding employment, saving money, affording good, reliable care, acquiring a healthcare setup that doesn't require us to stay in poverty — it's a piece-by-piece building project and can feel like trying to construct a tiny planet from scratch in a windstorm. Even when we're hard at work, trying to build a life for ourselves, so many of us find ourselves forced into relying on our families. I've seen how

this kind of relationship can offer a picture of interdependence and a care that laughs in the face of our culture's worship of independence above all else. I've also seen how these forced relationship dynamics can make it really difficult to carve out a space for self-definition — practically and psychologically.

I imagine you know there are many resources out there that can help you do the practical work to assemble a life of more autonomy (see Resources, page 15). And while the process of researching options and taking steps can be overwhelming and full of starts and stops, the steps do add up and often pay off. As I've been reading and rereading your question, though, the most pronounced longing I hear is for a deep breath — a chance to find and assert your own unhampered style — all within a complex relationship dynamic with people you need close and want distance from. It's a path that's hard to chart with a Google search, but it's one I've been trying to piece together for years.

One of my earliest memories is the sound of my dad's voice reading me stories in the quiet moments between the pounding, pounding, pounding of the MRI machine. I'm almost 40 now — my parents in their 70s — and still, whenever I'm with them, I'm also a little kid tucked beneath their wings. For years, we were a trio, doing battle against cancer, against pain, against inaccessibility. I clung to them. Even now, I feel the ways I cling to them. We were all shaped by my early cancer and paralysis, but as I got older, I struggled to understand where their experience ended and mine began. Asserting any kind of separateness — developing my own perspective, telling a different story — felt like a betrayal of the ones I am so lucky to have and to whom I owe so much.

I've found two portals that helped me sink deeper into my own sense of self. Writing was my first entrance into the wide-open spaces that allowed me to tell my own stories for myself. It was through self-narration that I remembered my own experience of being a tiny child in those MRI machines — how every time my dad's voice disappeared in that pounding, pounding, pounding,

Each time, I felt the confusing tension between deep gratitude for my parents' help and resentment that I needed it at all.

I would close my eyes, picture myself in a rocket, and leave my body for outer space.

My parents were there with me, and there were places they could not go. I'd depended on them for my survival, and also, I'd found my own ways to survive. I didn't understand that until I wrote it. The other way I started to feel myself bloom was through friendships with other folks who live with disability, others who moved through the world the way I do. I recognized my own experience more clearly when I saw it reflected back to me in them. I dreamed more for myself when I witnessed them living bigger, softer, bolder than I knew I could.

All of this makes me wonder — what are the stories that live inside of you alone? Where are the places — what are the experiences — your parents can't access, even if they wanted to? What are the secrets your body holds? And who might listen to you share them with a great big exhale of knowing? I find myself wondering what kinds of deep breaths you might be able to take as you explore the infinite space of your internal and interpersonal worlds. I wonder what kind of style might emerge as you mark the map of your own story among companions who've traveled some of the same roads.

Love,  
Rebekah

### Dear Needing Space,

After finishing grad school in Kansas, where I lived on my own with the help of hired caregivers, I moved back home to Iowa to live with my parents. I hoped that I'd be able to move into my own apartment again within months, that finding enough caregivers and an accessible apartment in such a short time-frame would be a breeze. Suffice it to say, this didn't happen.

I love my family very much, and, like you, feel very lucky to have such fiercely supportive parents with whom I have a very good relationship. But straining against any sort of limitations

to our autonomy is hard, especially when we keep coming up against the same barriers, and especially when those barriers are so often systemic.

My case manager had successfully written a Medicaid Exception to Policy (something you should look into) which increased my allotted hours of care to the amount I needed, a process which had been such an exhausting battle, getting the Notice of Decision in my favor felt like a miracle. It is not lost on me that this miracle is in part due to the fact that my parents

have always been my fiercest advocates, and that my case manager understands my needs and fights for them — something which is not always the case for people dependent upon state-funded services.

And yet, even with this Exception to Policy in place, finding enough caregivers for me to move into my own space again felt like searching for wildflowers in acres of dirt. I'm sure you know why it's so hard to find caregivers as well as I do — low wages, lack of insurance benefits, a care workforce depleted by a global pandemic (just to name a few).

Sometimes, within the walls of my parents' house, I felt these barriers coalesce into a net, which seemed to shrink closer and closer around me until I could feel the fibers scratching at my skin. As if on

instinct, I turned to an activity from my childhood — going for strolls around my community — except unlike in childhood, this time, I walked (rolled) by myself.

Being alone was liberating, invigorating. I didn't like to decide where I was going before I left. Of course, all routes lead back to the driveway of our house, the shade cast by the ash tree out front, the "can you let me inside now?" text to my mom. But the space in-between leaving and returning was ripe with possibility, a time to sink into the rhythm of the sidewalk felt through my wheelchair, the rhythm of words in my mind. It was time to be alone, although only to an extent — I ran into neighbors



frequently, witnessed squirrels and birds and insects going about their daily lives. My walks were a chance to feel held by the environment around me, and just as importantly, a time and space for me to grow far, far beyond any walls or net.

It took me over a year to cobble together enough long-term caregivers for me to move into my own apartment, and another year before I had a stable care situation. I'm lucky, as I live in a sizable city with a steady supply of college students. Soon, however, I'll be losing a handful of these helpers as they move away for various reasons. The stability of my current situation is always in flux, as is my living environment — having twelve different people come in and out of my apartment on a weekly basis to be my arms and legs can be its own sort of exhausting. When I feel the net shrinking around me again, I do what I've learned to do: take solo walks around my community.

At the end of the day, those of us dependent on caregivers to keep us alive must find ways to carve out our own space and story, from day to day, in whatever present reality we find

It took me over a year to cobble together enough long-term caregivers for me to move into my own apartment, and another year before I had a stable care situation.

ourselves in. I don't know if you're able to go on walks by yourself around your neighborhood (I had to assure my parents I'd be OK and remind my mom how to view my location on her phone in case she got worried), or if you even enjoy the outdoors. But I do know that this space we hold just for ourselves can come in every shape imaginable, and taking the time to occupy that space is sacred. Are there places you can be without your parents there, too? Are there activities or passions that you could cradle and nurture as just your own? I know these suggestions don't solve the overarching problem of lacking outside caregivers. But they might help you breathe deeper in your current situation, which you very much deserve.

Love,  
Hannah

*This is the final installment of Roadmaps in NEW MOBILITY, but you can subscribe to the column on Substack at [messyroadmaps.substack.com](https://messyroadmaps.substack.com), and you can still submit questions to Rebekah Taussig and Hannah Soyer at [messyroadmaps@gmail.com](mailto:messyroadmaps@gmail.com).*

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Employment Services

## RESOURCES FOR INDEPENDENT LIVING

United Spinal Association is committed to helping you become more independent via an array of programs tailored to your specific needs.

United Spinal's Resource Center offers a help desk staffed by information specialists – wheelchair users and disability experts – trained to answer your questions and supply you with additional information and resources. You can call 800/962-9629 or submit an inquiry at [unitedspinal.org/ask-us](http://unitedspinal.org/ask-us).

United Spinal's Chapter Network has over 40 branches nationwide supporting wheelchair users by promoting health and well-being, inclusion and independence, organizing local events, advocating for rights and accessibility and offering infor-

mation and support to their chapter communities. [unitedspinal.org/support/chapter-network](http://unitedspinal.org/support/chapter-network).

United Spinal also offers one-on-one peer mentoring that matches you with someone else with a similar injury, gender and lifestyle that lives in your area. They provide friendship, support and camaraderie and can help you work towards your goals of greater independence. [unitedspinal.org/peer-mentoring](http://unitedspinal.org/peer-mentoring).

Here are some other excellent local and national resources.

- Centers for Independent Living (CILs) offer resources and information related to living as independently as possible. Locate a CIL near you: [ilru.org/projects/cil-net/cil-center-and-](http://ilru.org/projects/cil-net/cil-center-and-)

[association-directory](http://association-directory)

- Medicaid Consumer-Directed Personal Assistance Programs provide an alternative way of receiving home care services in which consumers have more control over who provides their care and how it is provided.

- Vocational Rehabilitation is a federally funded program designed to help individuals with disabilities prepare for, secure, retain, or regain employment. Find VR in your state: [rsa.ed.gov/about/states](http://rsa.ed.gov/about/states).

- National Paralysis Resource Center (where Roadmaps author Hannah Soyer works) provides free, comprehensive resources and programs for people living with paralysis, their families, and caregivers. Visit [ChristopherReeve.org/ask](http://ChristopherReeve.org/ask).



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# NOLAND ARBAUGH'S LIFE AS THE FIRST NEURALINK RECIPIENT

BY IAN RUDER

**B**efore Noland Arbaugh became the first person to have Neuralink's brain computer interface implanted in January, before he used it to break the world record for speed and precision controlling a cursor with your brain, and before he did a media tour

that would make even some Hollywood A-listers jealous, Arbaugh was like many other high-level quadriplegics trying to find their path post-injury.

Since dislocating his C4-5 vertebrae in a 2016 swimming accident, Arbaugh had dropped out of Texas A&M and re-

turned to live with his family in Yuma, Arizona. Due to the combination of Yuma's scorching heat — from May to September the average high temperature is 99 degrees or more — and the intense spasms he experienced when sitting in his power chair, Arbaugh

spent most of his time in bed, watching TV. With no sensation or function below his shoulders and having limited caregiving hours provided by the state, he relied heavily on his parents and brother and often felt like a burden.

When a friend suggested he apply to Neuralink, Arbaugh knew he was ready for a change. “In seven-plus years of being a quad, I’d not had much opportunity to do a whole lot with my life, and I thought that this would be my chance,” he says.

## ‘A WHOLE NEW WORLD’

Neuralink has brought more visibility to BCI than any of its predecessors, in part thanks to its founder — tech billionaire Elon Musk — and its novel implementation. Unlike other BCIs that require the user to be plugged in, Neuralink uses a coin-sized implant that sits under the skull and transmits wirelessly via Bluetooth. Small threads connect the implant directly to the brain and read electrical spikes in the neurons, allowing the implant to learn what Arbaugh is trying to do. Most of the early research involves using his thoughts to control a digital cursor via an app designed by the Neuralink engineers.

The prospect of having 64 microscopic threads attached to your brain in a first-of-its kind surgery might seem daunting, but Arbaugh says he wasn’t too concerned. “I’m really grounded in my faith, so I felt like I was ready for whatever was to come,” he says. The desire to give back to his parents after all they did for him clearly factored in his decision. “I thought about how it might change my life and how it might change my parents’ lives. It could open up a lot of doors for us, for me, and then, by proxy, them. It made me feel like, if I was ever going to give back to them, this was my opportunity.”

Surgeons implanted the device on January 29, 2024, and by March 20,

Arbaugh was live on X, showing off his new ability to move the cursor and click with his mind. In the early days, Arbaugh spent 8-10 hours a day working to train the software with Neuralink staff. Neuralink reported Arbaugh broke the world record for human BCI cursor control in his first session.

When he wasn’t working, he was making up for lost time. “At the beginning, in my free time, I was doing nothing but playing video games,” he says. He had tried adaptive mice and other voice software prior to the implant, but never found any that gave him the level of control he desired. The implant made playing into the wee hours of the morning easy. “I missed playing games so much that I just played for hours and hours and hours. ... It’s addicting. It’s so much fun — it opens up a whole new world.”

In May, Neuralink revealed that a number of the threads had retracted from Arbaugh’s brain, likely as a result of his brain moving more than Neuralink had anticipated. In addition to impeding his speed and control moving the cursor, the retractions forced him to adapt to a more cumbersome way of clicking.

“To lose all of that kind of sucked,” he says. “I was pretty upset when I first found out, but I just realized that everything that I go through now will make this better and will help other people down the road. After a few days of being down in the dumps, I got right back up.”

Instead of trying to reconnect the threads via surgery, engineers reworked the software and ended up boosting his speed despite having fewer connected

threads. “The thing about these Neuralink guys is they can do anything,” says an impressed Arbaugh. Additionally, the developers built a custom speech-to-text program that he says is far superior to what is on the market, and they have helped him improve his home automation setup to boost his independence.

## FINDING PURPOSE

Because Arbaugh is part of an FDA study on the implant, there are limits on what Neuralink can provide. He is not compensated, and they cannot pay for his normal care. That means his family is still doing all of his care, except for the 10-15 hours a week he receives from a state-paid caregiver.

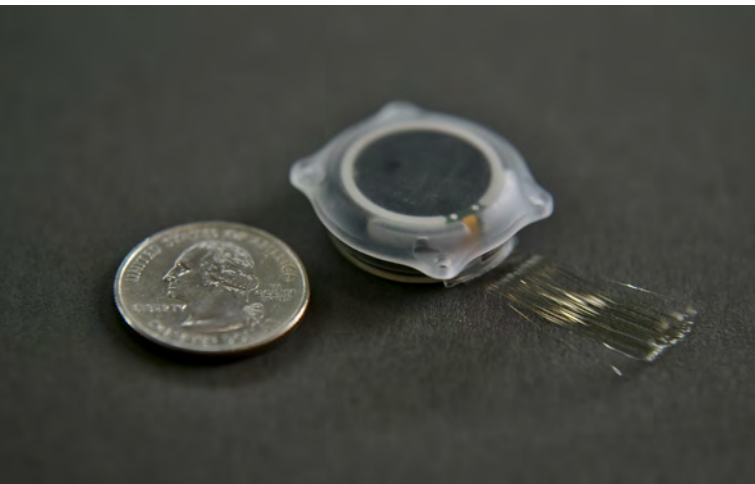
“Before, I would wake up and just [watch] my TV,” he says. “Now, I wake up and [work] on my computer. It’s very similar, but at the same time, my daily



Arbaugh works with developers and engineers from Neuralink to learn and improve how the implant works.

routine has changed from just watching stuff to being more active and interactive with the world.”

Arbaugh still spends upwards of four hours a day working directly with the Neuralink team on improving the app and understanding how the implant works. He says using the implant isn’t that mentally draining, but he makes sure to take breaks so as not to burn out. “I’m trying to be a lot



**Left: The coin-sized Neuralink implant contains a small battery, advanced low-power chips and 64 threads containing 1024 electrodes. Right: A wireless charger is used to recharge the implant battery.**

more intentional with it,” he says, “so not as many video games, and more focus on making the app better for people who come after me.”

Aside from setting new world records for speed and accuracy, perhaps Arbaugh’s biggest breakthrough has been realizing that the implant can respond to imagined movements in addition to attempted movements. Originally, Arbaugh controlled the cursor by attempting to move his arm and hand in the desired direction. His arm and hand wouldn’t move, but the neurons would fire, the implant would pick that up and move the cursor correspondingly.

“At some point, I realized I could just move the cursor around with my thoughts. I could just think cursor go here and it would move and that worked just as well, if not better,” says Arbaugh. Researchers dubbed this imagined movement. “That blew my mind when it happened for the first time, and it kind of supplanted the attempted movements.”

