GEEK MEDIA EDITOR

Jill Pantozzi:
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“I feel more like I did before my accident – an independent 26-year-old man”  Thomas*, catheter user

After his accident, Thomas had to rely on other people to help him catheterize. With SpeediCath® Compact Set, he’s gotten back his independence.**

Once his initial rehab was over, Thomas, 26, was determined to get out and about and meet friends. The only issue was his injury meant a caregiver, friend, or relative had to help him catheterize. He explains: “I couldn’t be spontaneous – it was like an anchor keeping me down.”

From the start, Thomas preferred intermittent catheters and felt they offered more control than an indwelling product. But the problem was finding one he could open himself. He adds: “My occupational therapist suggested SpeediCath Compact Set, but I couldn’t open it at first. But I tried with the Dycem gripper and I could do it. It was exciting – to actually have it work and to know that I could do it made me happy.”

Thomas got his driver’s license around the same time as he started using SpeediCath Compact Set and he identifies that as the time things started to turn around for him on a personal level. He continues: “Now I don’t have to ask my friends or family to take time out of their day to come and help me. I feel more like I did before – an independent 26-year-old man.”

It’s now the only product he uses when catheterizing himself and Thomas is particularly happy about its discreet size and the hydrophilic coating, which makes the catheter pre-lubricated. He goes on: “The reason it’s so much easier is there are so few steps involved – you don’t have to lubricate it, or push through the bag. The catheter’s already out so you just put it right in and you’re good to go.”

“It’s easier to keep more of them in a bag, and they’re easier to handle and use. It goes into the bladder easier and with less resistance, and the handles on the bag are useful.”

For Thomas, just 15 months after his injury, his focus is still firmly on his rehab. He’s taking part in the Activity-Based Locomotor Exercise (ABLE) program close to his home in Minnesota and is beginning to think about looking for his own apartment. And with SpeediCath Compact Set, he has found a product that is playing a key role in improving his quality of life. He concludes: “Now I can do things on my own and take care of myself, which is a good feeling.”

About SpeediCath Compact Set
SpeediCath Compact Set is an all-in-one catheter and bag solution. Rated easy to use by 88% of users¹, SpeediCath Compact Set is designed for everyday use both in and out of the home.

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SpeediCath Compact Set is available by prescription only.

1 Product evaluation of SpeediCath® Compact Set, response from 70 HCPs and 550 end-users, Feb. to April 2013.

*Thomas is a SpeediCath® Compact Set user who has received compensation from Coloplast to provide this information.

** Individual results may vary.

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**COVER STORY**

**QUEEN OF THE GEEKS**

As the deputy editor for io9, one of the web's leading geek culture sites, Jill Pantozzi is uniquely positioned to influence the mainstream discourse about comics, sci-fi, fantasy and more. As an outspoken woman with a disability, Pantozzi provides a perspective not often heard or desired by some of the community’s less progressive voices. AARON BROVERMAN profiles Pantozzi and reports on her efforts to fight trolls and change the conversation around how women and people with disabilities fit into geek culture.

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IT’S NOT SCI, IT’S HBO

This fall HBO debuted a new documentary called Any One of Us that follows mountain biking star Paul Basagoitia in the wake of a 2015 bike crash that left him paralyzed. Using first person footage captured by Basagoitia and short interview segments with an array of familiar and unfamiliar SCI personalities, the movie aims to pull back the curtain and allow the millions of people who tune in to HBO for entertainment escapism a glimpse of the realities of spinal cord injury.

As a sucker for a good documentary, and someone with an obvious interest in anything and everything SCI-related, I was stoked to dig in, even if the movie poster’s lone image — Basagoitia standing with hand crutches in a desert and looking at his reflection in an oasis — had me a little leery.

If 30 years of New Mobility have proven anything, it’s that there is much more to life after SCI than trying to walk again. That’s not to downplay the importance of walking — it’s huge. Most of us would be thrilled to wake up tomorrow and go for a leisurely stroll in the park, but working to walk again is only a piece of a much more complicated puzzle of recovery.

Yet all too often, media portrayals get so lost in the easy (and ableist) “will he/she walk again” narrative that they forget the other pieces and leave their audience with an incomplete picture.

While Any One of Us is not without its strengths, most notably Basagoitia’s willingness to bare himself both physically and emotionally on camera and the insights of some of the interviewees, I couldn’t help but roll away feeling like it had missed an opportunity.

Since the poster shows Basagoitia standing, I’m not spoiling anything by saying he makes significant strides in his recovery. His steady progress, contrasted with his sometimes frustrating lack of awareness thereof, makes for compelling viewing.

In light of his regained function, Basagoitia’s decision to focus so intently on walking again makes sense. But the movie’s heavy focus on his progress, combined with some melodramatic editing and a few interviewees who come across as single-mindedly obsessed with getting back on their feet, comes with a cost.

“While Any One of Us is not without its strengths, I couldn’t help but roll away feeling like it had missed an opportunity.”

Intended or not, these decisions have the effect of reinforcing the idea that in addition to the actual physical damage, a spinal cord injury leaves us broken people, and walking is the sole ticket to health and a truly happy life.

It’s disappointing because the antidote to that message is right there on screen in testimonials from the spinal-cord-injured talking heads interspersed throughout. With years of experience under their belts, former Push Girl Chelsie Hill and surfer Jessie Billauer of Life Rolls On are two of the many wheelers who eloquently talk about their experiences after SCI and move the narrative beyond physical recovery and walking.

The short clips of Hill dancing with the Rollettes and Billauer riding a wave tease the wider world of SCI that so many of us inhabit — a more complex and, I would argue, more interesting world than the one that usually makes it onto the silver screen.

There’s a great documentary out there waiting to be made that will take people into this world and put all the pieces together. Until then, I’ll keep watching.
As a writer and podcaster who covers pop culture and comics, and, most importantly, a fan of the “geek” world, Aaron Broverman has followed Jill Pantozzi’s career for a long time. “Jill was always somebody that I really, really admired,” he says. “We both use scooters, and she worked for many of the places I wanted to work.” Pantozzi made a name for herself as an outspoken woman with a disability covering a field that evolved from subculture to part of the mainstream. Broverman’s cover profile of Pantozzi comes at a perfect time, as questions about diversity, inclusion and much more are being heatedly discussed therein. You can find more of Broverman’s insights in his podcast, *Speech Bubble*, and his various writings online.

When she’s not writing articles, speaking or working on her book, you might find Sheri Denkensohn-Trott scouring the sale racks of Northern Virginia’s leading department stores. As she writes in her candid essay this month, that wasn’t always the case after her spinal cord injury. The story of her road back to the department stores and her refusal to wear a sweatsuit will resonate with many readers who struggled, or are struggling, to rediscover their sense of self after an injury. You can find more of her writing at happyonwheels.com, and look for her book, *Happy on Wheels*, in 2021.

Brook McCall has quickly earned a reputation on staff for her thoughtful and creative story ideas. This month’s feature on the pluses and minuses of comparing yourself to other wheelchair users is a nice complement to her previous articles on dreams and self-reflection. She says the obvious underlying theme is no mistake, “I like to get introspective, and these stories give me an outlet.” While looking inside comes easily for her, working on this topic reinforced that’s not always the case for others. “Comparison is a natural struggle, but it seemed difficult for others to admit they get jealous or judge themselves unfairly.”

*Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org*
**Couldn’t Put It Down**

I was amazed by the September issue (“The Big Ideas Issue,” September 2019). As a person with a new SCI, I am learning so much about how each of us travel on our own journey, and this issue was great in that it showed how technology will help us. I remember my great grandma being in a nursing home and how she used a similar chair to the one I am using now. It amazes me the lack of [new] technology for anyone using a wheelchair.

The article on “Disregard SCI Dogma” was eye-opening. It shows that people are working on ways to improve our lives. I look forward to reading more about this research as it unfolds.

This is the first magazine that I could not put down until I read everything. I would love to see more about our SCI culture. I appreciate the way this magazine can show inclusiveness of all SCI people. Thank you,

Melissa Kirkpatrick
Via Email

**Big Ideas = Best Ever**

Your September issue that examines technology, transportation, community, etc., is the best issue you have ever done. Every single article is well-written and well-researched. As a 61-year-old woman living with spina bifida, the articles have given me great hope for the future. Thank you for such an amazing collection of articles.

Nancy Gore
Roswell, Georgia


It’s always "manual" wheelchairs! Especially cosmetics to "customize" the look to help the person in the wheelchair feel better about being in the wheelchair. Also, wheelchairs are expensive and we don’t have much say in what wheelchairs we really get with insurance/Medicare/etc. It’s what we “need” and never ever what we want!

Dereck Lockwood
Newmobility.com

**A Strong Hart**

Happy to see Anne Hart getting some recognition for her valuable impact in the sport of wheelchair rugby (“Make Medals Meaningful," September 2019). Keep up the great work, Anne! Thank you for all you do.

Bob Lujano
Newmobility.com

**The Long Road Back**

Great article (“Recovering from Bed Confinement,” October 2019). I was 44 years post injury (T7-8 complete) when I developed my first decubitus. This was as a result of slipping while transferring to my chair and landing hard on the tile floor — not realizing I hurt myself until it developed into a stage 3 ulcer. For 14 months I was treated at a wound care facility with daily nurse home visits to change the dressings and 80 hours in hyperbaric chambers. I finally had the flap surgery performed and was bed ridden on a Dolphin mattress for 49 days. After that I was able to sit up for two hours and gradually moved to full day seating. However, I lost all muscle tone and it took over one year to not only regain my muscle tone but my confidence to transfer as well. I was 76 years at the onset and thankfully had no pain, shoulder issues, or anything else other than rebuilding muscles and confidence. My GP stated that for every day I was bedridden it would take one week to recover. He was close, as it would have been 49 weeks by his prognosis and actually took about 52.

Stan Swish
Newmobility.com

**Tantalizing, Not Realistic**

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INCLUSION AND ACCESS: BEYOND CAMPAIGN SLOGANS TO TRUE PARADIGM SHIFT?

Given the media black hole that Donald Trump’s impeachment inquiry has become, it might be possible to forget there is a presidential election coming up in less than a year. But the early race for the Democratic nomination has been fascinating so far. At one point there were upwards of 20 candidates, and, as of the moment this is being written, the field has been winnowed down to 17, all before the first primary ballots have been cast.

Seeking to make a sharp contrast with the rhetoric of the past four years, Democratic candidates are promoting a vision of a more inclusive, welcoming America. And in a way that we haven’t seen in the past, disability policy is making its way onto the campaign trail as part of this broader focus on minority rights. So let’s take a look at where our community sits in the 2020 presidential race.

What They’re Talking About

We can count on politicians to speak in platitudes, and plenty have already done that for the disability community. In July, on the 29th anniversary of the Americans with Disabilities Act, 13 democratic presidential candidates made statements, either in person or via social media, saluting the landmark legislation. Cory Booker, senator from New Jersey, sent a tweet typical of the tone of the day: “The ADA was signed 29 years ago today. We have more to do to ensure equality for Americans with disabilities who still face high poverty rates and barriers to health care and quality of life. As president, I’ll fight for equal rights and inclusion for people with disabilities.”

Even Trump—who has been roundly condemned by the disability community for mocking a disabled reporter, encouraging the Social Security Administration to monitor the social media accounts of disability benefits recipients and gutting programs many disabled Americans rely on—issued a proclamation of support for the ADA.

The public acknowledgement of the ADA’s importance is welcome, but we all know the law is not a panacea. In elections past, specific policy proposals relevant to the disability community have been few and far between. In the 2020 race, that is finally starting to change. Whether through their campaign speeches and websites, or in answers to surveys from the American Association of People with Disabilities, 2020 presidential candidates have put out disability policy platforms and taken positions on many of the issues that advocates have been fighting for years to bring into the national conversation. Here’s where some of the candidates are on disability issues:

- Joe Biden has been around long enough that he cosponsored the Americans with Disabilities Act. His current disability plans are similar to his broader campaign themes: protecting and strengthening the systems we already have, namely the Individuals With Disabilities Education Act, Medicare, Medicaid and the Affordable Care Act.
- Elizabeth Warren was an original cosponsor of the Disability Integration Act. Her campaign has detailed a wide-ranging disability platform that touches on education, employment, inclusion of long-term supports and services in universal health care coverage, making America’s polling places more accessible, and even increasing funding for biomedical research through the National Institutes of Health, among others.
- Bernie Sanders co-sponsored the DIA as well. His and Warren’s disability platforms echo each other’s in many ways. Sanders is also calling for a federal jobs initiative that would guarantee employment to people with disabilities who want and are able to work.
- Pete Buttigieg released a similarly comprehensive disability platform that reads like it came directly from a disability advocate’s wish list. In addition to staples like healthcare and IDEA, Buttigieg’s plan has some interesting additions, including

“We could congratulate presidential candidates for finally realizing that people with disabilities are a large and important voting bloc. But damn, it’s about time.”

