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**COVER STORY**

**THE MAN BEHIND AIRBNB’S ACCESS PUSH**

As the head of Airbnb’s push for accessibility and inclusion, Srin Madipalli is overseeing the $35 billion peer-to-peer rental giant’s efforts to make travel more accessible. With rentals in almost 200 countries and over 150 million users, the company could be a game changer. But is that what it wants? IAN RUDER profiles Madipalli and reports on his “once in a lifetime” opportunity to change the global conversations on disability and access.

Cover and Contents Photos by Clara Rice

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U CAN TOUCH THIS

It seems like not a week goes by without some story in the news about inappropriate touching. Thanks to the overeager hands of politicians, entertainers, businessmen and other public figures, there is more discussion about the boundaries of “proper” touching and how we physically interact with each other than at any point I can remember.

I bring this up not because I have some brilliant solution or “best practices” that will change everyone’s perspectives, but because I can’t imagine a better time to examine where those boundaries lie in regard to us — people with disabilities.

On the one hand, none of us want strangers accosting us and pushing our chairs when not asked; on the other hand, ignoring the need for closeness and the connections bred by human touch can be equally harmful, and even dangerous.

Whether I’m out for a roll, at a social event, or even hanging out with friends, I am constantly reminded that most people simply don’t know how to interact with people who use wheelchairs and other assistive devices. I see the confusion and uncertainty on strangers’ faces as they take in my bulky power wheelchair — how do I approach him? Should I extend a hand to shake? Is a hug even possible?

I understand the confusion, and I’m the first to admit I wasn’t totally comfortable with how to interact with people with disabilities before I became one, but I also understand how important touch is.

In addition to telling us how something feels, touch carries emotion and shapes our perception on a level much deeper than the physical. A warm embrace, a slimy palm or a firm handshake can tell you everything you need to know about a new acquaintance. A good massage can alleviate pain and stress, and something as simple as a hug can improve your mood and stave off depression.

These correlations aren’t just anecdotal either. Among other positive results, studies have shown that hugs can help ameliorate cold symptoms and that as little as 15 minutes of touch can have helpful effects.

After reading about some of these studies in a recent article in The Atlantic, I emailed Tiffany Field, the founder of the Touch Research Institute at the University of Miami’s Miller School of Medicine. Field, a developmental psychologist, is known for her studies on the importance of touch. She studied the impact of touch deprivation on infants and found that simple, repeated touch could help them gain weight and avoid medical problems.

I told her I was a quadriplegic with limited sensation, and how much more difficult I found it to have meaningful physical interactions with others. It’s a reality that I’ve heard many other wheelers bemoan, and one that I don’t think many nondisabled people even consider. I asked her if she was aware of anyone studying the effects of touch deprivation on our community.

Sadly, aside from one study on massaging quadriplegics, she said she didn’t know of other such studies. But she did seem intrigued and promised to pass along the correspondence to the spinal cord research team at the hospital. Maybe that will lead to something, maybe not. But in the meantime, now seems like a good time to engage people from both inside and outside the disability community and get the conversation going.

If you have a disability, take the time to educate people you care about regarding how you can physically connect. If you don’t have a disability, look for appropriate ways to ask questions and facilitate discussion. Loneliness and depression are all too common in the disability community and to ignore such a simple remedy would be negligent.
So many of our best stories come out of personal experiences, and Paula Larson’s article on menopause in this issue is a great example. “Just going through menopause, I realized that I didn’t have anybody to talk to about the experience of being a wheeler and what I should expect,” she says. “I figured if I had that experience maybe there were other people in the same boat.” When she started reaching out to discuss the topic, people were open and candid with their responses. “Almost all the women I spoke to were looking forward to our conversation,” she says.

When I think of Kate Matelan, I think of a fierce woman who takes no guff and is ready to kick some ass. Some of that is because she wrote a great article on self defense for the magazine I worked on before NM, which featured an iconic image of her on the cover, but it’s also because I have had the privilege of getting to know her over the years. So when the time came to select a writer to profile another strong woman, Assistant U.S. Attorney Lauren DeBruicker, Matelan was an obvious choice. The fact that they both live near Philadelphia and happened to know each other? Icing on the cake.