“We’re just now scratching the surface of the capabilities and possibilities of this thing,” he adds. He has been working to train the implant to recognize sign language and thinks texting is one of many future capabilities. “I think down the road, it’s going to make a lot of people’s lives a lot better and make people much more

independent and much more capable of doing a lot of things.”

As the first recipient, Arbaugh knew there would be setbacks and that he likely wouldn’t reap all the benefits that future users would, but he seems very happy with the functionality he has gained and his contribution to the field. He has no current plans to have the retracted threads surgically reinserted, or to get a future version installed.

When he is not working on Neuralink business, the implant is at the center of his rigorous online self-improvement plan. He is teaching himself Japanese and French, relearning math from the ground up and working through self-help books.

“There’s this bottomless pit of everything there is to learn in the world, and I just don’t know where to start,” he says. “So, I just thought if I could learn one thing every day, that’s a good place.” Arbaugh hopes all his educational efforts will make a possible return to college easier and help him towards a job and financial independence.

## MEDIA FRENZY

Thanks to a steady stream of media appearances, and his new connection to Musk’s empire, Arbaugh is well positioned to have an impact beyond BCI, should he decide he wants to. He

has been featured in most major newspapers and websites and has guested on a number of popular podcasts, including the most-listened-to show in America, *The Joe Rogan Experience*. “It was a cool experience with someone on my bucket list,” says Arbaugh. “I was always worried that we wouldn’t have enough to talk about, but the hour and a half went by really, really quickly.”

On the same trip he recorded the interview — for which he flew for the first time since immediately after his injury — Arbaugh also got to meet Musk in person and tour many of his Texas facilities. The two chatted about the future of Neuralink, Musk’s space venture, Space X, and family. “It was super cool and really quick, but I’m glad I finally got the chance to sit down and talk to him.”

Despite the bucket list encounters and media attention, Arbaugh is adamant his focus is elsewhere. “That was never something I was really looking forward to in this whole process,” he says. “All I’ve been trying to find a way to do is help people, share my faith and get the news about Neuralink out there.”

This August, Neuralink announced that a second person had received their implant. If you are interested in finding out more about Neuralink, or signing up to be considered for future implants, visit [neuralink.com](https://neuralink.com). NM

# SHIFTING BROADWAY'S SPOTLIGHT TOWARD INCLUSION

BY SHERI DENKENSOHN



Photo by Jenny Anderson

Jenna Bainbridge

Amid the scrapbooks and memorabilia documenting Jenna Bainbridge's childhood, there's video footage of her at 15, insisting, "I will never be on Broadway." Despite performing since age 12, and graduating from Denver's Lamont School of Music, Bainbridge — who sustained a spinal cord injury at 18 months — couldn't envision herself performing in the nation's premier theaters as a wheelchair user.

Now those scrapbooks will have to add a new photo, capturing Bainbridge's speechlessness upon learning last year that the musical she had been cast in, *Suffs*, was headed to Broadway. "I was ecstatic about the opportunity," she says, "but at the same time I was left with the questions I often end up with: 'Why is the history and lived experience of those with disabilities not present in Broadway productions? Why aren't there more disabled playwrights?'" Bainbridge feels there is value in having a disabled character play a nondisabled role, but she is also striving for larger goals, like helping others understand the importance of showing disability as part of our history and culture.

# ACT 1:

## THE DREAM OPPORTUNITY

For years, Bainbridge acted in local productions and gave voice lessons, and when the pandemic hit, she was working in the Oregon Shakespeare Festival in Ashland, Oregon. To maintain her unemployment benefits, she had to audition for a certain number of shows per week. “I decided to try out for any pipe dream job,” she says. One audition in particular caught her eye: *Suffs* at The Public, one of New York’s premier nonprofit theaters.

Bainbridge had long wanted to work with The Public, and everything seemed to be aligning as the theater had started offering video auditions during the pandemic. “The concept of auditioning remotely opened opportunities for actors with disabilities. If not for that, I don’t know if I would’ve auditioned,” she says. Bainbridge was upfront about her disability and sent a wide-angle shot so the producers could clearly see her wheelchair.

# ACT 2:

## THE BIG CITY

When Bainbridge found out she had been cast as a member of the ensemble, she quickly had to decide if she would go to New York City. Luckily, her sister was living near the city, and she

was able to live with her for the workshop. Bainbridge and her husband opted to live outside the city. “I wanted to maintain my suburban life and still experience the hustle and bustle of Manhattan,” she says.

Her first challenge as a disabled actor in New York was transportation. “I was daunted by the idea of trying to make New York accessible for me,” she says. “I was used to the suburbs and driving everywhere. It sounds crazy, but I never envisioned that I could drive in New York.” Public transportation was a big challenge, but Bainbridge made sure her contract with The Public included nearby parking.

# ACT 3:

## BROADWAY BECKONS

The next challenge Bainbridge anticipated was accessibility. Fortunately, The Public’s architecture readily accommodated Bainbridge’s wheelchair. The stage level had no steps and there was an elevator to the third level for any scenes there. There was an accessible bathroom, but it was inconvenient to access from where the performers were located. “The producers were very open to working with me and told me that the backstage bathroom was not ADA-compliant, but they would do whatever was needed to fit my needs. I was able to use the bathroom, so it worked out,” she says. “Their open communication about accessibility challenges and willingness to make accommodations was refreshing.”

The show’s run at The Public came to an end in the spring of 2022, and in October 2023 it was announced that *Suffs* would make the move to Broadway’s Music Box Theatre in March 2024. On the positive side, the theater was on Broadway. On the negative, like many Broadway houses, the Music Box is designated a historical landmark, and its layout poses significant physical barriers.

“The producers supported me,” says Bainbridge. Just for access to the stage door, the crew had to build a ramp. Immediately inside the stage door there was another ramp on three steps. The crew built railings because of its steepness. “I doubt most wheelchair users without significant strength could get up that ramp,” she says. They also converted a closet on the stage level into a



The directors of *Suffs* sought out a diverse cast.

dressing room and installed an accessible bathroom for cast members on that level. “When I leave this theater, I know that it has been made more accessible,” she says. “It may not be perfectly accessible, [but] I am hopeful that the modifications will be retained because it benefits wheelchair users and hopefully ... the entire cast.”

## ACT 4:

### BRIGHT LIGHTS, BUSY SCHEDULES

Bainbridge points out that starring in the ensemble is physically demanding regardless of disability. A typical day starts by driving to the theater and arriving by noon, with extensive stretching to get warm and flexible. Bainbridge does not get home until midnight. “The days are long, and especially exhausting when we have five performances in a row,” says Bainbridge. “We are dancing the entire time. Once the performance begins, it is like being shot out of a cannon. ... Between performances there are cots provided by the union for resting and napping. Sometimes I choose to rest and other times I have the energy to go out for a meal with members of the cast.”

Bainbridge wonders if Broadway should rethink its scheduling. “This is the time to rethink how theater, and especially Broadway, works,” she says, adding that *Suffs* has performances Friday night at 7 p.m., Saturday at 2 p.m. and 8 p.m., and then Sunday at 3 p.m. “Weekends are extraordinarily brutal. ... Should we be having so many performances in a row?” she says. As Bainbridge points out, this grueling regimen is partially built into the very ethos of Broadway. “There is nothing more ableist than the saying, ‘the show must go on,’” she says. Difficulties aside, Bainbridge loves her roles. From the outset, the directors worked with her so as an ambulatory wheelchair user she could play both seated and standing roles. “This show was built so that it would be accessible for me. I always play the same roles, but I have a choice to either walk or use my wheelchair,” she says.

## ACT 5:

### A BETTER FUTURE

When asked if Broadway has made significant progress toward accessibility, Bainbridge is hesitant. She praises the inclusive viewpoints of *Suffs*’ writers, directors, producers and choreographers. “Because of the subject matter of the play, from the outset they wanted a diverse cast,” she says. “They made it clear that they would work with me and wanted my input.” But she sees significant room for improvement across Broadway.

Bainbridge is eager to work through her firm, Consult-



Bainbridge enjoys the audience reaction to her first performance of Doris Stevens.

“

This is the time to rethink how theater, and especially Broadway, works. There is nothing more ableist than the saying, ‘the show must go on.’

Ability, educating theatre companies, unions and educational institutions about access on Broadway and beyond. “Until we get accessibility built into safety budgets, there will be no change,” she says. “We need the architects and everyone involved in theater to understand that access is not an aesthetic, it is a part of life.”

Bainbridge says, “The biggest gratification for me is getting messages from individuals seeing what I do and visualizing their dreams. Whether they are going to be an actor, advocate, journalist [or] senator, they see that it is possible. For those with disabilities [who] want to perform on stage, it makes me passionate to make change.”

MI



FINDING SISTERHOOD AND SPORT IN  
**ADAPTIVE  
MOUNTAIN  
BIKING**

BY CHERYL ANGELELLI

PHOTOS BY RONIA NASH

**S**ierra Roth loves adaptive mountain biking. Barreling down slick mountainsides at over 20 mph while careening past sudden drop-offs, navigating steep climbs and rocky terrain and being surrounded in thick, green forest are a few of the reasons. But there's another perk of the sport that keeps bringing her and many others back: It's an amazing way to find disability community.

A self-described adrenaline junkie from Calgary, Alberta, Roth says that in many ways adaptive mountain biking reminds her of her former life as a motocross racer. The 27-year-old competed in Canada's national women's series until 2013, when she sustained a T6 spinal cord injury in a motocross accident.

"Growing up 45 minutes from the Rocky Mountains, I spent a lot of time biking and snowboarding. So when my injury happened, that was probably the hardest thing — not doing all those things," says Roth. "Adaptive mountain biking has given me an opportunity to do things with family and friends that I used to do and given me a piece of my life back."

Some friends with SCI, also injured in motocross accidents, introduced her to the sport in 2021. She bought an adaptive mountain bike and, a month later, those same friends talked her into doing her first downhill race series. From that moment on, she was hooked on the sport.

At that first race, however, there was one thing that really stood out to her ... she was the only woman.

## CREATING A SAFE SPACE

Hoping to change that, Roth started an all-women's adaptive mountain biking retreat in 2021 to introduce more women to the sport. "I found that a lot of outdoor adaptive recreation wasn't really geared toward women," she says. "I wanted to create a safe space for women to learn the bikes, have a good supportive crew around them and just have a good time being outside." It also inspired her to become a certified adaptive mountain biking coach in 2021 through the Professional Mountain Bike Instructor Association. The certification was started to help get more individuals with disabilities on bikes through safer, better learning experiences. "I realized how important it was for someone like me [as a wheelchair user] to be coaching because adaptive mountain bikes are



**"ADAPTIVE MOUNTAIN BIKING HAS GIVEN ME A PIECE OF MY LIFE BACK."**

**SIERRA ROTH**

an intimidating thing to learn," she says.

The annual retreats bring together as many as seven adaptive riders, with Roth as coach and mentor. The past two retreats have been held in Arizona and Squamish, British Columbia. Most of the women are newly injured, so traveling with a disability is the first hurdle they have to navigate. The women are together 24/7 for about a week, including three days of active mountain biking, riding an average of 6-8 miles a day, but the real magic happens in the moments between trail rides.

"We get to see really vulnerable sides of our participants, which I think is a big part of being a woman with a disability moving through soci-



Adaptive riders (left to right) Lorinda Bye, Elsa Lalonde, Laura McNutty, Ryan Barbée and Chelsea Ogilvie.

ety,” says Sierra McCann, a nondisabled retreat coordinator. “Yes, we talk about riding bikes and the best catheter to use on the trail, but we also talk about dating, or being a mom. It’s like the stress of navigating an inaccessible world is slightly taken off you because you’re with a group of people who get you. Most of us have formed a friendship and have stayed connected afterwards.”

Roth says it’s very rewarding to see the confidence that women gain from the retreat, and the ripple effect it has when they take what they’ve learned back to their own communities.

## GIRL POWER

Jen Gadoua, 44, is one of those women. She attended her first of three retreats in 2021, shortly after sustaining an L2 spinal cord injury. “Before my accident I had never been around another wheelchair user. I learned more in that [retreat] experience in a few days than I had in a year and a half [of living with a disability]. Like how to cath on the trail. It was really transformative to be within my community,” she says. “And it’s not so injury-focused. People aren’t sitting around sharing their sob stories — they are sharing real stories about practical life. There is an instant understanding that comes from being among your peers.”

Prior to her accident, Gadoua used to run trails. “Being able to get outside to a place where a normal wheelchair can’t go was what was missing for me. And you don’t fit in anymore with your regular group of outdoors people. My adaptive mountain biking friends are my new social group. We have a group chat where everybody is so stoked

to talk about bikes and when the next trip or adventure is going to be,” she says.

Gadoua and three adaptive mountain biking friends are trying to start a program around Kitchener, Ontario. They are fundraising for equipment and working with trail builders on how to make trails and the entire experience more accessible and inclusive to riders with disabilities.

The retreat also helped her find her voice to advocate for herself and others. “Before the retreat, I would have never spoken up for myself or complained about something not being accessible — I just wanted to blend in. I know biking isn’t really related to that, but in a way, it is helping me to develop that assertiveness,” she says.

Gadoua plans to become a certified adaptive mountain bike coach like Roth and is looking forward to helping others find joy in a sport that has given her so much. “At last year’s retreat we had two newly injured quads and they were learning how to use different hand controls and doing so well. There is something about watching other people’s joy and being able to spread it,” she says. “I know what it did for me, and having this sport that I look forward to and an activity and a social group and a connection to people — it gives you something to work toward.”

Roth remains dedicated to growing the sport by blazing a path on and off the trail. Retreats have shown how valuable carving out a space dedicated to women can be, and they’ve also brought a lot of joy to Roth’s personal life. Adaptive mountain biking “has introduced me to a community of people I didn’t know existed and needed in my life,” she says. **MI**



Gadoua

## HOW TO GET INVOLVED

Today, Roth works for Bowhead Corp, an industry leader in adaptive mountain-bike design. Other brands, like ReActive Adaptations, Sport-On and Lasher Sport, also offer off-road capable handcycles. The quickly improving technology in adaptive mountain bikes, pushed along in part by the rise of light-weight e-assist motors, is enabling more people to get into the sport and explore terrain they wouldn't be able to with arm power alone. However, e-assist adaptive mountain bikes can start at \$13,000 to \$16,000, with upgraded components taking prices even higher. Organizations like the High Fives Foundation and the Kelly Brush Foundation offer grants to help offset the cost of this equipment.

Most adaptive mountain bikes are custom-ordered, so Roth encourages others to try before they buy. Her retreats and other adaptive sports organizations hold camps and clinics where you can try bikes and receive instruction and support. The Kelly Brush Foundation's Active Project features a search engine (see resources) that can help you find an adaptive sports organization offering mountain biking near you. Follow Sierra Roth on Instagram @sierraroth22 to learn about upcoming retreats.