By Seth McBride
creating a national apprenticeship program to boost disabled employment and ending the SSDI benefits cliff by allowing recipients to earn partial benefits while earning wages up to nearly $45,000 a year.

- Second-tier candidates — Kamala Harris, Cory Booker, Julian Castro and Andrew Yang, among others — are weighing in with similar proposals to end the sub-minimum wage loophole for disabled workers, increase access to complex rehab technology, ensure climate change mitigation and disaster relief strategies are inclusive of disabled Americans, and prioritize disabled applicants for accessible housing units.

As with any issue, your views on specific platforms will be dependent on your politics and your trust of individual candidates. But in the 2020 Democratic primaries, unlike any presidential election before, it will be possible to make a decision for whom you’re going to vote based entirely on comparing disability platforms.

For those wishing to take a deep dive into the different candidates and their positions, the AAPD’s Presidential Candidates: 2020 page (aapd.com/advocacy/voting/presidential-elections-2020) is a great place to start.

What They’re Doing

Framing disability through the rosy lens of candidate websites and stump speeches, it can be easy to get hopeful — until you remember what happens when policy ambitions meet the unforgiving world of Washington, D.C., politics. The odds of success for turning campaign rhetoric into legislative action are as low as they are for a sea turtle journeying successfully from nest to sea — it’s a nasty business, full of vultures that want to eat your baby for lunch.

Politicians need sustained engagement with the disability community to keep relevant issues at the forefront of their agendas. Two good ways to do that are by making their events accessible and by hiring staff with a variety of disabilities. Warren’s campaign has stated that they won’t sign any leases on buildings for their offices or venues for public events if the locations are inaccessible. Other candidates are making similar pushes for accessibility at their offices and events. Such efforts are a welcome no-brainer when it comes to reducing the casual exclusion of disabled people from the political process.

Similarly, bringing disabled people onto staff can change the way that candidates think about disability. Campaigns, including those of Warren, Sanders, Buttigieg and others, are pledging to hire disabled campaign staff. Emily Voorde, a wheelchair user, is serving as the travel manager for the Buttigieg campaign, allowing Mayor Pete a unique perspective on the airline industry. "It means that when Emily’s wheelchair gets broken by the airlines, all of a sudden we have a political campaign see firsthand the kind of rampant discrimination and mistreatment that disabled people face by the airline industry … they actually have to live the consequences of that now, which is pretty freaking amazing," says Rebecca Cokley, the director of the Disability Justice Initiative at the Center for American Progress. Perhaps unsurprisingly, Buttigieg’s platform now includes a piece on airline accessibility.

Campaigns are also reaching out to disability leaders, both in national organizations and in the early primary states. "We are getting a lot of phone calls from the campaigns," says Jenn Wolff, a longtime disability advocate and chapter leader for the Iowa Chapter of United Spinal. "I actually got a phone call the night before Kamala Harris released her disability platform, asking my opinion on it."

No election cycle is perfect, but advocates are saying they have never seen these levels of engagement between the presidential campaigns and the disability community, nor the willingness to learn and try to be better when it comes to inclusion and access.

Why Now

Presidential candidates didn’t just appear out of nowhere with a conviction that people with disabilities are worth appealing to on the campaign trail. The current moment — where candidates are thinking about inclusion and how to rectify programs and policies that have long discriminated against disabled Americans — has come on the back of decades of work by disability advocates. It is about us and our community making society understand that disability isn’t just a medical issue but a civil rights issue. It’s about Judy Heumann and the 100-plus protestors at the 504 sit-in, ADAPT activists storming congressional offices to save the ACA and everyone before, after and in between. It’s about disabled Americans living well, contributing to our communities and to society as a whole despite a system that’s stacked against us. We could congratulate presidential candidates for finally realizing that people with disabilities are a large and important voting bloc. But damn, it’s about time. If anyone deserves congratulating from the disability community, it’s ourselves.

Good job, everybody. Alongside other marginalized groups with whom our community so often intersects, we’ve pushed politicians to start acknowledging that progress doesn’t count unless it includes everyone. The reward? We get to keep forging ahead. The vultures are waiting.

A AAPD’S ELECTED FOR INCLUSION’ PRESIDENTIAL FORUM

On January 13, at the AT&T Convention Center in Austin, Texas, the American Association of People with Disabilities is hosting a forum for presidential candidates to talk disability policy and engage with the community. “We’ve seen a lot of the momentum in terms of the disability vote over the past few years," says Keri Gray, AAPD’s senior director of stakeholder engagement and strategic communications. "The forum is really about building on that momentum and showing that the disability vote does exist. ... The goal is to make sure that whoever sits in the office understands who our community is and what are priorities are."

If you’re in the area, tickets are only $10 and can be purchased through the Elected for Inclusion website (aapd.com/advocacy/voting/2020-presidential-forum-on-disability-issues/). The event will also be webcast.
United Spinal Association is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D) by providing programs and services that maximize independence and enable people to be active in their communities.

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**NEW MOBILITY magazine**

**NEWS FROM UNITED SPINAL**

**NYC SIDEWALKS FINALLY COMPLYING WITH ADA**

After three administrations and 25 years of litigation, New York City’s sidewalks are finally on the path to complying with the ADA. Under terms of an historic settlement between disability-rights organizations and the administration of Mayor Bill de Blasio, the NYC Department of Transportation is spending $1.55 billion to survey, install and repair curb ramps at every street corner in the city’s five boroughs.

It’s a huge investment requiring both manpower and new technologies. The initial survey of the city’s 162,000 street corners has been completed. The city used vehicle-mounted lasers that measured the key dimensions of each corner to tell if there was already a ramp there and whether it was compliant with current codes. According to the settlement, approved in July by Judge George B. Daniels of the Southern District of New York, the city is required to conduct similar surveys in 2033 and 2046. In addition, NYC has added a Pedestrian Ramp Unit to its Department of Transportation and is hiring hundreds of workers to conduct the massive, decade-long project of bringing code-compliant ramps to all of the city’s corners.

“The De Blasio administration agrees with us that an aggressive approach to accessibility of streets and sidewalks would be the only remedy for decades of business-as-usual,” says James Weisman, CEO of United Spinal Association. “Judge Daniels facilitated a comprehensive settlement with disability groups, led by United Spinal Association, that recognizes that access is a civil right, and requires transparency, significant expenditure and effort.”

Weisman and United Spinal Association have been fighting for full access to New York’s streets since 1994, when it became clear that the city would not meet the 1995 deadline for installing curb ramps that was set by the ADA. The resulting decades have been full of legal wrangling, false promises and slow progress. While there are now curb ramps on all but an estimated 3,100 of the city’s street corners, large numbers are not up to code or have fallen into disrepair, making them dangerous and sometimes impossible for wheelchair users to navigate.

The new settlement requires the city to maintain its curb ramps and provides the funding to make sure they stay up to code. “I'm glad they put in the stipulation that they have to maintain them, because often trucks will damage ramps, and in the past, even if you filed a complaint, who knows when the city would get around to fixing it,” says José Hernandez, advocacy coordinator and president of United Spinal’s New York City chapter. Hernandez, a longtime resident of the Bronx, says that he can already see the effects of the settlement, as crews work to install new ramps. “Just the other night I went out to a restaurant in my neighborhood, and they were working on two corners at the same intersection. You can see the same thing all over the city.”

With all the construction, the city is putting up temporary ramps at corners that are being worked on. In addition, the whole curb ramp project will be overseen by a court-appointed monitor, tasked with making sure that the city is living up to the settlement’s demands. While there are still many significant barriers to access in America’s biggest city, this is a huge step forward for making New York’s sidewalks more accessible to users of all types.

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

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
Mary Twohey loved helping people as part of her job at an independent living center but says she couldn’t turn down the opportunity to become a partner of the vitamin company, Ubee Nutrition. “I’ve always been concerned about health, especially after SCI,” she says about what drew her to the supplement field. “I’m thrilled to be working with great people who value quality.”

The company uses no additives, fillers or flow agents, which Twohey says can cause gastric upset. “Our approach is fresh, handcrafted. We get an order, and the bottle is often made that day and sent out.”

Twohey, a quad, knows first-hand how important this approach can be for a customer’s health. In 2016, six months after she became a partner, she came down with a terrible UTI. “When I got out of the hospital, the four partners sat down and decided we wanted to do something all natural and proactive, instead of waiting for an infection and getting antibiotics.”

Tasked with doing the research and talking with health professionals, Twohey dug into which natural products could make a good preventative. This process led her to D-mannose, cranberry juice and vitamin C, “and I thought how cool if our product included not only those three but turmeric to help with pain and inflammation,” she says. “So we came up with a blend called ProFlo and started selling it and getting positive feedback. You notice right away your pee looks better. It’s not a cure all, but taking it regularly helps improve the health of your bladder and urinary system.” She takes two in the morning, two at night, “and if I notice something going on, I’ll take two right away and up my water intake.”

ProFlow retails for $24 a bottle and is available on Ubee’s website, ubeenutrition.com.
United Spinal Association knows that disability is a shared experience that affects you, your family, friends and communities. Fortunately, we are stronger together, and United Spinal brings decades of expertise to help: information, peer mentoring, advocacy and much more. Become a member today and Share the Journey.

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United Spinal Association
800.404.2898 • unitedspinal.org
Matt Tilford always thirsted for adventure, and he wasn’t about to let a T12 spinal cord injury quell that need. Twelve years later he is busy travelling the world and testing his limits, while also working as a sales rep for Apple West Home Medical Supply.

As a high school senior in Modesto, California, Tilford was an adaptive equipment installation technician. He never could have guessed he’d find himself on the other side of the relationship one day, but he did learn a lot about the lives of people with disabilities.

“I saw two types of people with disabilities — go-getters who were going to get shit done and people who were just kind of stagnant. That pushed me to succeed in life because I wanted to do something crazy, beautiful and wonderful,” says Tilford, and he has been doing that ever since.

Before his injury, Tilford was an incredibly active person. One of the first things he took to again after his injury was wakeboarding. “I went to the boat dealer that my family purchased a boat from to try to figure out how I can adapt things. One of the sales reps there was like, ‘Hey, I have another customer in a chair who’s a pretty badass wakeboarder, and I’d love to connect you.’ I called that guy, he told me what to get, and as soon as it came, he was like, ‘All right, come over right now. Let’s set you up,'” says Tilford.

In the early years post injury, Tilford passed on that sense of possibility to others — running adaptive sports programs at Society for disABILITIES, the nonprofit that first got him back into sport. “Families got to see me running programs for their kids, and it helped them see that their kids could have a future,” he says.

But while giving other families hope, a divorce tore his own family apart. His wife had two kids from another relationship, and losing his connection with the kids forced him to re-evaluate what he truly wanted in life and how he would define himself going forward.

“It kind of lost it. Not being part of the kids’ lives anymore was really, really tough,” he says. “Strangely, I could go on without her, but I helped raise these kids. Once we divorced, I resigned from the nonprofit and travelled for a bit — just going off the grid for a while,” he says.

For the better part of the year, he communed with nature — just him, his truck and a tent deep in the wilderness, refreshing

**BEST TRAVEL EXPERIENCE:** I went to Puerto Rico for a month last November and that really got my travel bug going. It’s not the most accessible place, but the willingness of people to help was amazing.

**ALL TERRAIN ACCESS:** When hiking in tough terrain, my girlfriend and I hook a rope to my chair, and she wraps it around herself to get me up or down.
The skydiving place I went to has the most deaths, but they also have the most jumps. When I looked at it statistically, I thought, of course there’s going to be more deaths here because they do the most jumps out of anywhere in the world. I had that in my head: I could die.

The place had experience with other people with disabilities who have jumped, but the guy I jumped with didn’t. When he said, ‘All right, we’ll figure this out together,’ I thought, ‘Oh, that’s not scary at all.’

Then we jumped. You’re not supposed to do barrel rolls with new people, but my guy wanted to show me a really great time, so he did, and we did some flips and stuff. Then we kind of just evened out. Being that high and seeing the world was really amazing. The whole time your organs are not understanding where they’re supposed to be. It was a really cool experience.

I’ve been in planes, but to be just free in the sky like that — it was freedom.

When we landed, I told the guy there was a possibility I might shit myself and he said, ‘Oh, I’ve been through worse.’ He was a paratrooper and a badass. Strangely enough, two years after my jump, he found me on Facebook and was like, ‘Hey man, I’m paralyzed. I need some help,’ That’s how I ended up mentoring the guy I did my first jump with.”
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Do you ever find yourself frustrated that you cannot do something someone else around your injury level seems to do with ease? It is a common struggle for many of us. Even if a diagnosis deems two people the same, when you throw in complete or incomplete injuries, body type, height and overall strength, no two spinal cord injuries are entirely alike. To compare is part of being human, though. After injury, we relearn who we are, and judging ourselves based on how we think we compare with others is a big way to evaluate our performance and place in the world.