We first introduced readers to cartoonist Mat Barton in a profile by Tim Gilmer almost five years ago, and these days we are fortunate to have him penning Please Remain Seated as part of our exciting new back page. He’s had a passion for art for as long as he can remember but ramped up his efforts after he was paralyzed in 2012, finding drawing to be “super therapeutic.” When he’s not sketching, Barton works as a graphic designer in Portland, Oregon. His work has also been featured in The New Yorker, Ruminate and elsewhere. Make sure to check it out at matbarton.tumblr.com and matbarton.com.

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

Fantastic article and kudos to those out there “doing it!” (“Disabled Doctors: Healing the Medical Model?,” March 2019). I am a C6-7 complete quad and was initially denied access to a demanding clinical psychology program in the late ’80s for similar reasons, including uncertainty about how I’d handle administering test materials using quad hands. Now I’ve got 30-plus years practicing as a clinical psychologist! The perspective and drive of an individual who has been physically — and mentally — put to the disability test, yet has the tenacity to get through the educational roadblocks, persevere for years and focus their energy on humanity is ... priceless! These folks are out there trailblazing in regard to what does matter most: the human spirit of caring, hard work, empathy, seeking of knowledge, sharing your expertise, refusing to settle.

*James Wolf*

Newmobility.com

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**I Want One!**

I would love to have a wheeler doctor, especially for my primary care! It’s frustrating to consistently run into physicians, most of whom are well-meaning, but who have little knowledge and even less experience with some of the most common medical issues we deal with.

*Jacquie Tellalian*

Newmobility.com

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**Invaluable Instruction**

Thank you, Eddie Crouch, for sharing your techniques (“Pushing the Edge of SCI Function,” March 2019). You demonstrate so well something I hammered into the heads of my PT students — the absolute importance of functional tightness in the hands of a quad and not overstretching the hand/fingers when teaching transfers and weight shifting. It upsets me tremendously when I meet a quad whose hands have been overstretched and have a flat palm, hyperextended fingers and zero tenodesis with wrist extension.

*Jeannie Reiner Senter*

Newmobility.com

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**A Bridge of Hope**

I certainly hope that this bridge (“3D Printed Implants May Offer a Unique Approach for Treating Spinal Cord Injury,” News, March 13, Newmobility.com) will result in positive trials very soon. I have been paralyzed 55 years and need to bridge the injury gap between C4 and C6 before I have no function left. It would be wonderful to regain function to my still healthy body in my 80s.

*Ronald W. Hull*

Newmobility.com

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**Dry Skin Solution**

For those dry cracks around my fingernails, I cut a tip off of a vinyl glove, squirt lotion in it, then pull that over my finger and tape it with skin tape (“Wintertime SCI Skin Protection,” Para/Medic, March 2019). I can only do this at night, but it helps a lot.

I have suffered dry and cracked skin much of my life and use tons of body cream, but I got an unexpected boost over the last month from a supplement. I never believe the hype on supplements, but I was searching for a protein supplement that would not aggravate my touchy digestion. For a month I’ve been using a collagen powder and am surprised to find my skin improved all over. There are two spots that chafe: one from my underpants on my belly and one in the gluteal crack, which must come from the chafing of my panty pads. Darned if those haven’t smoothed out a lot and feel softer. Who knew?

*Patty Lee*

Newmobility.com

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“Kudos to those out there ‘doing it’!”
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Guinness World Record: 123 Floors, 1,821 feet, 2,917 Stairs

A Paralympian from Albania recently set a Guinness World Record when he wheelied down the 2,917 steps of South Korea’s tallest building. Haki Doku completed the feat in 49 minutes using a regular manual wheelchair outfitted with SoftWheels to cushion the impacts. Next up? He has plans for a speed run to descend 100 stairs in 30 seconds. Check out his “Gravity Tour” at hakidoku.com

Para Makes Off-road History

At Dakar 2019, Italian racer Nicola Dutto became the first paraplegic to ride a motorcycle in the world’s most famous off-road endurance rally. Speeding over the sand dunes of coastal Peru, Dutto was able to complete four of the rally’s 10 stages riding a KTM motorcycle with modified controls, a custom seating system by Vicair and roll cages to protect his legs in the event of a crash. Despite a controversial disqualification following mechanical issues with his support bikes, Dutto is confident his team has what it takes to complete the full event. For more on Dutto’s story and how he handles the planet’s toughest terrain, check out: youtu.be/_dnpM00DIQg