## RESOURCES

- Adaptive Sports Organizations, [activeproject.kellybrushfoundation.org/programs](http://activeproject.kellybrushfoundation.org/programs)
- Adaptive Mountain Biking Equipment, [activeproject.kellybrushfoundation.org/sports/mountain-biking](http://activeproject.kellybrushfoundation.org/sports/mountain-biking)
- High Fives Foundation, [highfivesfoundation.org/program/empowerment-fund](http://highfivesfoundation.org/program/empowerment-fund)
- Kelly Brush Foundation Grants, [kellybrushfoundation.org/theactive-fund](http://kellybrushfoundation.org/theactive-fund)
- Social channels: @bowheadcorp @squamishadaptivemountainbiking

Ryan Barbee enjoys a trail, thanks in part to equipment like the Bowhead Reach ([bowheadcorp.com](http://bowheadcorp.com)).



**“THERE IS SOMETHING ABOUT WATCHING OTHER PEOPLE’S JOY AND BEING ABLE TO SPREAD IT. I KNOW WHAT IT DID FOR ME, AND HAVING THIS SPORT THAT I LOOK FORWARD TO AND AN ACTIVITY AND A SOCIAL GROUP AND A CONNECTION TO PEOPLE — IT GIVES YOU SOMETHING TO WORK TOWARD.”**

JEN GADOUA

# NAVIGATING THE JOURNEY **BACK TO WORK** WITH THE TICKET TO WORK PROGRAM

**R**eturning to work after a spinal cord injury (SCI) can be a challenging journey filled with physical, emotional and logistical hurdles. Employment rates among individuals with SCI are lower than those of the general population.

According to a statistical report from the National Spinal Cord Injury Statistical Center (NSCISC), only about 19% of people with SCI are employed one year after their injury, and this rate increases to about 36% after 20 years. Common challenges include physical limitations, the need for workplace accommodations, and psychological barriers such as depression and lack of confidence. However, with the right support and resources, individuals with SCI can successfully re-enter the workforce, reclaiming their independence and improving their quality of life.

One of the key resources available to assist in this transition is the Ticket to Work (TTW) Program, a little known component of Social Security Disability Insurance (SSDI). The valuable combined benefits that come with SSDI include monthly income, as well as free assistance returning to work with Social Security-authorized Employment Networks like Allsup Employment Services (AES).

## UNDERSTANDING TICKET TO WORK AND THE VALUE OF RETURNING TO WORK

The Ticket to Work Program helps individuals with disabilities find and retain work while protecting their disability benefits. This free and voluntary program offers personalized support, including career counseling, job training, job search assistance, and help with accommodations.

Returning to work after an SCI is important for several reasons. Firstly, it offers financial stability. Many individuals with disabilities rely on SSDI or Supplemental Security Income (SSI) benefits and, while this provides income, it is limited. Employment can provide a more substantial and adjustable income, reducing financial stress.

Secondly, work plays a significant role in improving mental health and well-being. Engaging in meaningful activities and contributing to society can enhance self-esteem and reduce feelings of isolation and depression. Work also provides a sense of purpose and routine, which is beneficial for overall mental health, as explained in a recent study on individuals with SCI.

Lastly, employment fosters social connections. The workplace is a social environment where individuals can interact with colleagues, form friendships and build support networks. These social interactions are vital for emotional health and can aid in the recovery and adjustment process after SCI.

## HOW THE TICKET TO WORK PROGRAM SUPPORTS EMPLOYMENT

The Ticket to Work Program helps individuals with SCI navigate their return to work. Here's how it works:

**1. Individualized Work Plans:** Participants work with Employment Networks (ENs) or state vocational rehabilitation (VR) agencies to create a customized work plan. This plan outlines the steps needed to achieve their employment goals, including any training or education required.

**2. Job Training and Education:** The program provides access to job training and educational opportunities to help individuals develop the skills necessary for their desired careers. This can include vocational training, college courses or certification programs.

**3. Job Search Assistance:** ENs and VR agencies assist participants in finding job opportunities that match their skills and interests. They also provide support in preparing resumes, practicing interview techniques, and navigating the job application process.

**4. Workplace Accommodations:** The program helps participants understand their rights under the Americans with Disabilities Act (ADA) and educates them on requesting reasonable accommodations from employers. These accommodations can include modified work schedules, assistive technology and changes to the physical workspace to ensure it is accessible.

**5. Ongoing Support:** Once employed, participants continue to receive support to help them maintain their employment. This can include assistance with any challenges that arise in the workplace and submitting earnings to Social Security.





## SSDI ASSISTANCE AND RETURN TO WORK

When dealing with the complexities of returning to work after an SCI, having the right support is important. SSDI representation and assistance services help guide individuals through the process of applying for SSDI benefits and exploring return-to-work options through the Ticket to Work Program. Here's how these services can help:

- **SSDI Application Support:** Navigating the SSDI application process can be daunting. Experienced representatives like Allsup can guide applicants through this process, ensuring all necessary documentation and requirements are met to help increase the chances of approval.
- **Financial Solutions:** While waiting for SSDI approval, the financial burden can be overwhelming. Disability Financial Solutions®, available only from Allsup, can help people with disabilities manage expenses by connecting them with resources to lower credit card and medical debt, and find savings on everyday items like meals, prescriptions and even health insurance.
- **Return to Work Assistance:** Once approved for SSDI, beneficiaries can access free assistance to explore a return to work using the Ticket to Work Program. Authorized Employment Networks like AES provide personalized support to help beneficiaries return to work without risking their SSDI benefits for a period of time.

## SUCCESS STORIES & GETTING STARTED WITH TICKET TO WORK

The impact of the Ticket to Work Program can be seen in numerous success stories. For instance, Christopher, a program participant, was able to return to his career in information technology after a severe spinal cord injury. With the help of Employment Networks, he received the necessary training to update his skills and secure a job that accommodates his physical limitations. Today, Christopher not only enjoys financial independence, but also the personal fulfillment that comes with contributing as an expert in his field and being able to help support his family.

Another participant, Lina, used Allsup Employment Services to transition from receiving SSDI benefits to working as a teacher full time. The services she received through the TTW Program helped her gain the confidence and skills needed to succeed in her role. Lina's return-to-work journey has provided her with a renewed sense of purpose and connection to her community. Lina enjoys making a difference through her students, one lesson at a time.

To get started with the Ticket to Work Program, individuals receiving SSDI benefits can contact an Employment Network or visit the SSA website to learn more about available services.

*Learn more at [Allsup.com/united-spinal](https://www.allsup.com/united-spinal).*



*the*  
**\$1,000**  
**WHEELCHAIR**

## How the YouTubers from JerryRigEverything are Making Affordable Wheelchairs Without the Red Tape

STORY BY SETH MCBRIDE

**T**anner Green is concerned about the tiny aluminum plugs left behind when you cut 30 holes in the seat rail of a wheelchair. The cutting is done by an enormous robotic laser controlled by a computer model. A tech feeds a 20-foot aluminum tube into the machine, makes a few clicks on the computer, and the machine gets to work, cutting the tube to length, 30 holes for the axle adjustment, two channels for clamping in the footplate tubes and two etchings to help line up the tube on the bending machine. Running at full speed, the cutting takes just a couple of minutes.

It's mesmerizing to watch. When the laser is done cutting, sometimes the leftover material just falls out, but sometimes it stays in place. "Then, you have to grab a screwdriver or some other tool and get them out yourself," Green says as he starts whacking and prodding at the just-cut seat rail. Some plugs come out immediately, some are more stubborn. In all, it takes as long to get all the plugs out as it took for the laser to make the cuts.

For Green, the chief engineer at Not a Wheelchair, this is one of the thousand complications standing between his team and a rather lofty goal: upending the manual wheelchair marketplace. If you've heard of Not a Wheelchair, it's

likely because of its owners, Zack Nelson, the star of the 8.8-million-subscriber YouTube channel JerryRigEverything, and his wife Cambry, a para and manual wheelchair user. The Nelsons got into the mobility equipment business a few years ago when they released The Rig, an electric, adaptive off-road device with a simple yet robust and functional design priced significantly lower than anything else on the market. Now, they're bringing that same ethos to manual wheelchairs.

Not a Wheelchair aims to offer a base-model, custom manual wheelchair at a similar or better quality than most of the insurance-approved wheelchairs in the U.S. for \$999. Yes, that's just under \$1,000 for everything — wheels, handrims, tires, side guards and rigid, angle-adjustable backrest included. And the company plans to have a turnaround time of weeks, rather than the monthslong slog that it typically takes from order to delivery.

When I first heard about this, it sounded awesome and a bit far-fetched. It's hard to find a pair of quality wheelchair wheels for less than \$500. Same with a rigid backrest. How were they going to offer both, plus a custom wheelchair frame without compromising on quality? I drove to their headquarters in Utah to find out.

PHOTOS BY KIM RAFF



Cambry and Zack Nelson



## Inside the Paradox

When you turn into the neighborhood where Not a Wheelchair's manufacturing facility is, you're greeted by about a dozen cows chewing grass in a smallish, triangular field. There's a busy road to one side and brand new, multistory apartment complexes on the other two sides. There's no indication of how the cows got there — as if a city suddenly sprung up around them. Past the cows and the apartments are rows of warehouses. Then you turn the corner and the buildings go from huge to enormous. Not a Wheelchair is housed in one of the largest buildings I've ever seen.

I roll inside and am greeted by Nelson and Green. Nelson looks familiar because he's exactly as he appears on YouTube — tall, muscular and shiny bald, with a soft, measured voice. The office space is still spartan — just a row of computers and a kitchen. "None of this was here even a few weeks ago," Green says. "We took over an empty building about five weeks ago, and it's been non-stop ever since."

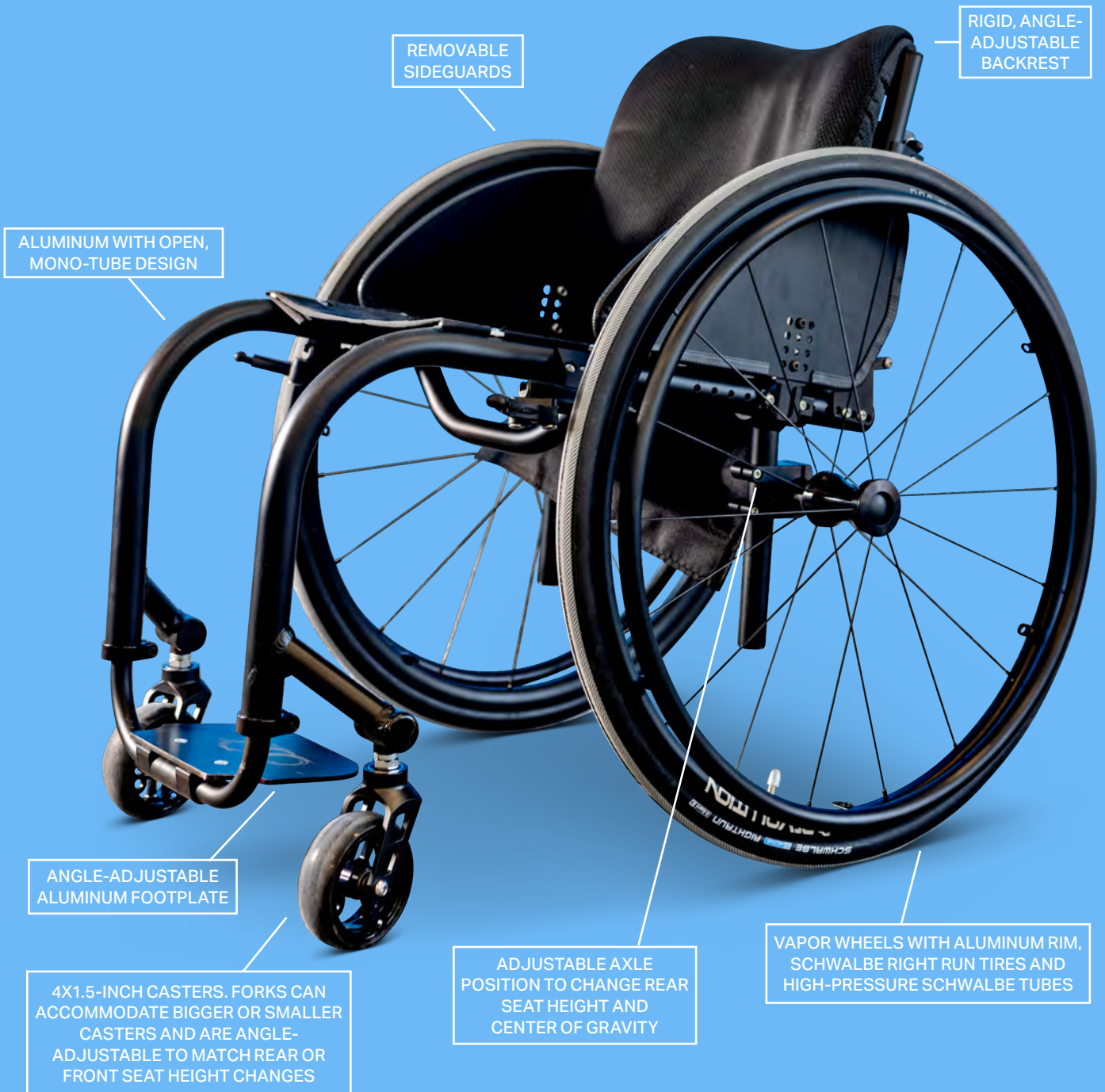
The Not a Wheelchair name started to differentiate The Rig — an electric offroad vehicle capable of going places that a wheelchair could not. Nelson is famous for building and modifying all sorts of things — from converting a Hum-vee to electric power to digging an enormous bunker in the couple's backyard, but Not a Wheelchair has quickly taken on an identity of its own. "We've always seen ourselves as an outdoor mobility company," says Nelson. "We want to make it easier for people to move around outside and in their

communities." Now though, Nelson finds himself about to release a manual wheelchair under the Not a Wheelchair name. "We started calling it The Paradox Project," he says. "But if you have a better idea for a name, we're open to suggestions."

When I roll out to the manufacturing floor, there are huge machines scattered across the 26,000-square-foot space. There's an apartment-sized laser cutter that looks like it should be stationed on a spaceship, a computer-controlled tubing bender, a welding station, powder coating and curing cabinets, an assembly area and a half dozen other prototyping and testing machines scattered along the perimeter. The machines are set up as a series of production pods that snake in a sequential line from start (cutting tubes) to the end (assembly) of the wheelchair-making process.