Given the unique ways our bodies function after injury, it’s simple to match yourself unfairly and feel deficient. There is a fine line between struggling for independence because of what you see others doing and making safe choices that are right for your body and situation. Figuring the best way forward is a constant consideration after paralysis — sometimes we choose the smart path, and other times, we learn the hard way.

A Double-Edged Sword
Comparisons do not have to strictly be a source for feelings of inadequacy — by paying attention to others we can learn a lot about ourselves and find motivation to do more. Jay Davis has always done things at 110%. An aerospace engineer and bike racer before the plane crash 19 months ago that resulted in his C6-7 injury, he actively measures his performance against others to stay ahead of the pack. “I have a lot of the same goals with my career. I’m traveling and trying adaptive sports. I’m still very driven to fly. Seeing others in chairs succeeding at these things motivates me that I’m on track,” Davis shares.

A Colorado resident, Davis had the benefit of doing rehab at Craig Hospital along-
side a handful of guys with lower level cervical injuries. “A couple of them are incomplete and walking now, while others had complete injuries, like me,” he says. “Through rehab, we all functioned pretty similarly. We were the Quad Squad, working out together and learning from each other. It was good camaraderie, but it also pushed me to pay attention to how they did things and challenged me to keep up.” Having friends who demonstrate their techniques and share their experiences is enormous as long as you recognize that everyone has some functionality mismatches. “It was like our basic training getting us prepared for war, and we have thrived from taking on the challenge together,” says Davis.

Rick Hayden had his T8 incomplete injury in 1976. There were no other people with spinal cord injuries at the stroke center where he rehabbed, but his first few SCI friends out of the hospital were hugely impactful lifelong mentors. “One guy was a T10, so full abdominals, and the other guy was a T9, so more abdominals, and then there was me,” he
says. “I don’t know if it was frustration or if it was just that I wanted to push myself to operate at the same level as them. It wasn’t going to be perfect, but I figured if I was in better shape than they were, I could compensate a level or two. I would notice their deficiencies more and find ways to keep up or do even better.”

Unlike Hayden and Davis, Lindsey Freysinger had no people with comparable injuries to learn from during her initial rehab from an incomplete C5-6 injury six and a half years ago. That further complicated how she understood her already-unclear incomplete diagnosis and left her seeking others to talk with. Finding people who had experienced enough return to take a few steps and use crutches as a tool for some walking, while still having substantial upper limb paralysis and limitations, was hard.

“My mom got in touch with an incomplete quad who had a full recovery,” says Freysinger. “When I spoke with him, he was able to explain things to me about his experience and inspire new hope to work hard to maintain things.” Still, she wasn’t entirely confident that she would make a full recovery. “I knew I would walk some, but it felt unrealistic to think I was going to get everything back,” she says.

Comparing herself to people with extremely incomplete injuries made it difficult to set standards and end goals for her rehabilitation. Even now, having regained significant function and en route to her doctorate in nursing, Freysinger wonders if she maximized her potential. “I second-guess myself and wonder if with more physical therapy, maybe I would be further along. I have the physiological knowledge to know that others have more nerve preservation, but I still find myself wondering if there’s a chance,” she says.

**Harsh Realities**

Dave Pierson’s six weeks of rehab were a bit of a blur given that his third daughter entered the world only 19 days after his C6-7 complete injury. Like Freysinger, Pierson was the only person with a cervical level injury present during his time in the hospital, but he drew strength from meeting a fellow dad who had been living for years with the same diagnosis. “I knew that he was raising four kids of his own, and had found independence and success,” says Pierson. “I’m an easy sell, so...
meeting him planted the seed that getting back into the role of breadwinner and super dad was going to be no sweat.”

Feeling pressure to pick up where he left off, Pierson went back to work full-time as a supervisor at IBM only months after his injury despite having little time to work on his independent living skills. “I relied on a lot of help those first few years. I did little else than work and attend my outpatient therapies. A year and a half in, my marriage was suffering, and I was feeling overwhelmed. As I started to meet others in the community, I realized that almost no one was working as much as I did who hadn’t been injured for at least a decade,” says Pierson. “Three years later, when given a choice to transition onto long-term disability or be downsized, it was beneficial to know that what I was doing was a little bit crazy for any of the quads I knew. That helped with the blow to my former identity.”

Pierson has since committed to conquering his daily goals for independence. “It has taken me seven years,” he says, “but I can get into bed and get myself up most days on my own when I’m not doing a bowel program. It takes a long time, and I’ve had to forgo non-sweats fashion to be able to access the loop system I attach to my pants to get dressed, but I can do it independently now. I didn’t like needing more care assistance than some of my peers with higher injuries. I know some who do it all, so I’m willing to sacrifice ease overall to see if that is possible for me too.”

For Davis, a complicated secondary condition and surgical setbacks have left him frustrated that he hasn’t been able to get back to things as quickly as others he knows. Instead, Davis lost his hard-won gains in hand function and had to recover from two subsequent neurosurgeries to drain and re-drain a syrinx in his spinal cord. “I’m human, and there have been times I can be happy for my friends and temporarily jealous of their recovery,” he says. “It’s definitely possible to feel both emotions when comparing injuries without feeling resentment towards anyone personally. I can get para-envy too, when I see someone using their fingers and hands or being able to lean and reach using their abs. The differences just feel bigger and heavier when you are facing a setback.”

Having a realistic mindset is essential. For Hayden, after years of working in the wheelchair sales business, it became clear that your injury level isn’t always the best point of comparison. “You can line up 10 people right now who have a T8 injury, and you would have 10 distinct situations, life scenarios, abilities and attitudes. So, a long time ago, I just stopped worrying about that, but I compare my body how it is now to the body I had in the past,” reflects Hayden.

Against Better Judgment
Knowing who you are comparing yourself to and your motivation for the comparison is an important consideration and a smart thing to periodically evaluate to keep your goals realistic. Pierson has fallen a number of times in his quest to do it himself. “I have gone headfirst into the fridge reaching for an item and tumbled onto the floor reaching for things I’ve dropped from my power chair,” he admits. In opposition to his indoor risk-taking, Pierson has started limiting his away-from-home activities to things he can do strictly on his own. “I’m at the point I avoid anything where I’m going to need assistance. There are a few things I’d like to try theoretically, but I’d rather do less than get help,” Pierson says staunchly.

In 1977, a year after Hayden’s accident, he and his friend and T10 mentor, Larry, met an inventor who crafted hand-powered trikes. The two friends had talked about biking the 75 miles across Cape Cod and decided to test the trikes there. Despite struggling to keep up initially, Hayden was feeling surly. “There was a news van and camera crews initially in front of us, and I knew if that made me need to slow down, I was going to struggle because I couldn’t lose momentum. Luckily though, it evened out, and it was a pretty amazing trip,” Hayden admits. “The beginning was hard, and I so wanted that bike to break, but I couldn’t quit. I did it to keep up with Larry. He was a big strapping guy, and he was always saying, ‘Oh, you skinny guys have it easy!’”

As years pass, people with spinal cord injuries often find their own level of what they are willing to struggle with and what is genuinely worth their time and energy. Our diagnoses become something we talk more about with clinicians, than with those in our lives. We become acutely aware of what works for us. We then can appreciate the accomplishments of others as ideas or motivation for expanding our own independence, while also recognizing that some things are just not in the cards. It is our responsibility to determine our metrics for personal fulfillment and to determine the level of sacrifice we are willing to make to reach goals on our terms.
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Jill Pantozzi is a rare bird.

That’s not because her social media handle is The Nerdy Bird, but because in a world where geek culture — comics, graphic novels, superheroes, science fiction, video games — has merged with pop culture, she analyzes it through the lens of a woman with a disability, but also gets to play an integral part in deciding whose voices get heard in that cultural conversation.

At a time when many people with disabilities still struggle to find employment, this 37-year-old mobility scooter user with spinal muscular atrophy has built a lengthy career as a reporter covering geek media and now serves as deputy editor of io9, one of the web’s pre-eminent geek media sites with over 44 million site visits per month.

A common refrain from the disability community is that we won’t see ourselves represented until more of us are working behind the scenes. Well, Pantozzi does work behind the scenes, and in addition to articulately dissecting key issues and themes affecting our community, she makes sure that more women, people of color and people with disabilities have their voices and perspectives included in the discourse.

This is important because as geek culture becomes more mainstream, with brands like Marvel, DC, Star Wars and Star Trek dominating on movie and TV screens, it is also becoming more diverse and more inclusive — think Black Panther, Star Wars and Star Trek: Discovery. These changes have inspired a backlash. A vocal minority fights vigorously behind their monitors to keep geek culture the way they remember it: white, male, sexist and insular.

From 2013 to 2016, a right-wing, anti-diversity voting bloc called Sad Puppies operated a failed attempt to suppress critically-acclaimed work by progressive or politically-leftist female or minority authors being nominated for The Hugo Awards — the most prestigious awards for excellence in science fiction and fantasy — in favor of less literary but more popular works by predominately white men, including the authors behind the campaign itself.

In 2014, Gamergate, a coordinated harassment campaign targeting progressive women in the video game industry, made national headlines for the extreme actions
“I didn’t think about seeing myself represented as a person with a disability for a long time because I guess I never thought it would happen.”
— death and rape threats, hacking, doxing (making target’s personal info available online) — taken by many of its anonymous antagonists.

Spinning out of Gamergate came Comicsgate, a smaller but just as harmful alt-right harassment campaign targeting female and minority creators in the comic industry who campaign proponents said were responsible for what they perceived as forced diversity in superhero comics. Campaign advocates argued that this alienated “traditional” readers and led to flagging sales across the board.

“The conversation in fandom has shifted from having to say, ‘Women play video games, women read comic books and you really need to start paying attention to this audience,’ to conversations about small but highly vocal groups who want to stop women from playing games, stop women from reading comic books and stop video game companies and comic book companies from making decisions based on the existence of those audiences, which necessarily acknowledges that those audiences exist,” says Susana Polo, co-founder of The Mary Sue, a geek entertainment news site focused on female fans.

As a fan and geek entertainment journalist, Pantozzi has both shaped and been shaped by the evolution of this conversation. As a bisexual woman with a disability who herself has caught shrapnel from these alt-right campaigns, she continues to fight on the progressive side of fandom’s culture war.

HAS BOOBS, READS COMICS

Pantozzi’s first forays into fandom began in childhood. She grew up in Jersey City, New Jersey, with three older brothers playing Nintendo and watching Star Trek. She always gravitated toward science fiction and fantasy, even if she didn’t make a big deal of it.

“I didn’t really share those things with my friends growing up because no one else talked about them,” she says. “I guess I thought it was weird for a while and it wasn’t until about the sixth grade when a friend said something about Star Trek and I was like, ‘Oh my gosh, you like Star Trek too?’”

In high school she branched out to superhero cartoons, but it wasn’t until her 20s that she picked up a comic book. She’d feared crossing the line into a whole other level of geek, but when a boyfriend introduced her to three years of DC Comics continuity, she was hooked.

“I think it was the escapism,” she says. “Always wishing for superpowers of some sort. I guess that was part of my diagnosis and just wishing that something magical would come along … and maybe one day I would wake up and I could fly.”

Strong female characters were also harder to find, which is why she gravitated so strongly toward Buffy the Vampire Slayer and the original Supergirl, Helen Slater. As much as she loved superhero comics, every once in a while she noticed things that left a bad taste in her mouth, like how female characters were drawn differently than male characters.

“The women are there as sexual fantasies for straight men, and the men are there as power fantasies for straight men and that was something not everybody was critiquing at that point,” says Pantozzi.

Another difficulty Pantozzi had was finding anyone like her who was into geek stuff. “Back then, a lot of people didn’t believe girls liked this sort of thing,” she says. Not only that, but some of the fanboys she encountered online would engage in a practice female fans call “checking geek-cred,” where they would test her credibility as a fan every time she declared her love for superheroes and science fiction.

“When women would show even the vaguest interest in something, they’d want them to prove that they’re already a superfan and know everything about everything,” she says. “I always hated the ‘fake geek girl’ assumption that people threw out there.”

So, in 2008, after a brief stint as a radio DJ and with her journalism degree in hand, Pantozzi registered thenerdybird.com — named after her Twitter handle — and started a blog titled
Has Boobs, Reads Comics as a pithy clapback to those who thought female fans didn’t exist.