IKEA Promotes Accessible Furniture Hacks

The international home furnishings giant IKEA has teamed up with an Israeli nonprofit to design accessibility add-ons for its most popular furniture pieces. The project is called “ThisAbles,” and there are currently 13 products available, from oversized switches and handles, to curtain grippers, to a snap-on bedside cup holder and more. IKEA has posted free design schematics for the objects online so they can be 3D printed by users. The company is also soliciting ideas for new accessibility hacks from the disability community. For more information visit: thisables.com/en/help-us/.
Access is Coming

After the new season of *Game of Thrones* premiered in April, the internet decided it was time to do something about the access issues in everyone’s favorite fantasy world. Bran might be the Three-Eyed Raven now, but he still uses a wheelchair, and as one Reddit user noted, “Bran is kind of stuck in the courtyard. It seems Winterfell isn’t exactly wheelchair accessible with all those stairs.” Let’s hope the GoFundMe campaign is successful.

Human Support Robots to Assist Wheelers at Tokyo Olympics

If you use a wheelchair and need help finding your seat or carrying a drink at the Tokyo 2020 Olympics and Paralympics, there’s a chance that you’ll have a robot assisting you. Toyota will be deploying Human Support Robots at competition venues to provide assistance for wheelchair-using spectators while showcasing the technology’s potential for wider application in everyday life.

“Toyota hopes to provide ‘the freedom to move for everyone’ throughout the Games and has developed various mobility solutions, including robots. We believe that the robots will help spectators in wheelchairs to enjoy watching the events without any restrictions,” said Nobuhiko Koga, Chief Officer of Frontier Research Center at Toyota.

The HSR, the development of which was first announced in 2012, is designed to provide personal assistance for everyday tasks, including picking up objects off floors, retrieving items, and opening doors or window blinds. To do this, the cylindrical base uses a retractable arm with finely calibrated pincers that can grab items like clothes or a small water bottle, while a suction cup can retrieve thin items like a piece of paper. With an integrated display, cameras and microphones, the HSR also provides remote video connectivity. It can be controlled by the user via voice or tablet, or by a care provider remotely. In a year and a half, we might finally get a glimpse of whether it has advanced enough to provide real world assistance.

Outrageous Airline Stats

Major airlines lost or damaged an average of 23 wheelchairs per day from December 2018 to February 2019, according to reports by the U.S. Department of Transportation. The numbers may not come as a surprise to many disabled travelers, but thanks to accessibility reforms included in the FAA Reauthorization Act of 2018, we now have hard data to confirm what is known to be an industry-wide problem. “I know from personal experience that when an airline damages a wheelchair, it is more than a simple inconvenience — it’s a complete loss of mobility and independence,” said Democratic Sen. Tammy Duckworth of Illinois, who uses a wheelchair and championed the new regulations.

According to the reports: from December to February airlines lost or damaged a total of 1,975 wheelchairs or scooters. Of the major carriers, American and Southwest consistently had the highest incidence of mishandling, while Delta and United had the lowest. The numbers are likely to change as more monthly reports are issued and there’s a larger sample size to analyze, but wheelchair users now have some valuable information when choosing which airline to fly.
Collector Car Questions

Mario asks:
Mike Collins’ article “Collector Cars” (October 2018) was interesting, but I have a few questions. First, how do the owners transfer from their chairs? And second, are they able to use the cars independently or do they need someone to help them store and retrieve their chairs?

I have a 2005 Corvette that I’d like to keep and use more often. Problem is that either I take my walker, which limits my mobility, or depend on my wife to handle my chair. I have a 2005 Corvette that I’d like to keep and use more often. Problem is that either I take my walker, which limits my mobility, or depend on my wife to handle my chair, both of which are major deterrents to using the vehicle.

Contributing Editor Mike Collins responds:
When it comes to types of wheelchairs and transferring, everyone is different depending on their physical capabilities and whether they are using rigid or folding wheelchairs. I use a power wheelchair and full-size van, so I can’t speak from personal experience. I do have many friends who take the wheels off their rigid-frame wheelchairs and are able to swing them over into the back seat and then do the same with the frame. Others put them in the passenger side of the vehicle. If there is cabin space, a folding chair might be able to slide behind the driver’s seat after the driver has transferred. One of those featured in our column drives a Corvette and is a quad who pulls the wheelchair in after him and travels alone, with his chair in the passenger seat.