"The culture I grew up in in terms of my career was very much around process improvement," says Green, who's worked with semi-conductors at Intel, missiles at Raytheon and medical devices at a smaller consulting firm. He first connected with Nelson after watching a YouTube video about The Rig and thinking it was a cool project. He cold-emailed Nelson, volunteering his engineering services for anything Nelson needed help with. Just a year or so later, Nelson convinced Green to move to Utah and work full time with Not a Wheelchair. Green has been working on the manual wheelchair project for almost two years and for him, having a good design is only the first stage in the process. Turning that design into a quality product, quickly, inexpen-

WITH THEIR CURRENT SETUP, THE TEAM CAN BUILD AN ENTIRE CHAIR IN A FEW HOURS, AND THAT TIME IS COMING DOWN QUICKLY AS THE COMPANY'S 15 EMPLOYEES GET MORE COMFORTABLE WITH THE PROCESS.



REMOVABLE  
SIDEGUARDS

RIGID, ANGLE-  
ADJUSTABLE  
BACKREST

ALUMINUM WITH OPEN,  
MONO-TUBE DESIGN

ANGLE-ADJUSTABLE  
ALUMINUM FOOTPLATE

4X1.5-INCH CASTERS. FORKS CAN  
ACCOMMODATE BIGGER OR SMALLER  
CASTERS AND ARE ANGLE-  
ADJUSTABLE TO MATCH REAR OR  
FRONT SEAT HEIGHT CHANGES

ADJUSTABLE AXLE  
POSITION TO CHANGE REAR  
SEAT HEIGHT AND  
CENTER OF GRAVITY

VAPOR WHEELS WITH ALUMINUM RIM,  
SCHWALBE RIGHT RUN TIRES AND  
HIGH-PRESSURE SCHWALBE TUBES

sively and consistently takes a dozen interdependent steps.

The first step in the manufacturing process is to cut the frame tubing, and you can't move to the next step without removing those annoying aluminum plugs. Green says they've been messing with the settings on the cutter to get more of the plugs to release on their own. It might only save a minute per chair — but when you're trying to change the wheelchair industry, every minute counts.

At the next stage of the process — bending — Nelson is watching the process as a tech slowly puts the machine through its process at about 10% of its capability. “Are we running at 100%? Why is this so slow?” Nelson asks. “Come on, let's get it moving. We can go faster than this.”

Speed is part of the culture at Not a Wheelchair. “The whole goal is to get from idea to drawing to actual physical product that we can test as fast as possible,” Nelson says. With their current setup, the team can build an entire chair in a few hours, and that time is coming down quickly as the company's 15 employees get more comfortable with the process.

Everybody I talked to was on the same page. Why go fast? Because it matters how long it takes for someone to get a new wheelchair. “The time it takes means that somebody is being impacted by not being able to get that chair sooner,” says Green. “If they're waiting six, eight, 12 months for a chair, that's six, eight, 12 months that they're going without. They're having to make do with what they have, whether it's something that doesn't fit them, it's broken, or some other issue. I don't want to make anybody wait that long for something that's an important part of their life.”

## YouTube \$

If you're looking at the reasons that Not a Wheelchair is able to make a \$1,000 wheelchair, hyper-efficient manufacturing

techniques and state-of-the-art equipment are near the top of the list. But factories and enormous fancy machines cost a lot of money, and in any normal business model, those costs are passed on to the consumer. But what if the owners aren't dependent on — or even interested in — making money from the business? Meet Zack and Cambry, YouTube stars.

Nelson started his YouTube channel 12 years ago. He was in college and had no career path. He just knew he wanted to be his own boss. He had a jeep with a busted gear inside the transfer case. “Instead of taking it to the shop and fixing it for \$1,000, I followed this YouTube video and fixed it for like 60 bucks instead,” he says. “So I emailed the guy who made the video and I was like, ‘Why did you make this video for people? It's such a nice thing to do.’ He said, ‘To decrease world suck, to make the world a better place, and also I make money for the ads that appear when the videos are playing.’ That was an epiphany for me, like, ‘Oh, I could be my own boss. I could do the projects that I'm already doing anyway, film them and make money on the internet.’ That satisfied every little box I was looking for in a career.”

Nelson started with videos of himself repairing his jeep and quickly moved onto durability and repair videos for smart phones, which turned into the bread and butter of his growing YouTube presence. Nelson didn't have any knowledge of mobility products, or any personal experience with disability, until he met Cambry.

Cambry is slight and blond. She got hurt doing equestrian vaulting — basically gymnastics on horseback and yes, it's as wild as it sounds. Zack and Cambry met via an online dating app and Cambry was upfront about her disability. “Before our first date, Zack asked me if there was anything he needed to do to pick me up,” Cambry says. “I really wanted to make up a big story about how he would have to go to DMV to get a special license to be able to take me anywhere, but I chickened out and told him, ‘You know, usually I just meet someone at a restaurant.’”

1

TUBE CUTTING

The wheelchair starts as 20-foot-long pieces of aluminum tubing. The tubes are fed into a laser cutter, which cuts the tubing to size for different pieces of the frame while also cutting any bolt holes or notches for tubing clamps.



2

BENDING

Tubing is bent to match individual measurements and frame angles. Modern, computer-controlled benders like this one can even account for how far different materials spring back after being bent, so you get the perfect bend, every time.



3

Welding is the one stage of the process that still relies on highly-skilled labor instead of robots. With the right fixtures, it takes the welder about 30 minutes to do every weld on a wheelchair frame.





Zack and Cambry Nelson, who were married in 2019, now have two children and a busy family life in Utah.

Like all wheelchair users on a first date, Cambry was worried Zack was going to be weird about her disability. “But his first disability-related question was to ask if I’d done any cool upgrades to my wheelchair.” She had not. But this was someone she could hang out with.

Not long after they started dating, Nelson surprised her with a DIY off-road wheelchair — two electric bikes with a welded seat in the middle, “chariot-style” as Nelson puts it in the video where Cambry tries it out for the first time. That video was also Cambry’s first appearance on the YouTube channel. She’s clearly nervous about being on camera and freezes for a second when Zack asks her a question. Once she’s on the bike, she quickly settles in, blasting around grassy fields and almost flipping herself as she climbs a curb at full speed.

That video has 11 million views and counting. A year later, when Zack and Cambry released a video debuting The Rig, Cambry looks like a pro. Zack and Cambry got married in 2019 and now have two kids. Cambry remains a regular presence on the YouTube channel. She explains the challenges of living with a disability in a straightforward, relatable way and is fun and adventurous when trying out the new gear. It’s a hard needle to thread when you’re living off YouTube views, but Cambry passes the realness test and does a good job of normalizing disability for the channel’s audience, the vast majority of whom aren’t disabled.

Videos with Cambry and accessibility projects consistently get millions of views. “The internet loves Cambry,” Zack says. “I’ve tested videos where I’ll do two versions of the exact same video, one with a photo of me as the thumbnail and the other with Cambry, and the one with Cambry will get like twice as many views.”

In the world of YouTube, putting out multimillion-view videos translates to millions in revenue in the form of ads, partnerships and affiliate sales. It’s that income stream that has allowed the Nelsons to fund a wheelchair production factory, along with the staff to go along with it, without incurring massive amounts of debt.

While I’m rolling around the Not a Wheelchair facility, marveling at the scale of it, I can’t help but wonder why they decided to do it. I mean, it’s one thing to build cool, one-off mobility devices. It’s another thing entirely to self-fund and spend years developing the capacity to mass produce affordable wheelchairs. For Zack and Cambry, it was pretty simple: There is clearly a need. And with Zack’s background and connections, combined with the income from JerryRigEverything, they were in a unique position to do something about it.

“Jumping through many levels worth of hoops just to get a wheelchair was incredibly frustrating for me,” says Cambry. “I got engaged to Zack in 2019 and wanted to buy a new

## WELDING

4

## POWDER COATING

5

## ASSEMBLY



The wheelchair frame is grounded, and electrostatically-charged paint powder adheres to the surface. The frame is then cured to hold the paint in place. Powder coating creates a thicker, more durable paint surface. Not a Wheelchair will be able to powder coat a frame in any color.



All the frame pieces are put together. The rigid backrest is attached, caster forks are installed, and wheels and hand rims are put on to make sure the frame is true and free of defects.





Not a Wheelchair is also developing more affordable wheelchair components like these wooden handrims.

wheelchair before my wedding, which was six months away at the time, and my new chair almost didn't even arrive in time for our wedding day. It was stressful knowing that my current wheelchair could break at any time and leave me stranded for weeks or months. I know I'm not the only one who had that stress in the back of my mind. So hopefully, now with our own wheelchair factory, we are able to fix some of those problems."

## The Wheelchair Business

Not a Wheelchair will sell its manual wheelchairs directly to consumers. That means if you want a wheelchair, you can go to the website, click through to an online configurator and spec out your wheelchair in real time. You enter your measurements, and a 3D model of your chair adjusts to your tweaks. You can see the difference that seat depths, backrest heights and frame angles make on the finished product.

Once the company opens to the public, Not a Wheelchair expects to have a custom, manual wheelchair shipped four weeks after you hit the order button. Ramped up to full speed, they hope to have that time down to two weeks. Compared to the typical wheelchair buying process, that is — to borrow a phrase from *Space Balls* — ludicrous speed. Not a Wheelchair aims to do it not only by automating as much of the process as possible, but also by eliminating the middlemen. That means no seating clinic, no insurance company, no DME supplier. This has pros and cons.

Let's start with the seating clinic. The main purpose of the seating clinic or a physical therapist wheelchair evaluation is to provide you with expert advice about what equipment — from wheelchair type to components and wheelchair measurements — is best for your body and for your needs, and to make sure, using pressure mapping, that the equipment you ordered fits you properly and protects you from pressure sores. I'll let you judge how often that process results in per-

fectly fitting equipment. Not a Wheelchair is making consumers supply their own measurements. That can be from the chair you're already sitting in, from a seating clinic or conjured up after comparing specs from your friends at happy hour. That gives you the power to order what you want. But it also means that if the chair doesn't fit, it's on you.

Next up, insurance companies. They're supposed to pay for your equipment. But they also require you to use other middlemen, which increases costs. In today's broken system of U.S. healthcare, most insurance, even private, will pay a bare minimum for manual wheelchairs and components. Copays for that basic equipment often cost more than \$1,000. For wheelchair users with specific needs (most of us) who go through the runaround of denials, only to be "approved" and still owe four figures, it can feel like a shell game.

Lastly, DME suppliers. Two helpful services that DME suppliers are supposed to provide are wheelchair setup and repair. In Not a Wheelchair's model, you do the adjustment and repair yourself, get a friend or family member to help, or find a local bike shop willing to work on your chair.

"The whole point of my YouTube channel is durability and repairability. I've been preaching that for 12 years, so we're bringing that into the chair as well. We're using standard hardware, and we're consolidating as many of the bolts as possible to as few sizes as possible so that there are fewer tools needed. We want to be able to make it simple enough that people can do the adjustments and the repairs by themselves, and if they need a caster replaced, something binds up or the bearing inside the caster seizes, they can pop the



One of the company's goals is to cut through the red tape associated with buying a wheelchair.

caster off and put a new one on and we'll sell those replacement parts. Or, if they're under warranty, we'll just give them those replacement parts."

Nelson says that they're pitching the chair as a secondary option for wheelchair users, something to have around for traveling or getting dirty or as a backup chair. For \$1,000, that seems reasonable. But for that price and ease of ordering, it's reasonable to assume that no matter how the chairs are being pitched, a lot of wheelchair users will choose to order one as their primary chair. How the easy order process and results will work at scale is a big unknown. Another big question: How exactly are they going to make a profit charging that little for a wheelchair?

They're not. Same as with The Rig and any other products they develop, Zack and Cambry won't be taking any profit from Not a Wheelchair, and they aren't taking any salary from the company, which operates separately from the YouTube channel. "It's a passion project for us," says Nelson. To be clear, Not a Wheelchair isn't a nonprofit — it's currently licensed as a benefit company, a newer designation of a for-profit company that provides a public service. "Once it's established, it's going to become an employee-owned company. I want my employees to be extremely well taken care of, but as owners, we have other ways of making money," says Nelson.

Second, they're offering the base model chair at low margins. If you order a chair with no upgrades from Not a Wheelchair, your costs won't be much more than it costs the company to get it to you. Margins are higher for upgrades — things like a carbon fiber seat pan, wooden handrims and more complicated frame bends. "As people change the options on their wheelchair and get a more premium version, we make more profit on that," says Nelson. "We'll happily take money from people who want to upgrade their machines, but we don't want to take money from people who just need the basics."

## Testing, Testing

So how does Not a Wheelchair's base model chair stack up to other options on the market? I hate to sound like a preacher, but ... it's totally reasonable! It hits the mark of being at least as good, if not better, than the majority of insurance-approved wheelchairs in the U.S.

Not a Wheelchair made me a base model chair to try for this article. They didn't ask me to write good things about it, and they're not paying for advertising. (The other benefit of having a huge YouTube channel, is you also have a built-in marketing channel with a worldwide reach.) The chair they gave me is basic. I've been using it on and off for a couple of weeks since I visited the factory. It rolls straight and smooth. It doesn't weigh that much more than my fully-fixed, titanium-framed chair. Its backrest is comfortable and angle-adjustable. The rear seat height is adjustable, along with the front caster height and angle, and the center of gravity. It feels solid, not all janky and rattly, like old-school adjustable chairs did.



The Nelsons keep miniature horses on their property, and Cambry wanted a wheelchair that could handle the rigors of an active lifestyle.

The wheels, which Not a Wheelchair commissioned from Vapors Wheels, are great. I liked them so much that I stole them to replace the \$900, fiber-spoked wheels that keep going out of true on my titanium chair. I put the old wheels with some fatter tires on the Not a Wheelchair and lowered the rear seat height so I could use it as an off-road chair for pushing around the dirt and grass around my house. I'll keep pushing my titanium chair for everyday life because I like how titanium rides, and my chair is fitted with ergo seating and other frame customizations that Not a Wheelchair isn't yet offering.

But the Not a Wheelchair won't sit in my garage getting dusty. It'll be getting dirty in the summer and snowy in the winter. And if my other chair breaks, I know I have a comfy, perfectly acceptable option to use while I'm fixing it. And that's kind of the point: Wheelchairs shouldn't be so expensive that you can't afford to have a backup or one with an alternate seating position for specific activities. Not a Wheelchair might finally be the company with the means and the will to change that.

Touring the factory, I saw other prototypes scattered all around the facility. There's a beefier, four-wheel drive version of The Rig that the company just launched. There's a track wheelchair that's still in development. It's clear that Not a Wheelchair doesn't intend to stop at a simple, manual wheelchair. Inexpensive components, more advanced electric off-road devices, power assist, it's all on the table. "We're just really excited to see where this leads," says Green. **MM**

# APPLYING FOR COLLEGE AS A WHEELCHAIR USER

BY ANJA HERRMAN

Like many high school seniors, I spent the last year preparing for my future — which, for me, has meant wading through the college application process. “Process” is an understatement for this massive undertaking: For months I researched schools and filled out applications until bleary-eyed, only to be rewarded with waiting and wondering about what the verdict would be. Many of my friends were also navigating this process, but because I’m a wheelchair user, I learned how disability can complicate applying to college.