The blog quickly gained over 10,000 followers and provided a place where geek girls finally felt safe to talk about their fandom. “The name was probably something that got me more attention because I was so rare at the time,” she says. “It’s not that women didn’t like geek stuff — they have throughout history — but not as many were comfortable talking about it yet. I’ve definitely had women over the years tell me, ‘Thank you for writing the way you did because you also inspired me to write about these sorts of things.’ I’m so glad I did, because I found all these other people just like me.”

Well, not exactly like her — at least, not at first. For as much as female fans began to come out of the closet, disability was still largely ignored in geek culture.

LOOSING ORACLE

It wasn’t long before Pantozzi’s blog got her the attention of the online fan press, and she began freelancing full-time for leading online geek entertainment news outlets like Comic Book Resources, Newsarama and IGN. Just as Twitter had helped build her following, it eventually helped get her a job.

It was through Twitter that she found out about an internship with The Mary Sue. Named for the putdown of female characters thought to be too perfect given their training or experience — think Rey from the last few Star Wars films — The Mary Sue is the premier site for female geekdom. Pantozzi eventually became a staff writer on the site before rising to editor-in-chief.

“Jill really has this very savvy way of being her own self-promoter online, and I mean that in an extremely positive way. She had a following and she had an established voice I really liked,” says co-founder Susana Polo. “Jill and I worked together for years, and for much of that time it was clear to me that she absolutely had the chops to run The Mary Sue. When I was forced to step away from the site, Jill was my clear successor — and I knew it was in good hands.”

“It was the perfect storm for me because these were people who not only had the same likes as me, they were also looking to talk about these creations that I love so much on a deeper level. Not just X was cast in Y movie, but what that meant for other people, specifically from a feminist lens,” says Pantozzi.

But as much as she got to tackle issues in fandom from a female perspective, her perspective as a person with a disability was initially absent. Sure, it would come up at comic conventions from time to time when she had to do a panel and there wasn’t a ramp, or when Comic Book Resources wanted to do interviews on a yacht but hadn’t given any thought to how she would get on the boat — but for the most part, her readers didn’t know she had a disability unless they noticed her occasional appeals for donations to The Muscular Dystrophy Association.

So why did DC decide to reboot Barbara Gordon as Batgirl without a disability after 22 years of kicking ass as Oracle, a paraplegic hacker/genius extraordinaire?

The change was part of 2011’s “New 52 initiative,” where DC planned 52 number one issues rebooting every classic DC character — Batman, Superman, Wonder Woman, etc. — to an earlier stage in their careers. DC tasked Gail Simone, who had written many issues of Birds of Prey from 2003-2011 and was known for flagging issues of inequality and representation in comics, with the makeover. Here’s what happened in her words.

“[DC] had asked me several times if I would put Barbara back in the batsuit, essentially ‘curing’ her paralysis. I always said no, it was a terrible idea, for the very reasons you’d expect ... I reluctantly agreed to write it, under the caveat that she would continue to be an inspirational character, in this case, a trauma survivor. Unfortunately, after the issues were turned in, they pulled back on the whole ‘reboot’ idea for half the characters. This made it look like Barbara was targeted specifically (among others) to be restarted from the beginning, rather than part of a line-wide plan to start the entire DC story over, and this gets repeated a lot, particularly by non-readers. Dozens of characters got started over, including Barbara.

“It was always my thinking that Barbara would retrace her story, starting as Batgirl, to become Oracle. It still stings. I doubt it was planned — I think it was sort of made up as they went along.”

Simone never got to complete her plan to take Batgirl back to Oracle — she was famously fired from the book and then rehired two days later, before quitting in frustration — and she’s not sure we’ll ever see Barbara as Oracle again all these years later, which she knows is hard for everyone.

“I felt I could at least try to present the story in a way that wasn’t simple erasure,” she says. “I don’t think I succeeded, and those editors are thankfully long gone from the company. I think they would have a more thoughtful approach now; I think everyone gets it a little better. I certainly hope I do, anyway,” she says.

“I miss Oracle tremendously and there’s a gap both in character and representation because of it. I’ve created a lot of other characters with disabilities, but they’re not Oracle, who was always something special.”
“I think my disability is so much a part of me that I almost forget about it sometimes because it affects every moment of my life. I forget, too, about the disability lens, which is terrible. It’s something each of us needs to keep in mind every day, because if we don’t, who else is going to?”

“It’s interesting because I didn’t think about seeing myself represented as a person with a disability for a long time because I guess I never thought it would happen,” says Pantozzi.

The first time she actually did see a wheelchair-using superhero was Barbara Gordon, aka Batgirl, in her Oracle persona on the 2002 live-action TV series The Birds of Prey. On the show, Gordon — a paraplegic after being shot by the Joker — teamed up with other female crimefighters to use her skills as an expert hacker and technology wizard with a photographic memory. Plus, she was a redhead, just like Pantozzi.

“Her skills weren’t a superpower; they were just who she was. There were a lot of things I saw later in the comics showing her everyday life, like using a shower chair, and not treating it like some bizarre thing, just part of life,” she says.

In 2011, DC decided to revert the character back to her nondisabled Batgirl persona. [See sidebar, “What happened to Batgirl?]” Pantozzi was devastated. “I remember being at a convention just a year before when someone asked DC Publisher Dan Didio whether Barbara Gordon would ever be Batgirl again and he gave a quick answer, ‘No,’ and moved on to the next thing. It was like, ‘Oh OK, he understands that Oracle is an important character for comics as a whole.’ Then, someone at DC actually called me to give me the heads-up that the change was going to happen because they knew I’d have a strong reaction to it.”

Did she ever.

In a subsequent op-ed for Newsarama she wrote: “People being disabled is part of the real world, [so] it is essential it be part of the fictional world as well. Especially if DC is dedicated to a diverse universe. And I don’t mean, ‘You have to keep Oracle around because I’M in a wheelchair,’ I mean for everyone. Are there people of every race, religion and sex in the world? Yes, so let your comics reflect that, as well as many other diverse subsets there are out there.”

A RISING TIDE AND ALL THAT

If Pantozzi’s readers didn’t know she was a person with a disability before, they certainly did after the Oracle fallout. But her coming out of the closet as a disabled person didn’t exactly see her write more about disability. Instead, she uses her editorial power to raise the voices of other fans with disabilities, even as that same vocal minority tries to silence them.

For example, when Pantozzi hired Ace Ratcliff, a geek culture journalist and wheelchair user with Ehlers-Danlos syndrome, to write an article about inaccessibility in science fiction, a segment of commenters loudly objected:

“Disability is a problem that should be solved. ... It’s not ‘ableist opinion’ to prefer having body parts that function and to cure those that don’t,” read one comment.

“Seriously, what a dumb article. They have conquered gravity and space time but you think there would still be wheelchairs? Also, if you would for some reason not want robo-legs or have them regrown in a protein bath, YOU WOULD HAVE A HOVER CHAIR! io9 sucks now,” wrote someone calling themselves Cybertrump.

Pantozzi wasn’t afraid to put herself in the line of fire by jumping into the fray. When someone insisted that the Millennium Falcon is ADA compliant by posting a photo of its loading ramp, she calmly retorted, “There’s actually a specific slope and rise for ramps in order to be ADA compliant. The Falcon’s is way too steep/short.”

“That’s why I said Star Wars ADA. It’s a different set of regulations!” was the reply.

Pantozzi says others with disabilities within geekdom continually reach out to thank her for being so outspoken and letting these issues be heard in a more visible forum than they would have otherwise. One of these is Jay Justice, a mobility scooter-using cosplayer and queer woman of color hired by comic publishers to edit for minority experience authenticity.

“I really feel you cannot truly witness inequalities unless you are inside the sphere of influence, unless you’ve really seen from the perspective of someone who has dealt with being disregarded because of a disability, and because Jill’s seen that and experienced it, she knows how important and how vital it is to lift people up who have never gotten a chance to be heard before. She makes a huge effort to do so, and we all really, really appreciate it,” says Justice, who values the light Pantozzi shines on her own projects and point of view. “We know how many eyes are on her Twitter [almost 33,000 followers as of this article], so when she retweets something, you can absolutely see the metrics go up. It’s amazing!”

If Pantozzi needs more evidence that her work spurs change, she need look no further than The Sony Pictures hack of 2014, where private e-mails between Sony Executives were made public. The emails revealed how an article by Pantozzi pushed Sony to expedite plans for a potential Spider Woman movie.
Former Sony Pictures Senior Vice President Rachel O’Connor sent former Sony Pictures head Amy Pascal a link to Pantozzi’s *The Mary Sue* article detailing the 2014 announcement of the female Thor. In response, Pascal instructs O’Connor to tell Lisa Joy Nolan, a prominent show creator best known for *Westworld*, “to hurry.” A month later it would be leaked to the trades that Nolan was scripting a female-centric superhero movie featuring Spider Woman and others.

For her part, Polo doesn’t want to overstate *The Mary Sue*’s effect on general discourse and the increased diversity we are now seeing in geek media. But to whatever degree the site made diversity more of a requirement for fans of geek culture to buy in, she agrees Pantozzi certainly helped.

“I think we were definitely a part of it, but I also think the culture was ripe for change to start occurring, for female fans to become more visible at conventions and for minorities to have more of a voice. This is what the internet does, it unites what may have been previously isolated pockets of people so they can connect to each other, realize they’re not alone and realize they have a larger voice and something to speak to,” says Polo.

Pantozzi doesn’t get to write articles where fandom and disability intersect all that often. Fans with disabilities still see her as a role model just for being so outspoken on Twitter or participating on panels at comic conventions, but she acknowledges that sometimes her identity as a person with a disability takes a backseat to her identity as a bisexual woman in her writing.

“I think my disability is so much a part of me that I almost forget about it sometimes because it affects every moment of my life. It’s one of those things that’s in the back of my mind. I forget, too, about the disability lens, which is terrible and it’s something each of us needs to work on every day to keep those things in mind, because if we don’t, who else is going to?” she says.

But other fans with disabilities say she shouldn’t be so hard on herself. Ratcliff is one of them.

“Everybody has a right to not necessarily be out about their disability, especially because there’s so much discrimination and ableism in society,” says Ratcliff. “For Jill to have a public persona that wasn’t necessarily all about her disability made her easier to connect to, and then for her to come out and say, ‘Disability is part of my existence,’ it really allows nondisabled people to challenge some of their preconceived notions around disability and how they feel about it.”

For Pantozzi, being able to give others a platform to talk about disability issues in her capacity as an editor is so much more important than taking it on herself because she knows there are lived experiences she couldn’t begin to cover herself and that much more lasting progress can be made from her fortunate position.

Kristen Lopez, who has osteogenesis imperfecta, agrees. When Pantozzi hired the wheelchair-using Rotten Tomatoes-approved film critic to review the live-action *Lion King* for io9, Lopez says she got paid more and was taken more seriously than in any other job she’s had. “Seeing Jill on the frontlines and being backed by her belief that disabled voices are important just furthers the conversation that will hopefully give us more room at the table,” says Lopez.

Ratcliff says she feels more secure writing for io9 than she does writing for any other site, knowing Pantozzi is at the helm. “Even though my direct editors are not disabled, they still approach the work in a way that is very clearly informed by a higher level that does have that knowledge, that does have that support and is looking to try and uplift disabled voices. Even though we’re one step removed from each other, I still feel Jill’s presence,” says Ratcliff.

**BACKLASH COMES AS HOPE REIGNS**

Positive change has come to geek culture. Women lead top science fiction and superhero franchises, movies centered on...
black superheroes break box office records and receive critical acclaim, and even new characters with disabilities have come to the forefront following the loss of Oracle. Not only did the popularity of Netflix’s Daredevil, which follows a blind superhero, pressure the streaming service into including audio description on all its content, but one of its animated shows, The Dragon Prince, features a deaf woman of color using accurate American Sign Language.

For every step forward, the backlash is swift. As much as the internet can bring people together, it can also tear them apart. Ruby Rose left Twitter in 2018 amid accusations that the lesbian actress wasn’t gay enough to play Batwoman, a gay character, and Kelly Marie Tran, the actress who plays Rose Tico in Star Wars, left Instagram because of racist harassment and threats from alt-right fans of the franchise.

But for every argument toward advancing diversity and inclusion in fandom, there’s someone there to tamp you down, check your knowledge or tell you why you’re being unreasonable. No one knows that better than Pantozzi herself. When Gamergate was at its height, she was a target simply because she ran editorial at a feminist website.

“After Gamergate, there’s nothing that can be thrown at me that I won’t roll with because I’ve seen the depths of internet hell. It was something that, looking back, I almost can’t believe was real. It started from a place that was very disingenuous in that people used it to claim they were working for some injustice or ethics in journalism. But when you saw the comments and tweets day-to-day, it was very clear that Gamergate was a campaign to silence women who were vocal,” she says.

Though her personal details were never exposed online and she didn’t have to rearrange her entire life just to get away from the harassment like other targets, Pantozzi still deeply felt the effects of Gamergate.