If you are in any of the Facebook groups that deal with spinal cord injury or are a member of “Handicap Hotrods” (facebook.com/groups/handicaphotrods), you might want to put a query out to their members to see if people can share their experiences with you. If you are able to use a walker, it undoubtedly gives you more options in some regards, but door dimensions and interior configurations are so different that I would be remiss if I tried to recommend something that would work exactly for you. Good luck, and thanks again for your input.

Portable Shower Chair Suggestions?

Karl asks:
Do you have suggestions for a portable shower chair/commode that’s suitable for air travel? And are there any financial resources to purchase one?

Editor Ian Ruder responds:
Almost 20 years of using the same Nuprodx travel shower chair has made me a firm believer in the company and its offerings. Go! Mobility Solutions is another popular option. Both were designed by quads for fellow wheelchair users. It’s not easy to get insurance to cover shower chairs, but that depends on your insurer. I recommend contacting the manufacturer and asking about potential resources/grants. Also, check out “Bathroom Equipment: Not Medically Necessary?” by Mark Boatman in our May 2015 issue (newmobility.com/2015/05/bathroom-equipment). Boatman covered a lot of ideas and resources to help mitigate the high cost of medical equipment.
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THE BENEFITS OF REDUCING/REPLACING SUGAR

Oh, how we love sugar. It tastes great, makes us feel good and gives us an extra kick to help get through the day. We can’t get enough of it. The U.S. Dietary Guidelines reveal that on average, Americans ingest 17 teaspoons of sugar a day, even though the World Health Organization recommends we eat no more than five to 10. Seventeen teaspoons a day adds up to almost 60 pounds a year! Think what 60 pounds looks like — that’s a lot of sugar — and it has absolutely no nutritional value or benefit to your health.

All that excess sugar is associated with the development of numerous health conditions such as weight gain/obesity, Type 2 diabetes, Alzheimer’s disease, build-up of plaque in your arteries, inflammation, weakened immune function, decreased bone health, depression, anxiety, fatigue and sleep difficulties. These are all common secondary health complications for people living with chronic mobility impairments. So, if you’re eating and drinking more than the recommended amount every day, it is critical that you reduce your sugar intake to help lower your risk of developing or compounding these serious health complications.

To give you an example, people with spinal cord injuries often have weakened immune systems as a result of the biochemical changes that occur following injury. If someone with SCI puts a couple of sugars in their morning coffee, eats a breakfast donut, then follows that up with a soft drink at lunch, a mid-afternoon candy bar and a big piece of cake after dinner, they are further depressing their immune system all day.

Here’s how. Vitamin C is needed by white blood cells to engulf and absorb viruses and bacteria. The white blood cells that do this need to contain 50 times the concentration of vitamin C normally found in the blood around them in order to continue to destroy bacteria and viruses. However glucose — sugar in its simplest form, as found in the bloodstream — and vitamin C have a similar chemical structure. So similar, in fact, that when a white blood cell tries to pull in more vitamin C from the blood around it, glucose can get substituted by mistake. And if the concentration of glucose in the blood is high from eating sugar all day, a white blood cell’s vitamin C concentration will start to drop because of the large amount of glucose it’s pulling in as a substitute for vitamin C.

In turn, the white blood cell’s ability to absorb and destroy viruses and bacteria is reduced by up to 75%. Moreover, it can take four to six hours for the vitamin C concentration in the white blood cells to reach the optimum concentrations again.

Part of the problem is people are over-consuming sugars without even knowing it. For instance, many people only associate calories with food but not drinks. Yet drinks often contain more sugar and calories than a plate of food.

A 12-ounce soft drink has approximately 40 grams of sugar, or 10 teaspoons, and some specialty coffees contain over 80 grams. If you’re drinking even one of these a day, you’re exceeding your daily amount.

A study released in March by the American Academy of Neurology also demonstrated that people with multiple sclerosis who drink sugar-sweetened beverages experienced more severe symptoms and a higher level of disability compared to people with MS who seldom drink sugar sweetened beverages.

Another problem with excess sugar consumption is there are over 60 different names for sugar listed on our food labels and many of them sound healthy, so we don’t think twice about eating them. Some examples are cane juice, corn syrup, high fruit concentrate, malt syrup, palm sugar, beet sugar and brown rice syrup.