As I went through my senior year, I felt a bit jealous of my peers who didn’t have to factor in the existence of ramps or door buttons or the strength of a college’s disability services office in making their decisions. In fact, when I recounted the stories of my college visits to my peers, very few even knew what a disability resource center was. Surprisingly, meeting with those offices was even more important to me than seeing a campus, since working with them would be one of the main ways I facilitated

my inclusion at the school.

Making four-year decisions based on ramps rather than sororities, and on pragmatic considerations instead of purely on possibilities, was frustrating to say the least. I vividly recall a conversation with the DRC at one of my top schools, where it came out that part of the “admitted student program” — the very mechanism the school relies on to convince students to attend — was held at an inaccessible location. Pro tip to enrollment managers and other higher ed professionals: That’s not the way to convince someone with a disability to pay tuition. That school also had only one accessible dorm and a weak paratransit system, so it was clear I wouldn’t be enrolling, even though I had gotten in.

Explaining to nondisabled people how inaccessibility robs us of opportunities is difficult. My attempts were usually met by blank stares or a well-intentioned but unhelpful “that sucks” from my schoolmates and other friends. Finding information on experiences of disabled students — or spaces to connect with a given

college’s disability community — was also difficult. At many schools, the administration left the visibility of the disability experience in the laps of the students. This made finding information hit-or-miss and often left me feeling like I was missing something. Alternating between valid rage and pep talks, I turned to my community to remind me that, especially in 2024, inaccessibility is a choice, and that I deserved to choose a school that chose me and was able and willing to support me.

Blessedly I live in the age of the internet, where a different kind of accessibility — the informational kind — is always at my fingertips. And, while I never thought I would do this, I’m endorsing Reddit. I did my best to keep boundaries with this website notorious for being a cesspool of negativity. But I was lucky to find something beautiful in this online space: students with disabilities who shared stories of how their institutions handled access and inclusion, so that I could learn from them. I never commented — because again, boundaries — but I loved the ability to stay connected and supported by past disabled students by reading their words of affirmation or abashment about their universities.

Now, as I finish the process, I’m holding on to the hope I find in being able to choose my own future. I want to say thank you to the disability community that supported me, both metaphorically and literally. I want



**NEW MOBILITY’s college guide, *Wheels on Campus*,** offers an in-depth look at accessibility and inclusion in higher education. We surveyed hundreds of colleges and interviewed more than 80 wheelchair-using students and disability service leaders to identify 20 colleges that create wheelchair-friendly campuses and cultures. [newmobility.com/category/wheels-on-campus](https://newmobility.com/category/wheels-on-campus)



Anja Herrman recently graduated from high school and has found disability adds an extra layer of complication to the massive undertaking of applying for college.

to thank the disabled trailblazers who fought for their own right to have an education, because likely I wouldn't be here writing this piece without their groundbreaking advocacy. We've grown from being denied access to education in the decades before my birth, to me now writing every "How will you contribute to College X?" essay about how I'll help create more of a disability community on campus.

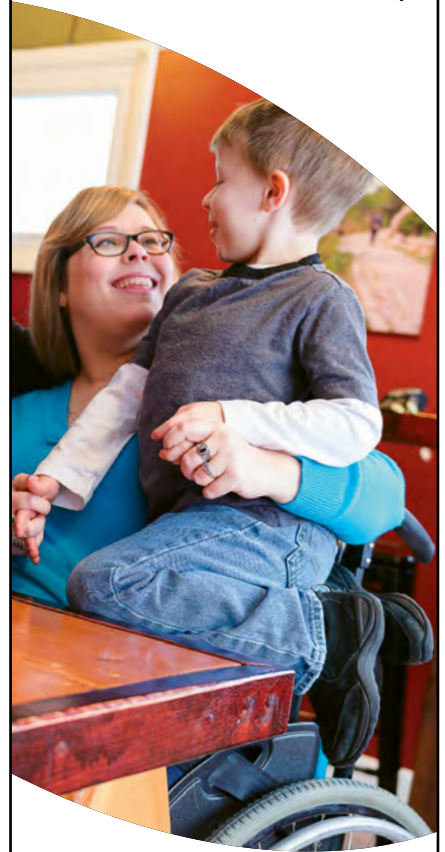
It is only because we have come this far that I even had the privilege of being annoyed about filling out another application. Reading up on the stories of the "Rolling Quads" — the disabled students who pioneered the

first American student-led disability services office — reminded me that I was part of a legacy, and that my voice and perspectives matter.

Ultimately, my last thank you to the disability community is for the lesson I learned in this process: Adapting is necessary and even beneficial when we all do it together. I know that college will likely bring new challenges, and not only do I feel ready for them, I also welcome them. As a disabled person, I always adapt to have space in the world. Now, with the support of my community, I can't wait to see how I create the college world of my dreams.

MM

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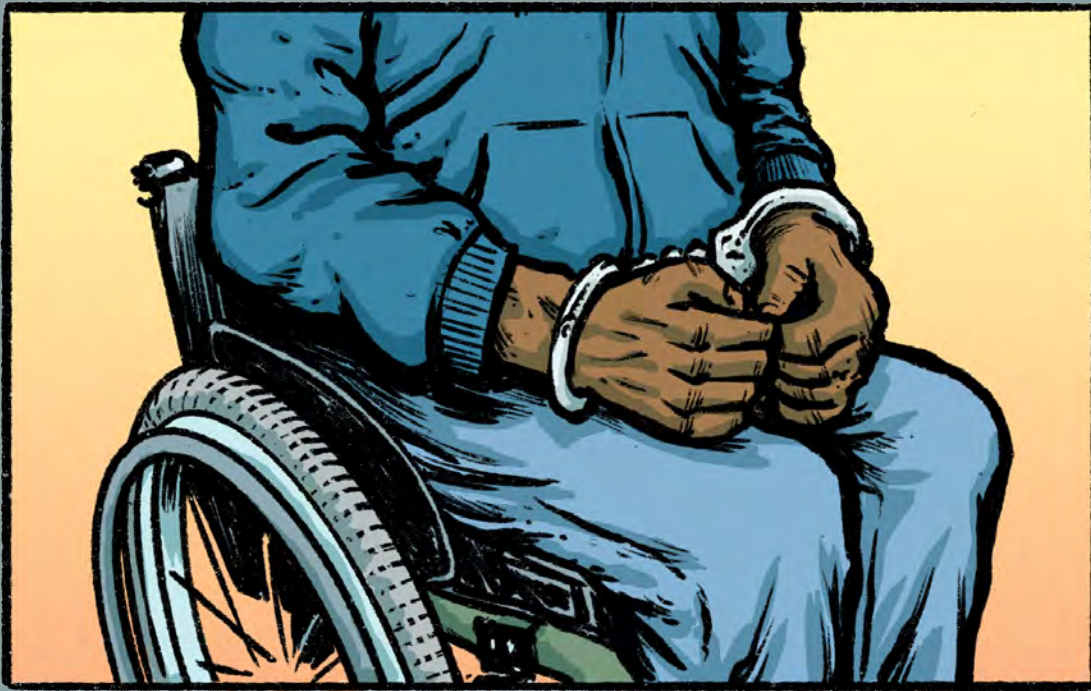
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# LIFE ON WHEELS BEHIND BARS



Illustrations by John G

When I became editor of *NEW MOBILITY*, I also became the de facto pen pal of dozens of wheelchair-using inmates around the country. I learned that for many wheelchair users doing time, the print copies of *NEW MOBILITY* are the only source for up-to-date information on DME, supplies and living with a disability. Several inmates told me that without the magazine, they never would have known about or been able to ask for contemporary equipment that has helped them survive.

The more I've learned about their world, the more I've appreciated that their needs and struggles on the inside share more similarities than differences with ours on the outside. We fight the same battles for supplies, access and equality, and face the same emotional and physical obstacles that come with disability.

Of all the inmates I've corresponded with, one in particular stood out for his candor, insight and willingness to answer my (possibly annoying) questions. Donovan Bryant is an L1-2 incomplete paraplegic from the Brooklyn borough of New York City, serving a 12-year sentence for illegal gun sales, conspiracy, and weapons possession. What follows, in his own words — edited from years of emails — is a look at his life in Walsh Regional Medical Unit at Mohawk Correctional Facility in upstate New York.

— Ian Ruder, Editor-in-Chief

# 10

## YEARS IN PRISON AS A WHEELCHAIR USER

BY DONAVAN BRYANT

I was born in Brooklyn, New York City, and raised in the inner city during the crack cocaine epidemic of the mid-'80s and early-'90s. My grandmother was one of the few people in my family who wasn't engaged in criminal activity or hooked on drugs. She worked at Brooklyn College in the mail room. She kept a roof over my head and my young self from starving. She was the most stable person in my life.

We may not have had the best, but we made the best with what we had. Unfortunately, my grandmother died of cancer in 1992 when I was 8. After her death, with no one to provide a buffer, my life moved into the streets. I witnessed a lot, and once I was old enough, I started in on a lot of criminal activity.

I eventually ended up in the child care system: foster homes, group homes, juvenile institutions. I've done the homeless teen thing, sleeping in abandoned buildings. I've done the homeless adult thing too. I received my GED when I was 17 and went to a community college. I majored in computer networking for a few months but didn't finish. Before my injury, my life basically was me having a lot of sex and engaging in criminal pursuits for financial gain.

When I was 18, I enlisted in the Army in hope of avoiding a life of crime. I had taken the test and was a physical away from shipping out when I got shot in the back, injury level L1-2 incomplete. Being in a wheelchair didn't stop me from engaging in criminal activities. To be honest, it gave me the drive to go harder. I had a family member come visit me in the hospital and he started



making statements like, “Whoever heard of a guy in a wheelchair running the streets?” I got angry. Angry at the world. Angry at the doubters. Angry that people no longer saw me for who I was. I made it a goal to prove them wrong.

And up until my arrest I was doing it. I had my own vehicle, my own place in Brooklyn. I sold a lot of guns. Since I was a child, I've had an infatuation with firearms. I'm extremely pro-Second Amendment. When I was coming up, guns were abundant and carried around like an AMEX card — you know the saying, “Don't leave home without it.”

I didn't know anything about [lawful] careers, like being a gunsmith or acquiring a license to sell or import guns, until after I started selling guns illegally. If I would have seen the movie *War Dogs* about how people were entering into contracts to legally sell guns to the U.S. military, I would have surely looked into going that route. In 2015, when I was 29, I got arrested. The charge was

illegal gun sales, conspiracy, and weapons possession. I was sentenced to 12 years in prison with no possibility of parole.

## DISABILITY ON THE INSIDE

I've been in prison for almost 10 years now. First I was sent to Rikers Island, where I spent 18 months, going back and forth to court. At the time, I had a Quickie 2 manual wheelchair and the bearings in the rear wheels were going bad. Out on the street this would have been a simple problem to get handled. But being in jail, it was a whole different animal.

Wheelchair maintenance did not exist. In the gym, there was what we called the wheelchair graveyard. I saw at least three dozen power chairs of all makes and models sitting around, abandoned, covered in dust and mold, and slowly rotting away — it was a place where wheelchairs went to die. My original Quickie is probably there. These days I roll in an old junker that has broken down on me a number of times.

Getting assistive devices was really hit or miss, and would take some back and forth haggling with the administration. At times, this back and forth would take weeks and months. But I would give Rikers' administration credit on one thing: They stayed on top of your medical appointments. No matter what specialist you had to see, they made it happen in a very timely matter.

Once I entered state prison, it was like things did a total flip. There was slightly more attention to wheelchair maintenance and assistive devices, but the system for setting up medical appointments was horrendous: If you weren't dying, you could expect to wait months and sometimes years.

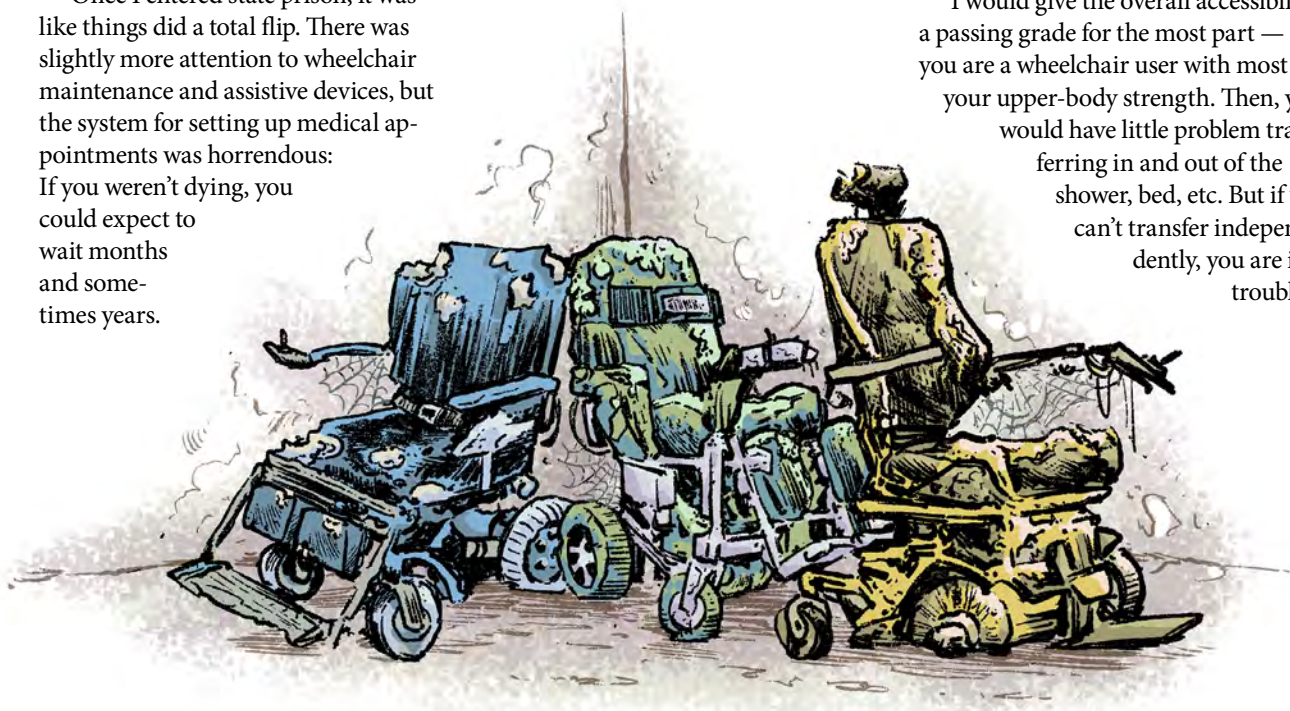
After Rikers, I was transferred to a prison downstate for about three weeks, before being transferred to Walsh Regional Medical Unit in 2017. I've been here ever since. This facility is supposed to be a temporary rest stop, where you come to die or get treated for whatever your medical problem is and then get sent back out into the general population. The only reason I've been here so long is that I have chronic pressure ulcers — it seems as soon as one heals, another opens. I also have really bad, chronic [urinary tract infections]. When they flare up, I'm damn near on the verge of death, with my temperature hitting 103.