“It takes a mental toll seeing such negativity day in and day out. I remember one day taking an hour just to block people on our Twitter account and not believing that others would pop up left and right, how organized it was and how methodical it was,” she says. “It was extremely tough, and I’ve probably blocked out just how bad it was simply so I could move on with my life. I’m lucky I got out of it as unscathed as I did.”

Though Gamergate itself has died down, the vitriolic assault on progressive change in geek culture remains. “This sentiment has only rooted deeper in broader culture since the end of 2016,” says Polo. “A lot of the playbooks that were written during Gamergate are now being used on a much, much broader scale. We’re in a very interesting place now that we realize Gamergate was a prelude to something that was happening in the general political discourse and now, three years later, we’re still wrestling with a lot of it.”

So, what do we do now? If you are Jill Pantozzi, you keep being vocal, you keep doing the work, you keep raising awareness, you keep fighting for change and you don’t stop until you see yourself represented in all media as a matter of course, while having the same confidence and privileges that a cisgender, nondisabled and straight white man enjoys.

“There’s a lot more work to be done, and that’s why I will not stop vocalizing where I can,” she says. “I now run io9 and have a platform with a bunch of writers that are really great at expressing these issues well. I will continue to give them a platform and make sure the vocal minority doesn’t take over the conversation to try and say that things are equal when they clearly are not. At the end of the day, we just need to keep going.”
Our Mission
VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

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

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

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

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

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

Our Core Beliefs
VetsFirst’s priorities are based on three core principles that will improve the lives of veterans with disabilities.

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

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

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

www.vetsfirst.org
Dreaming of a Good Night’s Sleep

BY ALEX GHENIS

Throughout his early teenage years, Ben Perez had insomnia that was hard to manage, allowing him only four or five hours of sleep each night. Every night he’d walk around his home until his energy ran out. He wished that he could regularly sleep through the night for all the benefits he knew it would bring: improved focus for school, enhanced energy for socializing and much more. The universe works in mysterious ways, as it took a C5-6 spinal cord injury at age 16 to fulfill that wish.

Post-injury, exhaustion triggered the sleep he had long dreamed of. Combined with the side effects of anti-spasm medication, Perez was able to simply close his eyes and let the drowsiness come to him. “For a period of time after my injury, I actually slept better,” says Perez. “At some point right after becoming a paralyzed person, I thought, ‘Well, I guess you aren’t going to deal with this [lying awake in bed or wandering around], so you don’t have a choice.’ And that led me to fall back asleep very quickly because it was a strangely freeing thing.” His newfound regular sleep was a welcome respite from restless nights, especially right after his injury when energy was so crucial.

Unfortunately, the improved sleep only lasted so long. “As the spinal cord injury became a part of my regular life, the sleep issues crept back into my routines,” says Perez. “They were more in line with what I had before, and they were compounded by my injury.” New issues included discomfort if the room was the wrong temperature, muscle spasms and simply re-discovering his body. Perez found his mind was “no longer distracted” by the need to go to sleep. “I’m suddenly aware of my own mental map and that can trigger a lot of nerve pain.” That pain was enough to knock hours off his sleep. Things became just like they were pre-injury, but without the ability to move around the house and manage insomnia the way he used to — so really, they were worse, with no solutions in sight.

Like Perez, a couple years ago, I found myself struggling to get a good night’s sleep. For the 15 years since I sustained a C5-6 injury, resting on my back on a memory foam mattress protected my skin and helped me sleep. However, in 2016 I removed the baclofen pump that mellowed my body through the night. After that, my lower back began tweaking out once I lay flat, causing major pain and violent spasms that re-positioned me in unwanted ways. Sometimes, I’d be unable to stay asleep and even when I did sleep, I’d often awaken to the heavy sweat that comes with dysreflexia. The discomfort was frustrating enough, but I also knew it was hurting my body and had to be fixed.

Sleep problems like Perez’s nerve pain and my spasticity are widespread for people with paralysis. Although there isn’t much research on the subject, professional studies show that many factors impact our community’s sleep, while restlessness can affect our lives in a multitude of ways.

Dr. M. Safwan Badr, a past president of the American Academy of Sleep Medicine and chair of the Wayne State University School of Medicine Department of Internal Medicine, says there is hope. Badr’s advice to people with paralysis is straightforward: “Do not accept poor sleep as ‘just the way it is.’ If you can improve your sleep, many aspects of your life will improve,” he says. “Prioritize sleep.”

Getting a good night’s sleep often eludes Ben Perez.
Complex Issues, Complex Consequences

Because muscles for breathing include both the diaphragm and the intercostal muscles, injuries ranging from C2, which first connects to the diaphragm, through T11, which controls the lowest intercostal muscle, can affect breathing patterns and sleep through the night. Additionally, nerve pain and muscle spasms — which occur at all levels of SCI — can keep people awake for long periods of time, and just waking up briefly can interrupt important sleep cycles. When you add in SCI-related body temperature regulation issues, you’ve got a multi-headed beast that can make good sleep seem unattainable.

Donald Fogelberg, a professor at the University of Washington, has researched the relationship between sleep and spinal cord injury for more than a decade. His sleep research began in the mid-2000s, when he was looking at pressure sores and realized that the ways people rest affect how ulcers might develop. “Sleep is multidimensional,” he says, citing factors ranging from the amount of sleep, to the timing of naps, to changes in mid-rest breathing and movement. In fact, there are over 90 sleep-related disorders one could be diagnosed with.

“Sleep problems after an SCI tend to be complex,” Fogelberg says, with the actual problems varying from person to person and by type of injury. For example, injuries at C3 or higher reduce the amount of melatonin the body produces, which makes it harder to rest at all. Unique sleeping positions and limited control of breathing muscles increase rates of sleep apnea, which can reduce oxygen flow to the brain.

Restlessness impacts lives in a range of ways. Multiple studies show that sleep can influence chronic pain, with less sleep leading to more pain the following day and night, building a vicious cycle that can last for days or more. Losing sleep affects energy, mood and one’s ability to focus in general. Fogelberg says this creates “functional consequences,” such as difficulty making it to appointments, holding jobs or being effective at work or school.

Beyond the obvious, there are theoretical impacts. For example, human growth hormone is produced as we rest, and HGH helps with repairing broken tissue — so losing sleep might affect the ability to heal pressure ulcers and other injuries, whether related to SCI or not. Fogelberg and Badr agree that there needs to be more research on the connection between sleep and SCI, and they also agree there is no reason to wait around: The time to take action is now.

Different People, Different Problems

As they do with many other obstacles presented by paralysis, quads and paras who don’t sleep well come up with creative solutions to rest through the night. Brian Swift has been a C5-6 quad since 1979, when he joined the SCI crew from a football accident at age 17. The first 30-plus years featured quality sleep, but Swift ran into a difficult spell of poor sleep starting eight years ago. He endured a one and a half year stretch where he only got around three hours of sleep per night, usually between 2 and 6 a.m.

His first round of attempted solutions took the form of medication: “I tried all the things my doctor recommended, like melatonin and a couple sleeping pills, but it had no effect,” he says. It wasn’t until he started to change the way he lived that Swift began to see results. His doctor suggested avoiding midday naps, keeping off his phone and computer starting a half-hour before bedtime, and tiring out his mind and body so he was exhausted by bedtime.

“I did a lot to try to stay more active during the day,” he says. Additionally, Swift tried to concentrate his work that required mental acuity earlier in the day, discovering that being engaged midday would help him sleep better at night. He found that reading a book in bed helped transition his mind to sleep and he made a habit out of it. The rewards for the lifestyle change were plentiful — not just improved sleep, but faster bowel programs and less spasticity.

Autumn Desmarias is just over one year out from a T5-9 incomplete injury. “It’s been kind of a roller coaster,” says the Michigan resident. “I was doing really well at first, then went kind of downhill, but things have evened out.” One thing that’s yet to even out, though, is sleep. “The main thing for me are the spasms,” she says, adding that body temperature swings and difficulty positioning had all combined to limit her to four straight days of fewer than three hours sleep.

On good nights, Desmarias only gets around five hours of sleep in total. “Even then I’m waking up in the middle of the night,” she says, “and the longest I’ll stay asleep at a time is two or maybe three hours tops.” Her lack of sleep affects her
energy level, her ability to focus and more.

Medications haven’t done the trick for more than a couple of days, as both natural sleep remedies and prescription meds would work for one or two nights then stop being effective. She tries to do relaxing things when she wakes up, whether it’s staying in bed and drawing or getting into her chair and writing short stories. “Sometimes I just try to close my eyes and relax,” she says, “even though it doesn’t work to fall asleep.”

Desmarias is looking into solutions to the sleep-interrupting spasms and might get a baclofen pump to mellow things out. The past year has been frustrating, but she is confident that she’ll come up with a better sleep strategy soon.

Rachel Wilson has been a C4-5 quad since she dove into a pool at the wrong angle in 2000. If the temperature isn’t just right, she is prone to sleeping problems — either spasticity when things are too cold, or dysreflexia when things are too hot. Staying warm on cold nights can be a battle. “If I sleep with a blanket on me, the blanket and I are eventually going to go to war,” she says.

The combination of temperature issues and Wilson’s sensitivity to light has led to another cover: her pillow. “I’m a weirdo, I sleep with the pillow over my face. . . . The biggest problem I worry about is breathing in too much carbon dioxide because I’m inhaling my own breath.” As a fix, Wilson positions the pillow so there is room for air to flow out the side.

Wilson originally had an alternating-pressure air mattress, but its loud pumping only complicated her sleeping. She eventually found another easy-to-buy system that still protects her skin. “I do have a memory foam mattress I use, and it’s amazing,” she says.

She was also taking over 120 mg of baclofen per day to reduce the spasms that interrupted sleep, but recent changes in California law have allowed her to use some CBD-based substances instead. A combination of tinctures, gummies, and smoking before going to bed has helped with spasms and sleeplessness.

It’s a constant learning process, but it seems that she has finally devised a combination of mattresses, temperatures, covers and medications that works for her. Now her biggest problems are temperature regulation and waking on account of personal attendants coming to turn her.

Finding Solutions That Work For You

So how exactly can somebody with SCI improve their sleep? There’s no easy answer, but there are steps that can help.

Badr notes that there are physicians who specialize in sleep and can give simple advice, prescribe medications or provide the right kind of medical devices. If somebody has sleep apnea, for example, they may need a CPAP machine, while the right kind of sleeping med can help with going to sleep and staying there. Fogelberg and Badr both recommend developing a sleep schedule. Although midday naps might feel good, developing a regular pattern that provides eight hours nighttime rest is usually the best way to go.

Because other health conditions impact sleep, addressing those issues — whether by consulting one’s doctor, exploring support groups or chatting with friends with paralysis — can improve the amount and quality of rest. “Solutions should be multi-component,” Fogelberg notes. “If you fix the other problems, like nerve pain and sleep apnea, then sleep will fix itself.” Folks might not sleep perfectly through the entire night if they address related health issues, but every bit of rest improves other parts of life along with it.

Thinking creatively can also be helpful. The solution to my sleep problems included a new bed set up, a new medication regimen and, unexpectedly, a tool used by snowboarders. I switched out my flat bed frame for a queen-sized frame that sits up. I now sleep with the remote nearby so I can adjust the bed to alleviate spasms and rest. Boosting my baclofen and adding edible CBD calms down spasms and mellow out my mind for deeper sleep.

Still, all that wouldn’t stop my right leg from spasming, so I kept waking up with twisted hips and sweaty dysreflexia. After some brainstorming and online shopping, I purchased a 20-foot strap meant for securing snowboards to SUVs, wrapped it around my bed, and put a folded towel between the strap and my thighs. Once I identified the proper strap tightness to keep things secure without hurting my thighs, it has held my legs straight and I haven’t woken up with twisted hips or dysreflexia.

Given the many barriers that get in the way of sleep, quads and paras sometimes need to be creative when finding solutions to improve their rest. Brainstorming and experiments range from positioning to managing temperatures, while changing medication regimes can be a worthwhile investment.

Fixing all of your sleeping problems post-SCI may be too much to dream for, but seeking solutions for a better sleep is definitely worth the time and energy. For me, it took a whole new bed frame, changing medications, and securing my legs. Rachel Wilson now uses a face-covering pillow and new medications. Brian Swift discovered exercise and good books as natural sleep supports. Ben Perez stays away from his phone and works with his partner to keep things the right temperature. He still says his sleep is interrupted “around once a month” but that’s way better than the several hours every night he dealt with before. All it took was some creativity, some effort and a little bit of time.
We all have certain triggers that bring back unpleasant memories. I grew up in the late 1970s and early ‘80s when Richard Simmons, Jane Fonda and aerobic exercise were all the rage. Whether it be sweatpants and a T-shirt, or a matching set with a jacket, the sweat suit design was intended to be comfortable and promote exercise and relaxation. For me it was just the opposite.