Here are five simple tips to help you reduce your daily sugar intake and stay healthy:

1. Read food labels carefully. When comparing package nutrition facts labels, always choose foods that have five or less grams of sugar per serving — this is just over 1 teaspoon. On the ingredients list label, items are listed from most to least. If sugar is one of the top three ingredients, it’s too much — don’t eat it.

2. Eliminate common foods and drinks with high sugar content. Stop drinking soft drinks, specialty coffees, sports drinks and sweetened store-bought iced tea. Stop eating obviously sugar-rich sweets like cookies, cakes, pies, donuts and candy bars. Cut out processed muffins,
TAKING UP SPACE

I wish I rode an ultra-light sexy wheelchair with a small turning radius, but I don’t. I traverse the world in a large, clunky, heavy power chair. It’s big, and together we take up a lot of space.

There was a time when my dimensions made me feel like I was in the way. I was embarrassed. I apologized for being there.

I was an inconvenience — an eyesore — a burden so big that all I wanted was to be invisible and disappear unnoticed. Taking up space was the last thing I wanted.

I am not sure how or when I started to realize that taking up space is wonderful, and I am deserving of it.

If someone needs to get past me, they can wait for a moment while I move, and we can both exist in the world. No apologies needed.

Sometimes ignorant strangers get too close and I ask them to move and give me space. Sometimes when they see me coming down the hall, they move all the way to the other side, body up against the wall, attempting to give me room to pass ... too much room ... and I laugh.

It is not easy to take up space when so often the world implies we are not deserving. I don’t want to shrink anymore. I want to inhabit every room I enter with a confident presence. I want my voice to matter and to be allowed to feel happy, sad, angry or excited without judgment.

I am not there yet, so I will practice until I can take a breath and fill my lungs and then fill the room with my physicality and the power of my voice. There is space for all of us, and I will claim mine.

REFRAMED

by Reveca Torres

processed cereals, fruit-bottom yogurt, canned fruit and even low-fat products, as sugar is commonly added to make them palatable. Eliminate condiments such as BBQ sauce and ketchup — you’d be surprised how much sugar is packed into just one spoonful.

3. Eat natural sugars. Fruits, pure maple syrup and honey are great (and tasty) sources of natural sugar.

4. Replace artificial sweeteners. Aspartame, sucralose, maltodextrin and saccharin are found in products such as NutraSweet, Equal, Splenda and Sweet’N Low. Recent statistics revealed that 41% of American adults consume these zero calorie artificial sweeteners, but these products are linked to long-term weight gain and diabetes.

5. Use healthy, low-calorie sweeteners instead. The three options below contain no artificial ingredients, preservatives or flavors and are safe for people living with diabetes:
   • Stevia is made from the leaves of the stevia plant and has 30-150 times the sweetness of sugar. It comes in liquid or powder form.
   • Monk fruit is derived from the South Asian fruit of the same name and has 150-200 times the sweetness of sugar. It also comes in liquid or powder form.
   • Swerve contains the natural sweeteners erythritol and oligosaccharides.

Make sure to use these natural, low-calorie sweeteners in moderation, as they may cause stomach upset for some individuals, especially when consumed in large amounts.

Resource
• U.S. Dietary Guidelines, health.gov/dietaryguidelines
Katherine Beattie glided around the *NCIS: New Orleans* set, helping make production decisions. The prop department had ordered wheelchairs for the guest star, whose character had just been injured and was in rehab. Everyone thought one chair looked better, but because of Beattie’s experience as a wheelchair user, she knew the other one would be more authentic. When it was time to start filming, Beattie transferred into a director’s chair. She put on headphones and looked at the monitor, watching her script come to life.

Beattie, one of a small number of TV writers with disabilities working in Hollywood, has been with the *NCIS* spin-off since it premiered on CBS in 2014. Starring Scott Bakula as Special Agent Dwayne Pride, the show has been a staple of the network’s Tuesday night lineup. Beattie started as a script coordinator — formatting scripts, proofreading and handling legal clearances. Two years ago, she was promoted to staff writer.

Her most recent episode, “In Plain Sight,” revolves around Investigative Computer Specialist Patton Plame, played by series regular Daryl “Chill” Mitchell (“Actor Chill Mitchell Conquers Hollywood,” Sep. 2016 NM). After his close friend — a member of the Valor Brigade, a group of disabled vets who are analysts in law enforcement — is shot to death in front of him, Plame discovers that the Brigade’s wheelchairs and prosthetics are being bugged, revealing top secret intelligence.