Despite this being a medical unit, we don't get any choice for what kind of supplies we get. I have a suprapubic catheter, and I basically roll the dice, cross my fingers and hope for the best when it comes to keeping things sterile. There is really no such thing as sterile in prison, not even in a medical prison.

The regional medical units are built more like hospitals. The cells are bigger. The bathrooms are bigger, and they also have grab bars and emergency call buttons. There is a 24-hour medical staff on hand, or at least there is supposed to be. There are PTs and OTs onsite as well, and a gym with a recreational therapist. Ironically, the first accessible scale I encountered in 20-plus years as a wheelchair user — after visiting probably a dozen doctors in four different states — was in the prison I'm currently at. Go figure, right?

I would give the overall accessibility a passing grade for the most part — if you are a wheelchair user with most of your upper-body strength. Then, you would have little problem transferring in and out of the shower, bed, etc. But if you can't transfer independently, you are in trouble.

**WHEELCHAIR MAINTENANCE DID NOT EXIST. IN THE GYM, THERE WAS WHAT WE CALLED THE WHEELCHAIR GRAVEYARD. I SAW AT LEAST THREE DOZEN POWER CHAIRS OF ALL MAKES AND MODELS SITTING AROUND, ABANDONED, COVERED IN DUST AND MOLD, AND SLOWLY ROTTING AWAY. IT WAS A PLACE WHERE WHEELCHAIRS WENT TO DIE.**



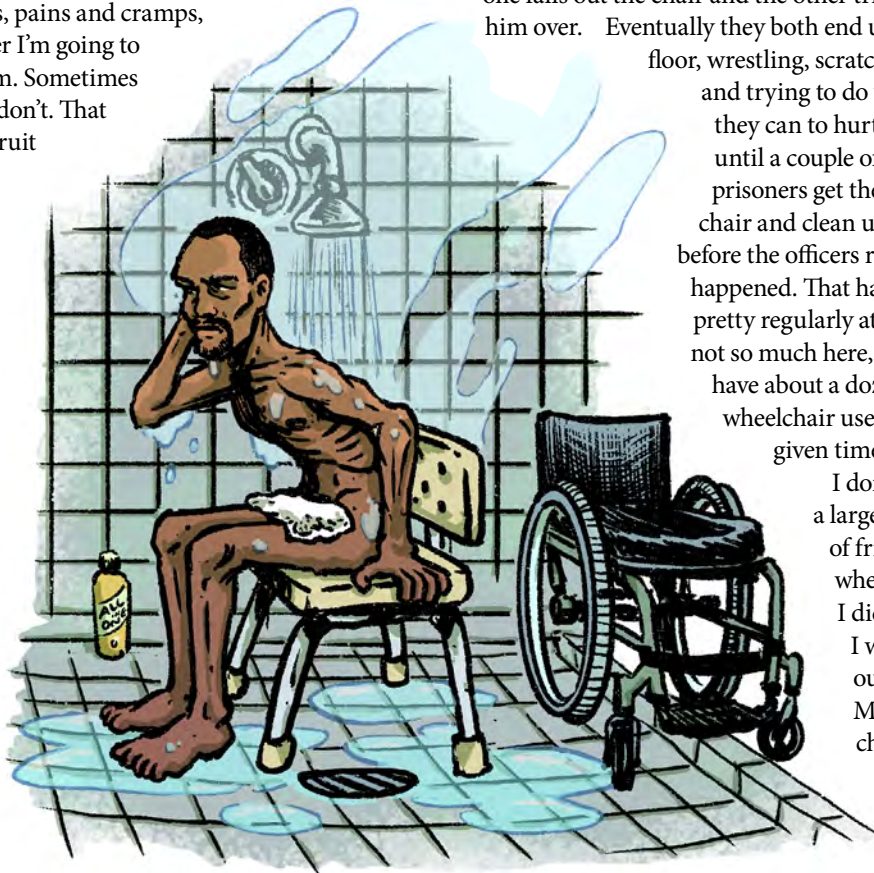
## DAILY LIFE

Every day starts at about 6:30 to 7 a.m. with the nursing staff coming around to take vitals, give meds and ask if you need supplies or a change of clothing. Since we are in a medical facility, we don't wear the regulated state green uniforms: a green button-up shirt and khaki pants. We wear green pajamas and a red and white striped robe. Picture a candy cane hanging from a Christmas tree. Plus, I'm a Black guy so I look like a chocolate-covered candy cane on a Christmas tree. It's not as bad as it sounds, but it sure isn't pretty either.

I take a full cup of pills — thankfully they're mostly vitamins — then I begin the talk to my body that all of us wheelchair users have when it's time to get up and moving. "OK body, how are you feeling today? Do you feel like playing nice or are you going to be an asshole?" Once I shake off the typical wave of aches, pains and cramps, I make up my mind whether I'm going to make it to breakfast by 8 a.m. Sometimes I do, but most of the time I don't. That leaves me eating a piece of fruit or a peanut butter and jelly sandwich to start my day.

The day-to-day meals are terrible. I live on peanut butter and jelly sandwiches, plus what I can get from food packages — a lot of tuna fish and oatmeal. Boiled eggs and toast are one of my better meals. It's hard to mess up a boiled egg. On holidays, they'll give us a couple of burgers and a hot dog for either lunch or dinner. On Thanksgiving, the meal is sliced processed turkey like you put on a sandwich, with "stuffing," which is just soggy, seasoned bread. [We] prisoners usually pool our resources and make our own meal with some of the food we get in packages from people on the outside. It's not great, but it's better than the usual.

After breakfast I do all the required hygiene rituals. I may or may not have wound care depending on the schedule of the medical staff. By 9 a.m. I'm in the school program where I'm the inmate program assistant, which is basically a teacher's aide. Here IPA is the only way to earn money legally. I only make pennies on the dollar, but I can also earn time off my sentence. If you ever saw the movie *Blow* with Johnny Depp [where] he was in prison teaching the class to get some time off his sentence, well that's me.



School ends around 10:30 a.m. and at that point I come back to my unit where I'll get wound care done or receive any meds I haven't taken yet. Lunch is around 11:15 a.m. Afternoon programs run from 12:30 to 3:30 p.m., but I only work mornings, so I will either go to the library (if it's a Monday) or to the rec therapy room. There I socialize with individuals from the other units, work out, play card games/board games, watch movies or just engage in whatever activity they're offering that day.

For the most part, I'm treated fairly by the other incarcerated individuals. Of course, just like in the free world, you might encounter an asshole here and there. When I was at Rikers there were about 20 of us who used wheelchairs, all as a result of gun shots. Have you ever seen two guys in chairs engage in hand-to-hand combat? They chase each other until one falls out the chair and the other tries to run him over. Eventually they both end up on the

floor, wrestling, scratching, biting and trying to do whatever they can to hurt each other, until a couple of nondisabled prisoners get them in the chair and clean up the mess before the officers realize what happened. That happened pretty regularly at Rikers, but not so much here, where we have about a dozen other wheelchair users at any given time.

I don't have a large circle of friends in wheelchairs, but I didn't when I was on the outside either. Most wheelchair users I encounter here are so down and depressed in their

situation they just want to escape reality. Not only are they fighting the day-to-day wheelchair life battle, but they are also dealing with being incarcerated. I can relate. I've done the angry/depressed phase, learned from it and moved on. As my uncle put it to me as a child, "Ain't nothing to it but to do it. Ain't nothing wit' it but to get it." Of course, it isn't always easy, I have my good days and bad days.

No later than 3:30 p.m., I'm back in my dorm, waiting for dinner to be called at about 4:15. There are another two med runs, plus general wellness checks. After 5, we can come back out of our rooms and spend time in the day room watching

TV, socializing, using the phone, getting emails and just killing time. Or you can just stay in your room. I try to balance my time between staying off my behind long enough so my wounds can heal and socializing enough so I'm not a complete stranger around here. I do a lot of reading on different subjects. I play a lot of chess, and I do a lot of periodic meditation to make it through each day without going crazy. There is a saying that hell is repetition. If that is true, I'm living in a realm of hell — or I like to think of it as the twilight zone or our bizarro world where down is up and up is down.

## LOOKING FORWARD

I will say that incarceration has opened up a new chapter in my life, one of self-discovery. Who am I? And most importantly, what makes me happy? Taking away all the distractions forced me to seek inner peace and balance within myself. Now I'm not saying I'm a leopard who has somehow learned to change his spots, or that I have become Gandhi himself. But I will say that I've discovered a new part of what makes me who I am. Being in a situation like prison, you're either going to have some serious personal growth or you are going to go mad, simple as that.

With good behavior and taking part in prison programs, I should get out in 2025. When I get out, I want to connect with the wheelchair community. I never did this prior to prison — I don't think I even knew there was a community. For me, it

took incarceration to learn about NEW MOBILITY, the resources, the community and all the networking possibilities.

I have nearly 10 years of life enjoyment to make up for when I get out. I'd like to jump out of a plane at least once. I want to travel. And, seeing as I'm single, I will surely be looking to mingle. I'm interested in getting into the jeweler field when I get out, being a broker selling and buying diamonds. I've done some research from here and came across the Gemological Institute of America, but my access to information is very limited. It dawned on me that I might not be the first wheelchair user to work in this field, and I'd love to talk to someone who knows more about what it's like.

Ironically, I would say, more than anything else, the wheelchair prepared me the most for doing prison time. When you first get injured and realize that you and your body are no longer on the same page with each other, that's one of the most dramatic and traumatic experiences anyone can go through. But if you can cope, adapt and evolve, you will come out the other end mentally and emotionally stronger. And that's the knack to doing prison time: The physical part is easy, but it's the holding on to and strengthening [of] your mental and emotional state that's the real battle.

If the wheelchair life — with all of its low moments, “my world is coming to an end” moments, “if only I wasn't in a chair” moments — hasn't broken me, then there is no way I'm going to let prison break me.

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# LETTERS FROM INMATES

## ENVISIONING A BETTER LIFE

I've been reading *NEW MOBILITY* for a few years. It's comforting to see that life in a wheelchair is possible on the outside. Reading about stories of travel, ordinary activities and the many other hacks people have figured out for themselves is truly encouraging. I read some stories of people working, traveling, going out on a date, and I can't imagine being in my wheelchair eight hours straight or 12 hours for a whole day! The last seven years I've spent five to seven hours in my wheelchair every day. That's not even in one sit, but broken up through the day and [lying] down in between.

It's difficult getting the help I need in here, but it sounds hard to get the right medical help out there as well. I've filed two habeas corpus writs just to see a physiatrist who understands SCI. I don't know if there's actually another specialist I could see who would look at my condition and see my posture, chair and cushion and be like, "Oh yeah dude, you need this and this to help improve your day-to-day life."

*A.V., Oregon*

## ALL ALONE

No one comes here to assist us with maintenance for our wheelchairs. Showers have no control over hot or cold water. I've been scalded. I attend physical therapy twice weekly [but] there are no opportunities for emotional support. Other inmates see us as handicapped, yet will help when no officers are looking.

*L.K., Arkansas*

## HELP GETTING NEEDED EQUIPMENT

In 2015, a fellow incarcerated disabled veteran shared *NEW MOBILITY* magazine with me, and I was amazed to find out an organization like United Spinal Association exists. During training for Desert Storm, I was seriously injured. My tailbone was fractured and my L5/S1 was twisted, impinging my spinal cord. My military career ended abruptly because I was falling a lot.

The police did not load my wheelchair when I was arrested. The sheriff refused to accept my wheelchair from friends who brought it to the county jail, so I arrived in the Texas Department of Criminal Justice stumbling and falling. My third day at the

intake prison, I fell, fracturing my right wrist. With a swollen black hand, wrist and forearm, I was accused of faking. Five years later, an X-ray diagnosed the old fracture.

In April 2023, the prison senior warden responded to my request for a power chair. Thanks to Mr. Bob Vogel's 2021 Power Chair Roundup, I was able to provide the warden with the information necessary for him to consider any security risks.

*J.H., Texas*

## SHOWER TIME

Showers vary greatly again by units you are assigned to. There are usually about 20 people in chairs trying to shower in only one shower. To describe this shower as a disaster waiting to happen is no lie. The showers have a plastic seat with metal leg chair which you approach from the rear. Once you transfer to the chair, you have a choice of a handheld or wall-mounted shower. Each one runs for about a minute each time you push the button. You have no control over the water temperature or the cold air conditioning blowing on your back.

I am [5 feet, 9 inches tall], but as I sit on the seat, the shower head is just below the top of my shoulder. To get my hair wet, I ease off the seat onto the floor and then have to climb back up onto the seat to add shampoo plus soap up. Then it's back on the floor to rinse my hair with the top [third] of my body to climb back onto the seat and finish rinsing off. It's a physical workout.

After the shower and drying, you dress in a flooded floor area at the bottom of the shower ramp. If 10:00 p.m. gets there and you're waiting for a shower, sorry, you don't get one. If you have an accidental bowel or bladder leakage, your options to clean up depend upon who the ranking officer on duty is. I once went 13 days before I got a shower one time in retaliation because I wrote an officer up for not doing their job.

*J.R.T., Texas*

## YELLING INTO THE ABYSS

I was a victim of a robbery and got shot. When I was arrested, the detective confiscated my wheelchair and left me inside my cell for five days, sitting on a metal slab, soaked in urine and feces. I became very sick, developed fevers, UTIs and an infection. Now I'm in a regional medical facility. My ROHO cushion was intentionally popped by an officer. It took several months to be replaced and in that time I developed another pressure sore. I've battled UTIs and bedsores for years. I complained to medical about lying on an air mattress that was too firm without any adjustability for months before I developed a bedsore. Complaints inside fall on deaf ears and you are judged for being incarcerated. In prison, you must learn how to take care of yourself in every aspect. You have to educate yourself and have family members

fill in the gaps with Google and internet research.  
*W.S., New York*



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FINDING A WAY OUT OF

# Bladder Hell

BY IAN RUDER

After years of relative ease with a suprapubic catheter, two years ago I emailed my urologist to ask about a curious new sediment that was blocking my catheter and causing incontinence. “It’s different from anything I’ve seen in 24 years,” I wrote, “more formed ... like a gluey cheese stick with tendrils.” My attendant said it looked like my bladder had been invaded by white worms. We both knew they weren’t actual worms and they weren’t actually alive, but joking about sentient white worms taking over made the depressing situation a little more manageable.

My quest to banish these white worms ended up taking almost two years, during which I went through four urologists, one ER stay, three different antibiotics — and more courses of those antibiotics than I’ve taken in the previous decade — plus enough loads of urine-soaked laundry to nearly fry my washing machine.