I became a C4 quadriplegic in 1983 when I was 16, and although very athletic, I did not willingly wear sweat suits before my injury. Like my friends, I’d wear a T-shirt with sweatpants. Suddenly, I was hospitalized and spending my days and nights in bed and for a long time was unaware of, or not focused on, my clothing. After a month-long initial hospitalization, I spent eight more months at a rehabilitation facility.

As usual for a 16-year-old girl, body image was quite important to me. However my daily “uniform” at rehab consisted of various multicolored velour sweat suits that my parents brought in. Regardless of the weather, I wore high-top sneakers, compression stockings and a sweat suit complete with long-sleeve jacket and pants. I hated how I looked.

Thirty-four years later, memories of my body-conscious days in rehab came flooding back to me when I saw the 2018 movie *Wonder*. The main character, Auggie, has a rare cranio-facial deformity, called mandibulofacial dysostosis. After being homeschooled, Auggie’s parents send him to a private school when he enters fifth grade. The process is excruciating for him. He wants to be completely covered, including wearing a space helmet, so his facial deformities will be hidden. He is consumed by worry that he will be mocked, ostracized and misunderstood by other students.

I identified strongly with his situation. Returning to high school after rehab, I did not want to keep wearing those velour sweat suits but had no interest in purchasing new clothing. Everything that I had in my closet from before my injury did not fit or look right because I was sitting in a wheelchair.

My clothing requirements seemed endless. I needed larger sizes for easier movement and pants without back pockets that wouldn’t cause a pressure sore. I refused to

BY SHERI DENKENSOHN-TROTT

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wear anything with short sleeves because my arms had atrophied and I didn’t want anyone to see my lack of musculature. I viewed my arms as “chicken wings.” I was at the mercy of others to style my hair and put on my makeup. I stuck with my high top sneakers because they accommodated the swelling in my feet that occurred during the day. I resorted to a few pairs of baggy pants and a limited selection of long sleeve oversize shirts — preferably men’s because they were usually roomier.

Going off to college amplified my intense discomfort with my appearance. I was about to meet many new people. What would they think of me? I viewed myself as ugly and out of style. I had moved on to a series of longer sleeve shirts and matching cloth pants with elastic on the waist. My outfits reminded me of Garanimals — the children’s clothes that used mix-and-match separates — for adults. I still wore the high top sneakers. And there was still no showing of skin.

My roommates were kind and often offered to style my hair and put on my makeup. On those occasions, I was able to glimpse beauty. But I still had a negative body image and continued to be self-conscious about the changes that had taken place as a result of my injury. I was not made fun of, and had many friends, but I longed to feel stylish. Observing other students, I was keenly aware of how I wanted to dress, but I didn’t have the courage to do so.

**BACK TO THE MALL**

A turning point came in 1990, when I was attending law school. My nurse badgered me — and trust me, it took a lot of badgering on her part — to at least try shopping at a local mall for new clothes and shoes. She was keenly aware of my body image issues and was able to slowly convince me that there were options: shoes that were more stylish and could accommodate my swollen feet, blue jeans that I could wear and shirt styles to try.

Without her nudging and taking me shopping (like Auggie’s father hiding his mask so he was forced to show his face), I would not have made any changes in my wardrobe. Not only was it mentally difficult, but it was impossible to navigate in the clothing store without catching my wheelchair on a rack and risk having everything fall on the floor — although that did happen a couple of times.

The new shoes were not ideal, and certainly not the latest style, but they looked worlds better than high tops. I was ecstatic to put on jeans, as I had not worn any since before my accident. And my nurse was willing to go back to multiple stores without me to find additional styles.

On one trip she arrived back with a short-sleeved shirt. It was very hot outside, and she convinced me to put it on. I felt completely naked. I stared at my arms in horror and did not want to go outside. But I had to go to class. So I did, and I survived. It wasn’t comfortable, and I wasn’t happy, but I finally showed some skin in public!

So began an evolution. Getting a legal job required me to wear clothing that I never dreamed I would be willing to wear. I started with very basic, elastic-waist skirts and extra-large jackets. I shopped at one store where I could easily navigate my wheelchair between racks and get assistance (these were the days before the Internet and online ordering). I slowly moved on to more stylish suits and became more adept at identifying the type of clothing that looked good in a wheelchair and accommodated my ostomy bag. I slowly began to like myself and feel that I looked good. I began to feel comfortable in my own skin. Shorts and a tank top took years. And even though over time I became much more comfortable with my body image, I still resisted wearing anything that revealed my chest area and legs.

**MY INNER FASHIONISTA**

I’m now considered a fashionista by family and friends. I enjoy shopping for a bargain and finding exactly what I am looking for. I’m pleased with the progress being made by advocates in the disability community that continue to put pressure on the fashion industry to design clothing for individuals with disabilities and to even consider using models with disabilities. In the meantime, I’ve found my way with conventional clothing and have my favorite stores and styles. And given that I enjoy the sun and the beach, I have finally
become comfortable wearing a tank top and shorts. On occasion, I’m willing to take off my scarf and show my trach.

In *Wonder*, Auggie develops deep friendships and realizes that what matters the most is who he is on the inside and not his appearance. And if people were not comfortable with him or mocked him, he realized that it was their problem and not his. Being kind to everyone regardless of appearance is a mantra that he exudes, and he no longer yearns for his mask.

Like Auggie, it was painful and took a long time for me to realize that my appearance did not define me. There is nothing wrong with wanting to look nice but covering everything up was a symbol of my own discomfort with my body. No more sweat suits for me. *Wonder* made me realize that for me a T-shirt is the simplest and doesn’t cause wrinkles.

**FASHIONISTA TIPS FOR WHEELERS**

Here are some shopping tips for fashionable clothes that I have found to be helpful:

- **Online vs. shopping in person:** I recommend shopping in person so that you can see the size and texture of the clothing. If you find a brand or style that works, you can then order online.

- **Functionality:** I purchase most pants in a size larger than I need so when I sit down the pants do not pinch my skin and are not too short. Because of my colostomy, my pants (or skirt) cannot be tight, but that doesn’t mean I need to buy everything with elastic. I look for blouses and blazers with buttons all the way up toward the neckline so they don’t flop open, and I avoid short shirts because they show my ileostomy bag. I find that longer shirts with slits on the side look the best when I am sitting down.

- **Find a good seamstress or tailor:** Most clothing that I purchase needs to be adapted. I use the same seamstress (and sometimes my mother-in-law) who knows where to put holes in the side of my pants or skirt to accommodate hooking up to a larger bag; where I will need buttons if a blazer or shirt has a V-neck and flops open; and when removal of parts of pockets or belt loops on the back of pants or shorts is necessary to avoid pressure sores.

- **Shoes:** Because my feet swell, I shop at the discount section of local department stores (Macy’s sale racks are my favorite) and find stylish and good quality shoes at a low price in multiple sizes. I do not purchase shoes that are narrow or have buckles that will leave marks. My shoe closet has a range of sizes to accommodate the swelling of my feet. I do stay away from high heels, as they are not conducive to good posture when they are placed on or over my footrests. The maximum heel that I can wear is about 1 inch.

- **Undergarments and socks:** I purchase regular underwear, and I buy specialized bras at Nordstrom’s because I am a breast cancer survivor and require a prosthetic bra. Prior to my mastectomy, I ordered bras online because navigating the lingerie section of a department store is a nightmare. Socks are useful to have in different thicknesses and once I find a type that works best for me I either purchase them in the same store or order online. When it comes to what I wear to bed, I find that for a heavy poncho and a hat.

- **Warm weather clothing:** I apply the same rule for shorts and Capri pants that I do for regular pants as far as size, design and tailoring. I wear tank tops and short sleeves, but sometimes I pin the back because I do not have musculature in my shoulders. I’m not a bathing suit person so that isn’t a problem. But I do like flip-flops and toenail polish!

- **Comfortable clothing:** Yes, I wear sweatpants when I am going to the gym. However, they are no longer the matching velour sweat suits. My preference is to wear sweatpants and a T-shirt.
REHABS

Hospital and Organizational Members

ALASKA
Providence Alaska Medical Center
Anchorage, AK; 907/562-2211

ARIZONA
Barrow Neurological Institute at Saint Joseph’s Hospital and Medical Center
Phoenix, AZ; 602/406-3747
HealthSouth East Valley Rehabilitation Hospital
Mesa, AZ; 480/567-0350
Honor Health Rehabilitation Hospital
Scottsdale, AZ; 480/800-3900

CALIFORNIA
Dignity Health - Northridge Hospital Medical Center, Center for Rehabilitation
Northridge, CA; 818/985-8500
Encompass Health Rehabilitation Hospital of Bakersfield
Bakersfield, CA; 661/323-5500
Providence Holy Cross Medical Center, Center for Rehabilitation
Arlington Heights, CA; 818/885-8500

COLORADO
Colorado Acute Specialty Hospital
Denver, CO; 303/264-6900
Craig Hospital
Englewood, CO; 303/789-8800

CONNECTICUT
Gaylord Specialty Healthcare
Wallingford, CT; 203/284-2800
Hartford Hospital - SCI Program
Hartford, CT; 860/714-3500

DISTRICT OF COLUMBIA
Medstar National Rehabilitation Hospital
Washington, DC; 202/877-1000

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

GEORGIA
Emory University Hospital Center for Rehabilitation Medicine
Atlanta, GA; 404/712-7593
Rehabilitation Hospital of Navicent Health
Macon, GA; 478/201-6500
Shepherd Center - Southeastern Regional SCI Model System
Atlanta, GA; 404/350-7645

ILLINOIS
Shirley Ryan Ability Lab
Chicago, IL; 312/230-1000
The Spinal Cord Injury Program of Marianojoy Rehabilitation Hospital
Springfield, IL; 217/788-3302
Rehabilitation Hospital of Indiana
Indianapolis, IN; 317/229-2000
Childserve
Johnston, IA; 515/727-8750

INDIANA
Marianjoy Rehabilitation Hospital
Auburn, IN; 317/393-6700

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

KENTUCKY
Cardinal Hill Rehabilitation Hospital
Lexington, KY; 859/254-5701
Frazier Rehabilitation Institute
Louisville, KY; 502/582-7490
Gateway Rehabilitation Hospital
Florence, KY; 859/426-2400

LOUISIANA
The Gilda Trautman Newman Rehabilitation Center
New Orleans, LA; 504/899-9511
Touro Rehabilitation Center
New Orleans, LA; 504/897-8560

MASSACHUSETTS
Spaulding New England Regional Spinal Cord Injury Center
Charlestown, MA; 617/573-2770

MARYLAND
Adventist Rehabilitation Hospital of Maryland
Rockville, MD; 240/864-6132
International Center for Spinal Cord Injury at Kennedy Krieger Institute
Baltimore, MD; 888/554-2080
Medstar Good Samaritan Hospital Spinal Cord Rehabilitation Program
Baltimore, MD; 443/444-8000

MICHIGAN
Mary Freebed Rehabilitation Hospital
Grand Rapids, MI; 800/528-8989
DMC Rehabilitation Institute of Michigan
Detroit, MI; 313/745-1055

MINNESOTA
Essentia Health Miller-Dwan Rehabilitation Services
Duluth, MN; 218/277-8762

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

MISSISSIPPI
Methodist Rehabilitation Center
Jackson, MS; 601/981-2611

NORTH CAROLINA
Cone Health Inpatient Rehabilitation Center
Greensboro, NC; 336/832-8153
Wake Forest University Baptist Inpatient Rehabilitation Program
Winston-Salem, NC; 336/716-2011
WakeMed Rehab Hospital
Raleigh, NC; 919/350-8861

NEBRASKA
Madonna Rehabilitation Hospital SCI Rehabilitation Program
Lincoln, NE; 402/489-7102
QLI - Spinal Cord Injury Program
Omaha, NE; 402/573-3700

NEW HAMPSHIRE
Northeast Rehabilitation Hospital

NEW JERSEY
Bacharach Institute for Rehabilitation
Pomona, NJ; 609/748-5480
Kessler Institute for Rehabilitation
West Orange, NJ; 973/252-6367

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

NEW YORK
Helen Hayes Hospital, West Haverstraw, NY; 845/786-4000
Mount Sinai Medical Center
New York, NY; 212/241-6500
Orange Regional Medical Center
Middletown, NY; 845/333-1000
Rusk Rehabilitation at NYU Langone Medical Center
New York, NY; 212/263-6012
St. Charles Hospital Rehabilitation Center
Port Jefferson, NY; 631/474-6011
St. Mary’s Hospital for Children,
Bayside, NY; 718/281-8987
Strong Memorial Hospital of the University of Rochester,
Rochester, NY; 585/275-2100
Sunnyview Rehabilitation Hospital
Schenectady, NY; 518/382-4560
The Burke Rehabilitation Hospital - Spinal Cord Injury Program
White Plains, NY; 914/597-2500