“The idea came from stories I shared with coworkers about how easy it is for me to sneak things into places,” shares Beattie, who has cerebral palsy. “Like bringing food into Disneyland or alcohol into a pricey music festival because security guards aren’t going to ask me to stand up to check my wheelchair cushion.”

The other writers laughed and thought it was interesting, so they brainstormed how it could fit into a military story. “Because Patton is a tech guy, we thought it would be cool to put those two worlds together,” says Beattie.

Directed by LeVar Burton, the episode offers a rich storyline. 

---

By Teal Sherer

**IN THE MEDIA**

**AN AUTHENTIC VOICE IN THE WRITERS’ ROOM**

This photo captures a rare scene that hopefully will become more common, as everyone in the front row worked on a popular TV series episode. Katherine Beattie wrote it, Daryl “Chill” Mitchell starred in it, and Teal Sherer guest-starred in it. In the back row are Kurt Yaeger, LeVar Burton and Scott Bakula.
for Mitchell that highlights his range, along with some impressive wheelchair rugby skills. "With Katherine, I know that my back is covered," says Mitchell. "I’ve worked on other shows that lacked African American representation in the writer’s room, and you can feel it because they are not writing in your voice. And now, with disability, we have someone that physically and emotionally knows what I’m capable of, because she’s been through it.”

In addition to Mitchell, a large number of disabled actors, including myself, were hired for the episode.

“Every disabled character is played by a disabled actor, and that is a hill that I will die on,” says Beattie. “Not because I think that nondisabled actors should absolutely never play a disabled character, but to me disabled actors aren’t even getting the opportunity to play disabled characters — let alone other characters — so I’m not going to take a role from somebody that deserves it. And, also, they just bring so much more authenticity to the roles. Everyone on the show feels the same way. We have Chill, who is a series regular, so everyone is used to working with a disabled performer. No one bats an eye, and we get the work done.”

The Hard Road to Hollywood
After Beattie joined the Writers Guild of America, the labor union representing professional writers, she attended a Writers with Disabilities Committee meeting. “Everyone there was shocked I had a job,” she says. “Even though we have a big group of disabled writers, hardly any are TV writers. It’s hard to break through.”

In TV writing, there are two main paths to getting a staff position. The first is to start as an assistant and work your way up, but it can be very physical. “When I started as an office PA, I wouldn’t use my wheelchair at work, so I was able to kind of pass for able-bodied,” explains Beattie. “I’d beat my body up doing these physical tasks. I don’t know if I was trying to prove something. I’d carry 50-pound boxes of paper up the stairs when someone else just could have done it. Most people with disabilities don’t have that option.”

The second path is to get into a fellowship or diversity program, but disability often isn’t considered a part of diversity. That is slowly starting to change. Last year, David Radcliff was accepted for the Disney Writing Program and recently finished his first season as a staff writer on ABC’s The Rookie. “These programs can be tricky though,” says Radcliff, who has CP, “because they often choose writers with assistant experience. So, these two paths become intertwined.”

The Writers with Disabilities Committee is working to increase visibility by planning an upcoming event where members can have round-robin conversations with TV showrunners, putting them in direct contact with the people who can hire them. They also host the Disability Scene event, where readings of short scenes that involve disability are performed by actors with disabilities.

Living the Dream
In between takes, I looked around the NCIS: New Orleans set. It was surreal to be surrounded by other disabled actors, telling a story by a disabled writer. I felt optimistic, like things were moving in the right direction, and honored to be a part of it. When the director called, “Action,” Patton Plame and Dwayne Pride entered the scene. A Valor Brigade meeting was in progress, and they needed our help.


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Ali Stroker won rave reviews for her portrayal of Anna in Deaf West’s 2015 revival of Spring Awakening, and now she is back on Broadway, playing Ado Annie in Oklahoma! at Circle in the Square. Performing now through September 1, 2019.
A fresh coat of paint can work miracles. There’s no easier way to transform your home, boost your happiness and, if you own the property, up your equity. As an added bonus, painting doesn’t require the specialized knowledge most other modifications demand and is manageable whatever your function. With the right tools and some hard work, your newly colorful abode will be the envy of your neighbors’ eyes. Here are some tips on tackling the basics.