The quest tested my faith in medicine and my sanity both, and gave me a deeper appreciation of how critical are creative problem-solving and persistence for those of us facing complex medical issues. While specific remedies that eventually resolved the issue won’t work for everyone, I am confident the steps I took and lessons I learned can help others avoid some of the hell I went through.

## A FRAUGHT RELATIONSHIP

It’s hard to pinpoint the exact origins of my skepticism in urologists’ ability to accurately treat those of us with neurological bladders. Maybe it was the cocksure urologist who all but ordered me not to get a suprapubic catheter in the wake of my SCI. Maybe it was the clumsy urologist

My attendant said it looked like my bladder had been invaded by white worms. We both knew they weren’t actual worms and they weren’t actually alive, but joking about sentient white worms taking over made the depressing situation a little more manageable.

who left a 12-inch drainage tube in my abdomen after surgery. Or maybe there was a point where I’d simply had enough of explaining what dysreflexia is and why they needed to be careful even though I can’t feel down there.

I’ve hired, fired and rehired more urologists than I can keep track of. While there have been a few competent ones, the totality of my experiences, coupled with conversations with countless other disabled friends, have led me to a sad but important realization: Most urologists have no idea what to do with us.

Don’t get me wrong, anyone who graduates from medical school can prescribe some Ditropan for bladder spasms, order an annual KUB X-ray and cystoscopy, and tell you your urine culture came back posi-

tive and that you need antibiotics.

Unfortunately, more than any other body part, the bladder relishes defying simple treatment. Problem-solving the neurogenic bladder requires intrepid explorers, willing to go where most urologists have never gone, and to persist when most sane people would give up.

## FAILED TESTS, NO ANSWERS

I started to question my sanity after two successive urine cultures came back showing no treatable bacterial infection. The sediment-like worms were right there, visible to the naked eye. I was sure whatever was growing was the result of some new bug that had taken a liking to my healthy bladder.

With no obvious culprit, my urologist went through the routine — cystoscopy, KUB, ultrasound, etc. — but turned

up nothing. When he stopped responding to my increasingly frustrated calls, I found a new urologist.

On the recommendation of a fellow quad, I switched to another urologist. His staff's professionalism was a breath of fresh air and his response to seeing the white sludge gave me hope. "I've never seen sediment like that," he said. "But we'll figure this out." He ordered the same tests, but I was hopeful because he seemed genuinely committed to working with me and we started a lively email correspondence.

A couple of weeks before our follow-up visit I received an email that the hospital was closing his clinic due to budget shortfalls and he would no longer be practicing locally. Back to square one, I sought another new urologist. None of my wheelchair-using friends had anyone to recommend, so I scoured the webpages of every local urologist for any experience with neurological bladders, eventually settling on two who had been recommended by another doctor I trusted.

## THE INVASION GROWS

While all of this was going on, the worms were building a full-fledged colony in my bladder. Apart from the rapidly thickening mucous, however, I felt fine and showed no obvious symptoms of an infection. Prior to the worms' arrival, I had never regularly flushed my catheter. Thanks to drinking copious amounts of water — usually 4-5 liters a day — I had stayed infection-free for years and avoided antibiotics. Why mess with what works?

By month two of the worms, not only was I regularly flushing the catheter with distilled water, but I had established an elaborate system to keep the syringes that I used sterile. Regular flushing became such a necessity that the "clean" and "dirty" trays where I kept my syringe rotation occupied a prominent spot at my bedside. Even with flushing, the sediment would eventually clog the catheters, forcing me to change them more and more frequently. Despite my best efforts to be sanitary, the frequent interruptions caught up to me. I woke up shaking with 103° fever and headed to the ER.

Previous trips to the ER for UTIs had taken away any illusions I'd had of a *House*-like doctor finding a miracle cure. But still I held out hope that a more thorough battery of tests would reveal some way to attack the worms and restore my health. The tests suggested my infection would respond to Bactrim, a strong antibiotic, and three days later I left with a clean catheter, no fever and a sense of hope.

I couldn't remember the last time I could see through my silicon catheter. For a month or so, I crossed my quad fingers and watched the clear catheter religiously. Just as I was regaining the confidence to be out and about, the sediment started returning. Soon the worms were back and more problematic than ever.

## TRYING ANYTHING & EVERYTHING

Though not unexpected, the return of the worms left me depressed and desperate. After disappointing meet-



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ings with both prospective urologists, I went back to my original one. We had a frank talk about communication, where he promised better response times and more urgency. Additionally, he proposed some new tactics, including referrals to an infectious disease specialist and a kidney doctor.

Referrals often strike me as passing the buck, but I was hungry for any new ideas. I tried upsizing catheters from a 22 FR to a 24 FR, but quickly abandoned that when it only produced bigger worms. I tried using silastic-coated catheters, supposedly designed to prevent sediment buildup, but found them ineffective. I talked with SCI-focused urologists around the country, and considered different irrigating fluids.

A quad friend recommended flushing with a mix of vinegar and distilled water but it had no effect for me. Another wheelchair user raved about finding relief with Renacidin, an acidic solution designed to break up sediment. My doctor agreed to prescribe it, but at over \$200 a bottle and no insurance coverage, I never got a chance to try it. I even spoke with a researcher conducting a study on the effectiveness of irrigating with probiotics.

As I was trying all these solutions, I was growing increasingly reliant on antibiotics to maintain any quality of life. A second weeklong course of Bactrim brought me another problem-free month, but my urologist worried that in addition to building resistance, the more regular usage could damage my kidneys.

We tried a weeklong course of nitrofurantoin and then a lower, daily dose of another antibiotic, trimethoprim. Sadly, neither affected the worms. A few weeks later I started another round of Bactrim. For all my quad life, to avoid developing resistance, I have avoided antibiotics except when desperately needed. But now it was the only thing keeping the worms at bay.

## DESPERATION SETS IN

In over 20 emails to my urologist, my desperation is evident. “My catheter is being incredibly problematic, with rapid forming sediment and the tube not working, causing incontinence,” I wrote. “It’s driving me crazy and making my life very difficult.” I bombarded him with possible causes and solutions I’d come up with after countless hours lying awake in bed and surfing the internet.

My most elaborate theory revolved around the coincidence that the worms had appeared about the same time I’d started taking milk of magnesia after getting a colostomy. The worms were white, the milk of magnesia was white: Maybe a surplus of magnesia was reacting with the bacteria in my bladder to create crazy new life-forms? My urologist was skeptical, but worked with me as I swapped laxatives to test the theory. It failed.

From the first time the worms appeared, getting rid of them seemed like it should be as simple as analyzing one of the sediment strands, determining what it was made of, and prescribing something — either a medicine or course of action — to eliminate them. I pitched this to every urologist I saw, and every one said they didn’t have the ability to

do so. They told me they could culture the urine sample, but not the sediment itself. This was of little good when every sample came back “contaminated” or with too many bacteria to read.

The first doctor who seemed receptive to my idea was the infectious disease specialist. She ordered another urine culture but gave me specific collection instructions. “Stop any antibiotics for at least 24 hours and change the catheter when you are well-to-over-hydrated. Let the catheter flow for 5-10 minutes after the change to let any blood or lube from the change flow through, then collect a FULL sample in a sterile container (provided by urologist). Take this to the lab immediately and request that if the urine culture is deemed a contaminant they should subplate the various bacterial colonies for identification and antibiotic sensitivity testing.”

Thanks to the countless cultures I had taken in during my worm invasion, I considered myself an expert on collecting samples. I doubted that this culture would reveal anything its predecessors hadn’t, but I followed her instructions to a T. That was the last time I saw the worms.

## A CLEAR START

In what seemed a miracle at the time, the culture came back showing a specific bacterium, *Klebsiella pneumoniae*. *Klebsiella pneumoniae* is a multidrug-resistant, gram-negative bug that produces urease, which can cause stones. My urologist didn’t think the levels were high enough to cause the worms, but after months of failing to even identify a culprit, I wasn’t about to ignore this evidence. I insisted on trying a targeted antibiotic and he prescribed one I’d taken many times before, ciprofloxacin.

I found myself checking the catheter whenever I could, but to my surprise it stayed clear. Once I allowed myself to believe I had truly snuffed the infection, I started to remember what it was like living without fear of accidents or emergency catheter changes.

By my estimate, I went through more catheters during the 18-month worm invasion than in the previous five years combined. Besides the catheters, the toll of the infection is harder to quantify. The ordeal tested my faith in my ability to manage my own body, and cost me hundreds if not thousands of hours of productivity and happiness, plus a ton of money. I worry that the multiple courses of antibiotics could have taken a hidden toll. And while giving up on my quest never seemed a viable option, there were times when failure felt inevitable.

Finally, my experiences stripped me of any faith I had in the expertise of urologists. It’s been replaced with a growing confidence that we are the only true experts in our bodies. The trick is figuring out how to work with doctors to get the services we need. It is exhausting, frustrating, infuriating — you name it — but sadly it’s the reality of our medical system. The next time my bladder is invaded by an alien bug, or some other mystery illness knocks me down, I have no doubt that what I’ve learned from this experience will make it more manageable.

MI

DAY IN  
THE LIFE



# INTERIOR DESIGNER MAEGAN BLAU

As a child, Maegan Blau was always painting walls, rearranging furniture in her bedroom and spending after-school time in her family's furniture store in Arizona. She had an eye for design from a young age, but never saw it in the cards as a professional career.

Blau sustained a C8 spinal cord injury right before enrolling at Arizona State University as an environmental science major. But when her postgraduation search for an accessible apartment became a nightmare, her career path took a dramatic turn to interior design.

Frustrated by tour after tour of "accessible" units with nothing more than grab bars in the shower and one-to-two-year wait lists at all the complexes with good accessibility, Blau decided to buy a home and renovate it to fit her accessibility needs. She fell in love with the whole process, everything from the design to the construction and the problem-solving in between.

**6:00 a.m.** The first thing I do is I feed my dogs: Odin, a 10-year-old Belgian Malinois, and Luna, a 4-year-old Corgi. I drink some coffee and I do my bathroom routine. And then I get ready for the day and eat breakfast with my husband, Chris.

**8:00 a.m.** I do my morning warmup, get my bearings for the day and complete any tasks to help make my day go smoothly. I catch up on emails, phone calls or admin tasks so I can get that out of my head before I start the day. I need that uninterrupted time to gather myself.

**9:00 a.m.** I have a virtual meeting with a new client. If the client is local, sometimes we will meet in their office or at a co-working space. During the initial consultation we discuss the scope of work, whether it is a new build, renovations or just furniture selection. For our full-service clients, we take care of everything and closely collaborate with architects, home builders and contractors with that service. With three different services, I can be working on 10-15 projects at once, with three to five being full-service design projects.

**10 a.m.** After meeting with a client and discussing their vision, I start creating a plan. This includes designing a floor plan, solidifying measurements, ordering furniture, window treatments, lighting, and selecting materials finishes. I send the client the plan for approval and edits.

**12:00 p.m.** Since I have a home office, I make sure to take time to separate my

personal and professional [lives]. I take an hour to refresh, have lunch, take my dogs out (again) and watch something on Bravo — I'm a huge *Real Housewives* fan.

**1:00 p.m.** Time for a site visit! My everyday vehicle is a Kia EV6: I've had it for two years, and I love it. It is electric, which means I no longer have to pump gas, which is a huge accessibility win!

For a project in Arizona, we usually go visit the site about five times during the process for all the milestone projects. I'll meet with the contractor before we start, once framing is up, to check on electrical

**WHEN I'M NOT WORKING:** I AM WATCHING DOCUMENTARIES, TRAVELING WITH MY HUSBAND, TAKING PICTURES OF MY DOGS, SWIMMING IN A POOL, OR — LET'S BE HONEST — IN A FURNITURE STORE SOMEWHERE (BECAUSE DESIGN NEVER RESTS).

measurements of the spaces I cannot get to. features and to do a final walk-through when we add furniture and take photos. A brand-new build from scratch typically goes a lot smoother than a renovation. We have a better schedule with new builds, but with renovations, we pop in a bit more unexpectedly.

Because our design firm has an emphasis on accessibility, I usually have no problem maneuvering [around in] the spaces. But I always carry a portable ramp with me just in case, and if a project is really inaccessible or has multiple stories, I have someone on site gather pictures, videos and mea-

surements of the spaces I cannot get to. Inspired by her own experience and driven to help other wheelchair users, she enrolled in a six-month, in-person certification program at the American Institute of Interior Design. She learned the history of design and furniture, design elements, how to explain design features, and how to create custom items.

In 2018, Blau started her interior design business, Blue Copper Design. Blau means blue in German, and copper pays homage to Arizona, as it is both the state metal and an element she loves using in her designs.

The company offers three levels of consulting and design — Full Service, Design Only, and Barrier-Free Consulting — so clients can decide how much help they need. Every day is different, depending on the project, but here is what a typical day looks like as an interior designer.

surements of the spaces I cannot get to.

**3:00 p.m.** I take a client call regarding our Barrier-Free option. This is a one-time, 90-minute consultation where we review your project, suggest customized accessibility solutions, and instill confidence in how to best move forward. Most of this work is done virtually with clients in other states. I prioritize this service, and 70% of my projects focus on accessibility. We're only as independent as our spaces allow, so I love improving the quality of life of disabled individuals through design.

**4:00 p.m.** I finish off the day by catching

up on emails, spending time on social media and taking care of business tasks like balancing the books.

**6:00 p.m.** After work I feed my dogs, have dinner and then I relax on the couch and watch one of my shows. When Chris gets home from work, we take a dip in our hot tub and recap the day.

**9 p.m.** I go to bed early. I love sleeping and I have no shame about being asleep by 9 p.m. I take a shower, get into bed and read a few chapters on my Kindle before I fall asleep.



# DISABILITY MATTERS

By Greg Moomjy

## HOW MEDITATION HELPS ME DEAL WITH DISABILITY GRIEF

I have spent the past decade slowly but surely morphing into an affluent white woman. Tickets to the Metropolitan Opera at least once every month during the season? Check. Living with my family on the Upper East Side? Check. And, I just started meditating. Yahtzee! Before you think I'm going to start selling jewelry on Etsy and eating avocado toast, let me just say I started meditating not to "manifest my best life," but to deal with the complexities of disability grief.

I've realized that meditation is indispensable to my well-being as a disabled adult. Simply put, I have depression due to disability grief, and meditation helps me deal with it. For me, disability grief comes from living in a world that isn't built with disabled people in mind. Nobody talks about this, but we certainly need to. It is a major part of my life as a person with a disability that is very hard to explain to my nondisabled friends and loved ones.

I have grown to realize that having a disability can be a very isolating experience. Yes, there are ways of finding friends and creating a support network for yourself that consists of other disabled people. Even so, I sometimes feel as if I live a double life. I'm a different person when I'm out in the world versus when I'm at home with my family or managing my aides and caregivers. This is where the isolation

comes from. Sometimes those people that by necessity are the closest to me because they handle my daily care understand me the least.