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

OKLAHOMA
Integris Jim Thorpe Rehabilitation Network
Oklahoma City, OK; 405/951-2277
Valir Rehabilitation Hospital
Oklahoma City, OK; 405/609-3600
OREGON
Legacy Rehabilitation Institute of Oregon, Portland, OR; 503/413-7121

PENNSYLVANIA
Allied Services Integrated Health System Spinal Cord Injury Program, Scranton, PA; 570/348-1360
Healthsouth Rehabilitation Hospital of Altoona, Altoona, PA; 814/944-3535
Moss Rehabilitation Hospital, Elkins Park, PA; 215/663-6000
Spinal Cord Program at The Children’s Institute, Pittsburgh, PA; 412/420-2400
UPMC Rehabilitation Institute at Mercy, Pittsburgh, PA; 800/533-8762

SOUTH CAROLINA
Greenville Health System - Roger C. Peace Rehabilitation Center, Greenville, SC; 864/455-3779
Roper Rehabilitation Hospital, Charleston, SC 843/724-2800

TENNESSEE
Patricia Neal Rehabilitation Center, Knoxville, TN; 865/541-3600

TEXAS
Encompass Rehabilitation of San Antonio, San Antonio, TX; 210/691-0737
Houston Methodist Hospital, Houston, TX; 713/394-6000
Texas Rehabilitation Hospital of Fort Worth, Fort Worth, TX; 817/820-3400
TIRR Memorial Hermann Hospital, Houston, TX; 713/799-5000
University of Texas Southwestern Medical Center - Rehabilitation Unit, Dallas, TX; 214/493-0597

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

VIRGINIA
Inova Acute Rehabilitation Center at Inova Mount Vernon Hospital, Alexandria, VA; 703/664-7924
Sentara Norfolk General Hospital, Norfolk, VA; 757/388-3000

Washington
Regional One Health Rehabilitation Hospital, Memphis, TN; 901/545-7100
Vanderbilt Stallworth Rehabilitation Hospital, Nashville, TN; 615/963-4051

WISCONSIN
The Spinal Cord Injury Center at Froedtert and The Medical College of Wisconsin, Milwaukee, WI; 414/805-3000
UW Health Rehabilitation Hospital, Madison, WI; 608/592-8100

Interested in becoming a hospital or organizational member?
Please contact Nick LiBassi at 718/803-3782, ext. 7410 or nlibassi@unitedspinal.org
I am 59 and in my 34th year as a T10 complete para. Over the past year I’ve developed numbness and tingling in my fingers that gets worse after pushing up hills. Tests say it may be cervical spinal stenosis.

What is spinal stenosis and what causes it? Is it a common secondary problem in long-term SCI? How is it diagnosed and what are the options to treat it?

— Dan

My own research and personal experience suggests that the answer to your question is yes, spinal stenosis is fairly common and can cause serious secondary complications in people with long-term SCI. For more on the subject I turned to Dr. Cristina Sadowsky, clinical director of the International Center for Spinal Cord Injury at Kennedy Krieger Institute in Baltimore, Maryland.

“Spinal stenosis is a narrowing of spaces within the spinal column and/or spinal canal and is caused by degenerative changes in discs and cartilage that naturally occur with age as well as use and overuse,” says Sadowsky. “Stenosis can be both a culprit for paralysis onset — acute SCI — and can cause serious secondary complications in people with long-term SCI.” According to Medscape.com about five out of 1,000 people over age 50 in the United States have symptomatic stenosis.

There are two types of stenosis, central and foraminal, says Sadowsky. Central spinal stenosis is a narrowing of the spinal canal — the hollow area that surrounds and protects the spinal cord — and occurs primarily in the cervical (neck) and lumbar (curve of the back) areas. This is because these are the areas of the spine that have the most movement and thus are subject to the most wear and tear. “As we get older the spinal canal suffers changes from use and overuse. There is thickening of ligaments in the spinal canal, along with degradation of the facets (the spinal joints located at the back of the spine) and the discs between vertebrae, which combine to narrow the canal around the spinal cord,” she says.

The second type of stenosis, foraminal stenosis, is the narrowing of the openings through which nerves come out of the spinal cord, resulting in “pinched nerves.” When this happens in the cervical area, it can cause tingling, loss of sensation and muscle weakness in the arms and hands. If it occurs in the lumbar area of nonparalyzed people, it can cause back and leg pain, numbness and walking difficulties like foot drop.

Aging with SCI exacerbates stenosis, especially in the cervical area. This is due to a combination of using our arms for locomotion and having our cervical spine in a state of recurrent extension by looking up at people from chair-height. This puts extra strain on the neck. In addition, lifespans for individuals with SCI are increasing, thus the likelihood of ongoing wear and tear, which can lead to spinal stenosis occurring, is high.

This makes it important to pay attention to tingling, numbness or weakness in the fingers, hands or arms, and/or neck pain. If a person with SCI notices any of these symptoms it is imperative to consult a physician, ideally a physiatrist or a neurologist, as they could be signs of stenosis at the cervical spine, or possibly another unwanted serious neurological condition such as a syrinx (see resources). In addition, any changes in bladder and bowel function, or in spasticity, should also be discussed with a physiatrist or neurologist since this could be symptomatic of stenosis or other possible complications in the lumbar area.

Diagnosis, Treatments

Diagnosing cervical stenosis starts with a careful neurological examination that could include a physical strength exam and a pin prick exam for sensation and reflexes. A nerve conduction study may be ordered to evaluate for nerve entrapments or pinched nerves, or X-rays may be used to look for areas of wear and tear on the vertebrae or narrowed disc spaces. From there a physician may choose to order an MRI or CT scan, both of which can show changes in discs, ligaments and narrowing of the spinal or lateral canal.

Treatment for spinal stenosis starts conservatively and includes nonsteroidal anti-inflammatory drugs like ibuprofen. The next step is physical therapy. Then cortisone injections to decrease inflammation, which can provide relief by allowing extra space for the nerves. The last resort is surgery, specifically decompression with or without fusion, done either through the front of the neck (anterior) or in the back of the spine (posterior).

The key takeaway is to be aware of symptoms of stenosis and see a physician if they crop up. The earlier the diagnosis, the more options you have and the best chance at resolving your symptoms.
Two SCI Perspectives

For long-term SCI perspectives on symptoms, diagnosis and treatment of stenosis I turned to Eric Stampfli, 61, in his 43rd year as a T11 para and Bill Bowness, 60, in his 42nd year as a T12-L1 para. Both Stampfli and Bowness contacted their physicians, and their diagnoses were pinpointed on MRIs. For Stampfli, narrowing of the cervical spaces at C5-6 was pinching nerves. Bowness’ diagnosis was stenosis in the disc space between C3 and C4.

When he was about 36 years post-SCI, Stampfli had successful surgery to relieve carpal tunnel, which had manifested in numbness in his middle two fingers. "Around 38 years post-injury I started to get pins-and-needles tingling starting at the wrist, and the tingling would get much worse after pushing up hills or pushing through soft dirt while gardening," he says.

A year ago, Stampfli opted for cortisone shots in C5-6. "The procedure wasn’t too painful, sort of like a pinch or two, similar to getting stuck with an IV but in your neck," he says. He got relief, including full return of sensation in his hands, that lasted for about four months. "Since then I’ve had two more cortisone shots with good results. The plan is to place the injections close enough to prevent symptoms returning and hopefully enable the nerves to heal."

Unfortunately, Bowness needed more intensive treatment for his stenosis. "Eight years post injury I started getting pins-and-needles tingling in my arms and localized pain in my hands. An MRI confirmed nerve impingement around the foramen near T1," says Bowness. "I had the impingement surgically repaired with a foraminotomy — grinding it to widen the area — which alleviated the symptoms."

His arms and hands remained strong until 25 years post injury when he started noticing numbness and weakness in his right arm. Within a year the symptoms progressed to significant muscle weakness that became so severe that he opted for surgery. "The surgeon went in through the front of my neck, shaved off calcified bone spurs and fused C3-4 with a plate," he says. He was in the hospital for two days and fully healed, with full return of sensation and strength, within six months.

Bowness, a world-class adaptive water and snow skier, didn’t back off competitive skiing and the symptoms returned four years after his surgery, requiring another fusion. "I’m now fused from C3 to C6, and again, am fortunate my neck and arm fully recovered. I’ve also learned my lesson. I’m slowing down a gear or two to preserve what I have left for the long haul."

Resources
- Charcot’s Spine a Potential Long Term Complication of Spinal Fusion, newmobility.com/2016/06/charcots-spine/
- Mayo Clinic, Spinal Stenosis, mayoclinic.org/diseases-conditions/spinal-stenosis/symptoms-causes/syc-20352961
- Syrinx and Pain, newmobility.com/2011/01/paramedic-syrinx-and-pain/
- To China and Back for Syrinx Surgery, newmobility.com/2019/10/to-china-and-back-for-syrinx-surgery/
THE STORY OF MY KAYAKING CATASTROPHE ALL
STARTED YEARS AGO WHEN WE WERE AT THE
END OF WINTER AND QUICKLY APPROACHING
SUMMER. IN CANADA, IT SOMETIMES SEEMS
LIKE WE GET 10 MONTHS OF COLD WEATHER
AND TWO MONTHS OF BAD SLEDDING. WE
WERE ALL TIRED OF THE WINTER DOLDRUMS. MY
PUZZLER WAS PUZZLIN’ ABOUT SUMMERTIME
FUN WHEN, AS IF ON CUE, THE HEADLINE OF
AN EMAIL FROM THE LOCAL SPINAL CORD INJURY
ASSOCIATION SHOWED UP AND GRABBED MY
ATTENTION: DISABLED KAYAKING.

BACK IN "LIFE NUMBER ONE," I USED TO
LOVE CANOEING. AS A CHILD I OFTEN TOOK
THE DOG AS FRONT-BALLAST AND CANOED AND
FISHED AROUND THE LAKE WHEREVER WE HAP-
PENED TO BE CAMPING. KAYAKS WEREN’T AS
POPULAR BACK THEN, SO THE IDEA OF GETTING
A CHANCE TO TRY ONE IN "LIFE NUMBER TWO"
WAS ALWAYS ROLLING AROUND IN THE BACK OF
MY HEAD.

MANY THINGS IN LIFE ARE DANGEROUS, BUT
THE GRAY MATTER BETWEEN OUR EARS IS THERE
to HELP KEEP US SAFE AND MITIGATE RISK. WE
ARE BORN WITH A GUT INSTINCT THAT LETS US
KNOW WHEN DANGER IS NEAR, BUT OUR "INTEL-
LECT" GETS IN THE WAY SOMETIMES. BASED
ON RESULTS — BECOMING A QUADRIPLEGIC — IN
THE PAST I MAY HAVE BEEN MISSING THE
OCCASIONAL DANGER CUE.

MY KAYAKING ADVENTURE WAS A PRIME
INSTANCE. WITH CAREFUL PLANNING, EVEN
SKYDIVING FROM 25 MILES UP LIKE FELIX
BAUMGARTNER CAN BE RELATIVELY SAFE.
LIKEWISE, IGNORING CLUES CAN MAKE SEEM-
INGLY MUNDANE ACTIVITIES LIKE KAYAKING TURN
INTO LIFE-THREATENING ORDEALS.

THE FATEFUL DAY
WE ARRIVE AT THE KAYAKING POND, AND
PROMPTLY GET TO BUSINESS IGNORING SAID
CLUES, EVEN AS THE INSTRUCTOR LAYS THEM OUT
IN FIVE SIMPLE ANSWERS.

"ISN'T THE KAYAK A LITTLE SMALL?" I ASK.
"OH NO, IT'S FINE," HE REPLIES.
"WHERE'S THE SEAT?"
"I'M GOING TO INSTALL IT, IT JUST CAME."
"ANY OUTRIGGERS?"
"NOPE, HAVEN'T ARRIVED IN THE MAIL YET."
"IS THIS THING STABLE ENOUGH WITHOUT
OUTRIGGERS?"
"SURE."
"YOU'VE DONE THIS BEFORE, RIGHT?"
"SURE."

DUE DILIGENCE COMPLETE, I AGREE TO GIVE
IT A GO. THE CREW PERFORMS THE
4 ½-PERSON, BACK-BREAKING LIFT TO INSTALL A
QUAD PADDLER INTO A GROUND-LEVEL KAYAK.
THEY ASK, "YA WANT YOUR HANDS TIED TO
THE PADDLE?" (WHICH IS AFFIXED TO THE KAYAK.)