You Take the High Road, I’ll Take the Low
Every painting project I’ve done has been with my wife, Kelly, and other family members. Over the years, we’ve developed a system that works well for us, one that should be familiar to any wheelers who’ve done projects with nondisabled partners. The gist of it is: I do whatever big areas I can reach, while Kelly gets the high stuff and any detail work. Not that the delineation of detail work had much to do with disability — Kelly was the kind of kid that colored between the lines, and I, most definitely, was not.

When updating our first home — a charmless ranch that looked like it hadn’t been touched since it was built in 1989 — Kelly started by pulling off trim and doors. At the same time, I was unscrewing light switch and outlet covers. Kelly would tape, but functionally there was no reason I couldn’t have taped the areas within my reach — it just would have taken me longer.

An ingenious system we cribbed from a professional crew I’d watched paint our condo building was to lay the tape down quickly, without worrying about the edges being perfect. You then go back over the tape with a razor, cutting right where you want your edge to be. It’s far easier to make a straight line and takes a fraction of the time, especially if you have weak hands or balance issues.

I would use a roller to paint the walls after Kelly finished the edging. As someone with limited hand strength, I found that it was more efficient for me to use a smaller roller because the lighter weight and smaller handle allowed for easier grip and less fumbling every time I had to reapply paint. Using a gripping aid, like Active Hands, is also worth considering.

Working from a chair, the low areas were more of a pain — in the neck and the back — than the high areas. I’m not sure why I never thought of it, but many wheelchair users just transfer to the floor, sitting on a cushion to save their butts, when tackling the low stuff. Eric Newby, a C7 quad recently updated a cabin that he and his wife bought in Bailey, Colorado. For him, sitting on a cushion on the floor with his legs crossed in front of him provides a stable base to do any work near the floor.

Zen and the Art of Painting
One unexpected bonus to living with limited function is the level of patience it forces on you. When updating a house, there are some things a nondisabled partner can do in a quarter of the time it would take me. There are others — painting the porous brick surface of the fireplace was my most memorable example — that took an extraordinary amount of time, no matter who was doing it. Strangely enough, I was usually better suited to these tedious, time-consuming projects. Nondisabled folks are used to being able to blaze through tasks; having to slow down can be maddening. For better or worse, I have plenty of practice with slow and pain in
the ass. Sure, that fireplace took me four days to paint, but it looked damn good when I was done, and my spending the time there allowed Kelly to use her function in places it was more valuable.

**Exterior Considerations**

Often the most labor-intensive part of painting the exterior of a house isn't the actual painting, it's the prep. Any loose, chipping paint has to be removed before new paint goes on, or it won't adhere properly. Without good prep, you could be right back where you started after only a few years. The most common tool for paint removal is the simple scraper. I experimented for a few hours with trying to find a technique that worked, but my grip limitations and lack of core function left me pretty well worthless.

On recommendation from a friend, I borrowed a Paint Eater ($69, available at many home improvement stores) — an electric-powered, handheld orbital sander with a sanding disk made specifically for removing paint. It has a strap on the side that allowed me to hold it with a single hand, though I did need to use both hands when I was actually sanding or it would buck around and bite into the wood. For those with grip issues and/or balance issues, I can't recommend it enough.

Don't be intimidated by the larger dimensions and increased obstacles presented by the outside of your home. Bob Vogel, a T10 para, says he was able to reach the entire exterior of his one-story house using roller extensions of various lengths. "In areas I needed to use a brush, I just duct taped the brush to the end of the extension," he says. "On the one hand, it was a lot of hard work, but it was a tremendous amount of satisfaction, sitting back, looking at the house and saying, 'Yeah, I did that.'"

If you can buy, rent or borrow one, paint sprayers are a wonder, and extension tubes are available to give you a few feet of extra reach. And if you already own one, Vogel recommends using a Freewheel to make getting around the outside of your house a little easier.

If you've refreshed your paint or undertaken any other DIY home improvement projects from your wheelchair, we'd like to hear about them. Comment online, or email smcbride@unitedspinal.org. We'll post a blog to share reader tips and tricks. Happy hacking.
Coaching, mentoring and education all blend together for Brian Weber, a 35-year-old football and wheelchair rugby coach from Rochester, New York. Whether teaching 250-pound high schoolers proper foot work, instructing 40-year-old quads in proper chair positioning or helping the newly injured learn how to adapt to their changed bodies, Weber knows that success in life and in sport is all about the details.