My mom recently commented that she had no idea that having a physical disability meant that I would also experience psychological and emotional hardship. I've come to realize that even though she's a doctor with a bachelor's in occupational therapy and a master's in rehab medicine, it doesn't mean she has the experience of living with a disability. I want to be angry at her, but I can't. There's no way she could know what it's truly like.

It is hard to say exactly where disability grief comes from. Really, anything can set it off. When my nondisabled twin sister got married, her wedding was a rollercoaster ride for me. Seeing her walk down the aisle before I had my first kiss and seeing her slow dance with my dad, realizing that I would never be able to have the exact same experience, made me nauseous. Don't worry, I now realize those instances were caused by the joint forces of internalized ableism and a lack of understanding that when you have a disability, milestones often happen at different times and look different than they do for nondisabled people. I am working on it and know better now. Still, those two made quite a toxic pairing.

The other main cause of my dis-

"I can't believe all the repressed memories that meditation brings up. It's pretty much all centered around medical trauma: being left on the hospital commode late at night as a toddler; getting anesthesia but having no idea what the surgery actually was."

ability grief is feeling like I'm not in control of my own life. When you live and work with the same caregivers you've had since your childhood, they tend to see you as the kid they first started working with, and it's difficult to assert yourself as an adult. Sometimes it's hard to tell if I can ask for certain things, like staying up later if my caregiver needs to get up early the next morning. Still other times I feel the need to look out for my care as-

sistants. Given all this, I frequently feel that I'm being pulled in multiple directions and I'm afraid of losing myself in the process.

I have tried many remedies for my depression, with varying degrees of success. Talk therapy is necessary, but sometimes it takes too long. I've also taken up boxing. Once, I might have joined a cult for a weekend (more on that later). Finally, an opera singer I know told me she also teaches yoga and meditation. Although I'd tried it before, I wasn't a fan of needing to stay absolutely still. Anyone with spasticity knows what it's like to go to physical therapy, only to hear them say "Just relax." Every time I hear this, I think, "If I could relax, I wouldn't need to be here." None-

theless, I decided to give meditation another go. And I love it. In the first place, my instructor believes that my spastic movements are just expressions of the tension in my body. This may seem blatantly obvious to those of us with disabilities, but her acceptance of my spasms is unfortunately novel.

More importantly, I can't believe all the repressed memories that meditation brings up. It's pretty much all centered around medical trauma: being left on the hospital commode late at night as a toddler; getting anesthesia but having no idea what the surgery actually was. I thought I had made my peace with this, but clearly, I haven't. However, the best part is, at the end of every meditation, my instructor repeats,

"It is safe for you to feel." Considering my disability forces me to spend a lot of time worrying about everyone else, it's such a relief to know that there's at least one thing I can have for myself. Honestly, the first time I realized this, I cried.

Ultimately, my instructor's goal is to help me find a way to give myself the space that I need to feel like a human. Truthfully, I don't know what that's going to look like. Growing up disabled made it difficult for me to put my needs first, so I'm kind of nervous, but sometimes nervousness can be a good thing. I will report back as the process continues. For now, I'm just relieved. And I want to celebrate the fact that "It is safe for me to feel."



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## TIPS FOR DEALING WITH SPASTICITY

Anyone who lives with spasticity can testify to just how irritating and inconvenient spasms can be. Spasms can cause pain, insomnia and secondary injuries, and have a knack for ruining any situation. At the same time, for many wheelchair users, maintaining a certain level of spasticity can help with functional abilities and maintaining blood pressure. Being able to trigger a spasm at will can help with a tricky transfer or grabbing a needed item. The trick is finding a management routine that maintains the balance you need to live your life to the fullest.

Alex Ghenis knows how difficult finding the right balance can be. Spasms immediately became a problem when Ghenis sustained a C5-6 incomplete SCI in 2004. He tried managing them with oral baclofen — the most-prescribed spasticity drug — but the dosage he needed left him drowsy and unfocused.

After conferring with his doctor and family, Ghenis decided to have a baclofen pump implanted in 2005. The small, refillable device infuses liquid baclofen directly into the spinal canal, hitting nerves head-on. Compared to oral baclofen flowing through his bloodstream, the pump's targeted, steady infusions reduced drowsiness and were easier to manage.

The implant dramatically improved Ghenis' quality of life. "It's super-easy not having to deal with medication, and my muscle tone is great and under control," he wrote in a 2017 *NEW MOBILITY* article. "I can be wide awake during the day while my muscles are mellow enough to let me easily sleep through the night."

But it wasn't all positive. His high dosage meant more

refills, leading him to upsize from a 20-milliliter to a 40-milliliter pump when the time came for a replacement pump in 2012. That extra bulk proved uncomfortable.

Despite the benefits, after 12 years, Ghenis decided to remove the pump in 2017 instead of downsizing and dealing with monthly refills again. "Those appointments and discomfort were just too much," he says. "So, we turned down the infusion and increased my oral baclofen. When I handled it fine, we removed the pump."

For seven years he managed with oral meds. Then a pressure sore in early 2024 triggered back-spasms beyond what baclofen, dantrolene and Zanaflex could handle. Ghenis often sat up at night to calm those rhythmic spasms, but that kept the sore from healing and made his sacrum break down too. His physiatrist explained that strong spasms tore at his wound tunnel from the inside, doing even more damage. "I told him, within a week I wanted another 20-milliliter pump and would deal with refills," Ghenis says, "and he agreed with my choice." He is currently waiting to get a new pump.

"I've learned that having tone is fine," Ghenis says, "but I need a way to virtually eliminate spasms when they are fighting hardest. The pump has that special sauce. Meds don't."



Ghenis

## MEMBER TIPS

“Getting my baclofen pump was life-changing. I was on the maximum amount of oral baclofen and still had bad spasms. Putting on or taking off a jacket was an ordeal. I was even afraid that a particularly strong sneeze might knock me out of my chair. Plus, as a high-level quadriplegic, I had to ask someone to help me take pills four times a day. The pump delivers the medication directly into my spinal cord so I don't have to be worried about processing so much medication, and it's infinitely more effective.”

— Daniela Castagnino, Washington, D.C.

## UNITED SPINAL RESOURCE CENTER MOST FREQUENTLY ASKED QUESTION

*I'M 10 YEARS INTO MY C8 SCI AND MY SPASTICITY IS RAPIDLY GETTING WORSE. I'VE MANAGED MY SPASMS WITH A HEALTHY REGIMEN OF STRETCHING TO THIS POINT, BUT THINK I MAY NEED SOMETHING MORE. WHAT ARE MY OPTIONS AND HOW SHOULD I PROCEED?*

RESOURCE CENTER SCI NURSE SPECIALIST JANE WIERBICKY:

Spasticity is common after spinal cord injury. However, a sudden increase or change in spasticity can be a sign of an underlying health issue and it's important to contact your health care provider right away for a thorough evaluation to determine the cause. Spasticity is a movement disorder resulting from disrupted communication between the brain, spinal cord, and muscles due to the injury of the spinal cord. Spasticity can be experienced as involuntary muscle movements, increased muscle tightness and overactive reflexes.

Triggers commonly associated with increased spasticity include urinary tract infection, pressure injuries, fractures, constipation and other bowel complications, and many other irritating stimuli. Management of underlying issues may lead to improvements in spasticity. A sudden change in spasticity is also symptomatic of a syrinx, a fluid-filled cyst in the spinal cord. Though a syrinx after SCI is relatively uncommon, it's important to be aware of its symptoms since a syrinx can affect sensation, movement, bowel and bladder function, and autonomic functions such as blood pressure control and sweating.

Spasticity treatment options include nonpharmacological treatments, medication management, and surgical procedures. Nonpharmacological approaches include stretching, weight bearing (such as through supported standing and walking), appropriately fitted splints and braces, whole body vibration, and cyclic activities with or without functional electrical stimulation, among others. If nonpharmacological methods are not effective, your doctor may consider medication management. Medications may include oral medications (such as baclofen), and/or injectables such as botulinum toxin (commonly known as Botox injections or Botox nerve blocks), which both treat spasticity isolated to specific muscle groups. Surgical options may be considered if oral medications are ineffective or not tolerated. One example is a surgically implanted intrathecal baclofen pump that delivers spasticity medication directly to the spinal canal, which may help minimize some side effects associated with oral medications.

## RESOURCES

### UNITED SPINAL RESOURCE CENTER RECOMMENDATIONS

**Manage Spasticity After Spinal Cord Injury (SCI):** Published by the Model Systems Knowledge Translation Center, this factsheet is a great primer on spasticity after SCI, including symptoms, complications and treatment options: [msktc.org/sci/factsheets/spasticity-and-spinal-cord-injury](https://msktc.org/sci/factsheets/spasticity-and-spinal-cord-injury)

**Finding the Right Doctor:** A physiatrist with SCI experience can help you manage spasticity. This MSKTC video describes the role of a physiatrist in the care of someone with SCI: [msktc.org/sci/videos/finding-right-doctor](https://msktc.org/sci/videos/finding-right-doctor)

### BEST NEW MOBILITY ARTICLES

**Searching for Solutions to Spasticity:** [newmobility.com/searching-for-solutions-to-spasticity](https://newmobility.com/searching-for-solutions-to-spasticity)  
An in-depth look at all the ways that spasms affect the lives of people with an array of disabilities, including the solutions and work-arounds people have developed to help them live their lives.

**Spasticity Relief:** [newmobility.com/spasticity-relief](https://newmobility.com/spasticity-relief)  
Bob Vogel works through the problem-solving steps that can help you pinpoint the cause of an increase in spasticity.

**Saying Goodbye to the Baclofen Pump:** [newmobility.com/saying-goodbye-baclofen-pump](https://newmobility.com/saying-goodbye-baclofen-pump)  
Getting a baclofen pump installed was a life-changer for Alex Ghenis (see page 52), but in this blog he explains why he had it removed.

### VIDEOS

**Quadriplegic Reality: Pros, Cons and Treatment of Spasms:** [youtube.com/watch?v=XKG3ZXUIG9k](https://youtube.com/watch?v=XKG3ZXUIG9k)  
A personal look at the pros and cons of spasms, and how one quad learned to manage his.

“ I feel grateful that my spasticity is relatively mild, but if I've learned anything in the 22-plus years since my injury, it's to not ignore it. If my legs are jumping, there is something going on in or around my body. Do I need to pee? Are my pants too tight? Have I hurt myself in some way? I have a quick list I run through — so I guess in a way, I'm glad that I have my spasticity warning system. ”

— Erin Gildner, Arkansas





# PRODUCTS

By Jenny Smith

## REVIEWING TWO QUAD-FRIENDLY REACHERS

*A C6-7 quad tests the real-world functionality of the Grip-Free Grabber and the QUADTOOLS Reacher.*

### Grip-Free Grabber: Affordable Function

As anyone with limited hand function knows, stuff ends up on the floor — frequently. I function on my right side as a weak C6 and on my left as a decent C7 with a triceps, and over the years, reaching for dropped items has grown more difficult, especially since my power wheelchair sits higher off the ground. So I was excited to review the Grip-Free Grabber by KFK Designs. It is one of the adaptive tools designed by Kelly Ferguson, a C5 quad with a degree in mechanical engineering. The company's website says its grabber "allows anyone with weak or limited hand function to use a reaching device."

The Grip-Free Grabber comes in three lengths: Youth (30 inches), Standard (36 inches) and Long (48 inches). I tried both the Standard and Long versions. Pushing down a plunger at the top of the grabber opens the pincers at the bottom, and my left hand could easily do so. However, operating the Standard-length grabber from my power chair proved difficult and time-consuming. For me, the Long grabber was quicker and easier to use. It's definitely a better option for power chair users.

### Other aspects to consider about the Grip-Free Grabber:

- The Grip-Free Grabber's grip. The grabber pincers close as you let off

on the plunger. If you can maintain a decent amount of pressure on the plunger, you can keep them open enough to grip an object gently. If not, they may crush more delicate items like food, paper, pills, etc.

- The Grip-Free Grabber is affordable at \$48 for Standard, \$42 for Youth and \$55 for Long.
- The Grip-Free Grabber requires use of both hands, one to stabilize the grabber and the other to push the plunger. It can be used in either hand. The functionality of the Grip-Free Grabber will vary from person to person since no two SCIs or disabilities are the same.

Overall, I found the Grip-Free

Grabber to be a well-designed and lightweight reacher for people with limited hand function, especially considering its affordable price. However, I feel it requires more function, strength and balance than the QUADTOOLS Reacher (reviewed below). The makers of the Grabber say that since I demoed the product, they have removed an internal spring, which they found was making it difficult for many users to open the grippers. They are offering 100% refunds for anyone who isn't satisfied with the product and say they can add the spring back for customers who'd prefer. For more information and ordering, visit [kfkdesigns.com](http://kfkdesigns.com).



The Grip-Free Grabber was designed for people with limited hand function to be able to pick small items off the floor or from up high.



The QUADTOOLS Reacher comes in a variety of lengths, and the pinch mechanism can be activated entirely with wrist extension, letting you use your other arm for stability.

### QUADTOOLS Reacher: More-Expensive and More-Functional

Before trying the Grip-Free Grabber, I'd been using the QUADTOOLS Reacher. It too is an extended-reach grabber that can be used by people with limited hand function. It is made from lightweight aluminum and steel, and available in lengths

from 17 inches to 48 inches.

You open and close its gripping mechanism entirely through wrist extension. I find it easy to use and to modulate the amount of pinch, letting me pick up delicate items without crushing them. Since the QUADTOOLS Reacher requires only one arm and tenodesis, the other arm is free to move your chair or stabilize your upper body.

The main drawback to the QUADTOOLS Reacher is the cost. Depending on length and whether you're getting the lightweight or heavy-duty model, it runs from \$229-\$299. Visit the [quadtools.com/products/the-original-cripper](http://quadtools.com/products/the-original-cripper) for more info and to check out their other products, like wrist-activated BBQ tongs and a quad-friendly kitchen knife.



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## SEE IT FIRST ON NEWMOBILITY.COM

### Omni Cuff

For people with limited hand function, it can be hard keeping track of all the tools you need to get through the day. The OmniCuff System was designed so you can independently switch between a wide variety of assistive devices. Michael Franz, a C6 quad, shares his review.



### Southwest Airlines Moving to Assigned Seating

Southwest Airlines announced over the summer that it will be doing away with its longstanding open seating policy. We talk to wheelchair users about how the move will affect their travel planning.

### Making Yourself Stick Out as a Wheelchair User

John Beer talks to wheelchair users and experts about how to be more assertive in large groups or other social situations where it's easy to get lost in the crowd.

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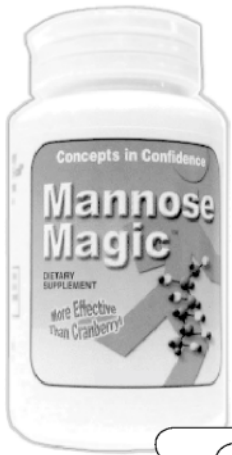


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TO ACCESSIBILITY  
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