OK, EVEN MY SPIDEY-SENSE TINGLES WITH
POSSIBILITY OF SURVIVAL IN THE EVENT OF A
ROLLOVER?

"NO THANKS," I REPLY.
"UM, 'SCUSE ME," I SAY TO GET INSTRUC-
TOR'S ATTENTION. NO RESPONSE — HE MUST
HAVE ME ON "IGNORE."

THE KAYAK STARTS TO MOVE.
"I ... UH DON'T HAVE A LIFEJACKET ON," I
SAY LOUDER. NO REACTION — PUSHERS KEEP
PUSHING.

"I DON'T HAVE A LIFEJACKET!" I YELL (AS
LOUD AS A QUADRIPLEGIC CAN). NADA ... NO
REACTION ... KAYAK IS ENTERING THE WATER,
AND PANIC IS REARING ITS HEAD.

OUTDOOR TRACKS
By Kary Wright
I yell at my wife, "Hey Terry, I need a LIFEJACKET!"
She lowers her camera and hollers, "Stop, he has no lifejacket!"

Low and behold, it works. There must be something about the pitch of a female voice that can cause grown men to freeze. Soon I am back on shore getting fitted with a life preserver. Safety first!

I feel kind of tippy on the shore, but things will be better in the water ... right?

Slowly they push me off the shore and into the water. I grab the paddle and smile for the camera, confident that this will be another successful adventure. I remind myself to be careful not to go too fast or far.

Uh oh, I’m starting to lean left ... whoops. Dang ... I’m going over! I take a deep breath and roll upside down. I hear the water splash and gurgle as it enters my ears. I can feel gravel on my forehead. I open my eyes to look around. The water is nice and clear, maybe a little cool but refreshing nonetheless. The bottom is covered with pretty round gravel. It must've been hauled in special, I suppose. There are tiny aquatic bugs happily zooming around, doing important bug-stuff.

I’m grateful for the big breath I took, allowing me to quietly savor the moment while I await rescue. I hear footsteps splashing in the water. They will set me upright shortly. The kayak moves, starts to twist upright. Apparently, it’s the second half of the roll that harbours all the trouble, the first half went smooth as silk.

Terry grabs me and drags me ashore. I get set up into the sitting position.

"Are you OK?" Terry asks, "you were under a long time!"

"Yes, seem OK, a little wet," I reply.

"Do you want to try again?" ask my trusted instructors.

"No thanks, I’m good."

I get lifted into my chair, wet and unhurt except for pride. We collect our cameras, bags, etc. and head off to get some sun to dry off, leaving the scene of the incident.

Lessons Learned
I came away thinking about how I got myself into such a mess. I came up with a few points:

1. You know your situation better than anyone else. I let things get out of control by being lulled into a false sense of security, as the event was set up by a reputable group.
2. If the helpers are not listening to you, call it off. I should’ve put the brakes on a situation in which good communication is paramount for safety.
3. Make sure you feel comfortable and have input on the situation.
4. Trust your gut. In hindsight, I ignored the many warning flags that went up. I was so excited to try kayaking that I forged ahead with the adventure, even when it became apparent that the instructors didn’t have experience with my situation. I know many quadriplegics have successfully kayaked and loved it, and I will one day too! We did come away with a funny video, and luckily nobody was hurt.

The video can be found at youtube.com/watch?v=PWntM7nwT3E.

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SHOULD I REPORT MY UROLOGIST TO A LICENSING BOARD?

I’m a male para, injured for 12 years, and I recently moved to a large city. At the time I needed to find a good urologist because I was experiencing recurring UTIs. I found a great SCI support group and got the name of a local urologist that many in the group recommended. They liked the doctor because he was friendly, easy to work with and seemed to know about spinal cord injury and neurogenic bladder. Also, he was an experienced surgeon.

On my first visit I explained that I suspected a problem with my urethra was causing the infections and might require surgery. He prescribed a new antibiotic and said he’d do a cystoscopy and inspect my urethra if the infection returned. He seemed nice as well as competent. However, I was shocked to smell alcohol on his breath and suspected he had been drinking.

At the next group meeting, I mentioned this to the others. Most of them defended the doctor. Only one other member said she had suspected him of drinking, noting that she too had smelled alcohol on his breath. After the meeting she also told me that she had seen the doctor visibly intoxicated at a popular local restaurant just two weeks earlier. Because of this, she said she was considering changing urologists.

My infection cleared, but I’m afraid it may return and I still may need surgery. In the meantime, I feel conflicted. I fear my new urologist may be a “maintenance alcoholic.” He may be like my dad, who drank every night but still functioned reasonably well during working hours. But he got worse over time, and his hands started shaking. I’m torn between staying with this doctor and not saying anything, looking for a different urologist, or maybe even reporting him to the state medical licensing board. But if I do this, I fear the rest of the group might feel I am betraying them, especially if they lose him as a favored doctor. Is there something I can do short of reporting him to the licensing board? I feel a responsibility to do something but I’m not sure what to do.

I see what you are up against. Let’s start with some factual analysis. Alcoholic behavior that eventually interferes with work is more common than you might think. Statistics vary, but many estimates put the incidence of alcoholism among men — who are more prone to the disease — at about 10%. Not all of these are severe alcoholics, but as you implied, unmanaged alcoholism is a progressive disease. Perhaps one-third of these are maintenance alcoholics, who, as you know, need to keep a certain level of alcohol in their blood throughout the day to feel comfortable. Quite often they will drink heavily in the evening, resulting in a substantial blood-alcohol level the next morning that steadily dissipates. At the end of the day, or sometimes earlier, they will start drinking again to satisfy their dependence. This kind of behavior is most often seen in men who have daytime employment, while steady “nipping” throughout the day is the preference of unemployed men. Over time, both habits can result in disease or nerve damage that causes the “shakes,” which is particularly dangerous in the medical profession, especially with surgeons.

A key factor in your dilemma, however, is the lack of definitive evidence about the drinking habits of the doctor in question. The behavior that the two of you who have witnessed, presumably related to heavy drinking, falls short of proof of alcoholism. But it may be a violation of your state’s medical licensing board’s standards of professional conduct. Each state board has a statute, most commonly known as the medical practice act, that lists examples of unprofessional conduct. Two examples that might apply in your situation are “impaired ability to practice due to

“SHOULD I REPORT MY UROLOGIST TO A LICENSING BOARD?”

By Tim Gilmer

NEW MOBILITY
addiction” and “dishonesty” (when the doctor hides his addiction or refuses to get treatment). Both examples are important, but the first one is obviously of paramount concern.

The situation you are in requires careful consideration in choosing what to do or not do, as well as ethical consideration of possible outcomes. If you take the position of the majority of the support group and do nothing, you may be avoiding the real problem out of fear of alienating the group and losing their support. Could this be a kind of subconscious enabling behavior that is related to your relationship with your father? On the other hand, if you decide to report what you have witnessed to a licensing board, your action may have consequences for the doctor, his family and all of his patients, including you. It is unlikely that the board would take action based on two anecdotal complaints, but they may inform the doctor of the complaints as a matter of course. If others have complained or complain in the future, the licensing board may revoke his license to practice.

Many licensing boards offer accredited rehabilitation programs if the case meets certain standards. Informing your state’s medical licensing board of a potential problem could possibly result in a positive outcome for everyone concerned. If your complaint turns out to be unwarranted and is dismissed, the doctor will most likely not be told who filed the complaint.

Perhaps a better approach would be to send a letter short of an official complaint to the medical licensing board. Simply tell them the truth of your dilemma and ask that your identity be kept anonymous. You could inform the board that you are uncertain if there is a drinking problem or not, and that you don’t want to cause undue concern since you have no specific complaints based on the doctor’s performance. In doing this, you will be leaving the decision to act with the board. In the meantime, you and your friends can remain watchful. Hopefully, this kind of approach will have beneficial results for everyone.
I need to figure something out. Why is it that I really get my back up when I hear politicians refer to the “most vulnerable” citizens? They do it all the time, and when they do, they always say they’re trying to protect the “most vulnerable.” The ones who say it most emphatically are those who want to cut the crap out of stuff like Social Security or Medicaid and then say they’re “trying to preserve scarce resources” so they can serve the “most vulnerable.”

When they say “most vulnerable” they want everyone to envision some weak and defenseless victim of fate. That’s intended to include cripples like me. We’re the ones who need their protection. And it makes me feel like angrily tearing up the “most vulnerable” label and throwing the pieces all over the floor just so nobody gets the impression that it refers to me. I feel it’s my duty to make it clear that I’m no more vulnerable than the walking/talking guy next door!

But who am I kidding? Of course I’m way more vulnerable than the walking/talking guy next door. I employ a crew of people to help me do stuff like get in and out of bed every day. I call them my pit crew. If one of them doesn’t show up, I have to scramble to find a way to get in and out of bed. It shoots the whole day to hell. But the walking/talking guy next door doesn’t have to worry about that because he doesn’t need any of that kind of help. And what if there’s a natural disaster, like a flood? The first responders will come rescue the walking/talking guy next door with a rowboat. But I doubt that rowboat will be wheelchair accessible. At best, the first responders might airlift me to the closest nursing home that’s only partially submerged. I get to sleep with the fishes. But most likely I’ll be left at home to drown. And even if I don’t drown, how are my pit crew members going to get to me in a flood? Will the first responders bring them to me in a rowboat? I doubt it. I’m pretty much screwed no matter how you slice it.

So why am I so afraid to face up to my enhanced vulnerability? Why play this big macho game of denial? It’s a losing game. Everybody is one big amorphous blob of vulnerability. Everything could fall apart for anyone at any minute. That ain’t such a bad thing. Why don’t I give myself a break and embrace that reality? Wouldn’t that be liberating? To be vulnerable is to be human, so to pretend that you’re not vulnerable is to pretend to be superhuman. And I hate that superhuman cripple stereotype.

But I don’t care. I don’t have any trouble acknowledging that my life is more of a house of cards than the walking/talking guy next door. But I’ll tell you what makes me that way the most. It’s those people who try to cut the crap out of programs like Social Security and Medicaid and then say they’re doing it to protect the “most vulnerable.” They are the scariest predators of all. Nothing makes me feel more vulnerable than when they try to cut the crap out of the state program that pays the wages of my pit crew.

And if being the “most vulnerable” means being defenseless, then they sure can’t be talking about me. Whenever somebody tries to cut the crap out of the program that pays the wages of my pit crew, the first thing I’m moved to do is get together with others and fight back hard. We don’t hide from the predators. We stalk them. We show up uninvited in their offices, homes and churches. We sue them. Whatever it takes to make them back off. If I was defenseless, I’d be way more than “most vulnerable.” I’d be dead.

So I guess when I reject the label of “most vulnerable,” I’m not denying my enhanced vulnerability as a cripple. I guess I’m doing the opposite. I’m defining my vulnerability for what it really is, so I won’t be so vulnerable to the predators who call me “most vulnerable.”

Thanks. I think I understand it now.
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What I would change: I want more fitness facilities that accommodate the use of mobility devices. Exercise is a prerequisite for us to remain strong. When the body moves, the mind adapts and ultimately, our spirits and confidence are lifted.

Meet New Member Edward John Carter II

Age 37, from Kirkwood, New Jersey T6 SCI due to a spinal stroke Sales consultant and DJ

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Andrew
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I agreed to get back out on the water with friends last summer on a hot September day. It was good, but I was stuck in one place since the boat was not made for a wheelchair. I was dutifully nailing flag duty as we towed some inner tubes behind, but as the day progressed, beer and ice water were no longer keeping me cool. My friends’ solution? It was my turn in the water, and they wanted to drag me in one of the inner tubes. Never one to forgo a challenge, I figured, why not? I traded my T-shirt for a life vest, and my friends managed to get me safely off the boat and into the blue stuff. Waterskiing had been a hobby growing up, so I was relatively comfortable with the logistics. I climbed up and onto the tube and held on for dear life as we picked up speed. Everything was going well, until the inflatable arced up and my bottom half slid off the back into the water. As a massive wake approached I held on tight … but my shorts didn’t. I lost them entirely once I came over the crest of the wave.

Saboataged

Instead of hitting snooze on my alarm one morning, I turned it off completely. Not only did I have an early hair appointment, but I had a lunch meeting scheduled across the county before heading into the office. I got dressed quickly, focusing on layering up for the late fall weather. I headed out in a flash, yelling goodbye to my husband and kids as I passed. I felt a few more eyes on me than usual but brushed it off as me being extra sensitive. The day was going fine until I ran into my office mate getting coffee in our kitchen that afternoon. “Giving your feet a break?” she asked. Confused, I replied, “No, because you don’t have shoes on.” she said matter-of-factly. With that, the reality sunk in that I had gone around my entire day with bare feet. There is now a full-length mirror in my garage.

Shoeless Jo

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