Sports have always been a big part of Brian Weber’s life. “I started playing football when I was in fifth grade,” he says. “I played football for 10 years, but I loved all sports, anything physically active.” So much so that he went to college to be a physical education teacher and a coach. He was working as an offensive and defensive line coach at his alma mater, Gates Chili high school, and substitute teaching in the same district, when he jumped into a wave at the beach and injured his spinal cord at C3-4.

Weber’s career path didn’t change with the accident. After rehab, he stopped subbing but stayed on as a football coach, though he had to modify how he went about it. “It took me a little while to adjust, it was hard,” he says. “To get someone to understand how to really hit or block someone, there would be times that I really wanted to just jump out of my chair and show them, but I couldn’t do it. I had to take a breath, calm down, and figure out how to break down a skill and explain it.”

In some ways, Weber thinks the shift has made him a better coach. Because he has to explain every part of a skill rather than demonstrate it, it’s given him a deeper understanding of everything that goes into seemingly simple movements.

Less than two years after his accident, Weber was approached by a couple of guys who were starting a local wheelchair rugby team and needed a coach. His only exposure to the sport had been in an adaptive sports class at college, but he was intrigued. “I went to practice, and they all seemed like pretty good guys. I said, ‘Sure, I don’t know a whole lot about it, but I’ll come out and help as much as I can.’” That was six years ago, and he’s been coaching the Rochester Wreckers ever since. Though the bodies of the football and quad rugby players may be worlds apart, Weber finds a lot of similarities in how he coaches the two sports. For Weber, success in both is founded on a mastery of the fundamentals. Whether it’s chair positioning, foot work or body mechanics, “the littlest thing can...
I was always into being active and working out, so after my accident I needed something like that. I now have an FES exercise bike. I stick electrodes on my arms or legs and they power my muscles to pedal it. It brings me back into that mode — I feel like I’m getting a workout. It feels good. I do my legs two times a week, and I also have an arm bike attachment on it, so I’ll do my arms two to three times a week as well.

The other pieces of technology that I use all the time are a sip-and-puff computer mouse from a company called Broadened Horizons, created by a couple of guys with disabilities that sell all sorts of adaptations for computers, phones or even video games. The mouse works perfectly. I can get around and do anything on my computer that anyone else can.

I also have a sip-and-puff straw for my phone that’s made by a company called Tecla. There’s a little box you hook onto the back of your chair that interfaces between the phone and the straw, and it allows me to control everything on my phone the same way I control my wheelchair — I can text, I can call, whatever I need, it’s great.

That’s true in everyday life as well. When people get out of rehab, they rarely have time to develop the various skills they need to live with reduced function — and that’s where mentoring and peer support can be so valuable. So when Scott Friel, a nurse manager on the rehab floor of a local hospital, started setting up a peer support group, Weber was all over it. “It’s great to give people with new injuries a sense of how to deal with all the different aspects of living life outside of a hospital,” he says.

**ADVICE FOR THE NEWLY INJURED:** It does get better as time goes on. Let the bad stuff roll off your back as best as you can, because there’s nothing you can do about it. Push forward and make what you have better.

**WHY I JOINED UNITED SPINAL:** I wanted to connect with and help be a resource for people with spinal cord injury throughout our community.
When it comes to my dreams, I’m generally unfazed by spotting polar bears in my bathtub or falling in love with a guy I haven’t seen since fifth grade. What strikes me as odd is that I’m always walking through dreams without my wheelchair, yet I still can’t maneuver stairs. This unexpected new reality is just one of the many puzzling things that I have noted about my dream world since becoming a high-level quadriplegic.

Dream Me is independent and has a full range of motion. Despite showing no visible signs of paralysis in my dreams, my legs often lack confidence. I move slowly, step gingerly and reach for handrails. In dreams, I’m a seeker; I search, and solve puzzles. Recently though, locating accessibility features has become a bizarre recurring theme in my twilight quests. Dream Me has no issue with seemingly endless hunts to locate an elevator in outer space or wandering through labyrinths looking for barrier-free exits.

I’ve started to wonder: Is my subconscious obsession with accessibility unhealthy? Clearly, the theme is relevant to my life, but with my limitless subconscious at its disposal, why isn’t my brain giving me the night off from ADA duty? Am I the only one with a spinal cord injury walking unsteadily up access ramps in my dreams?

It turns out, I’m not. In fact, 60 percent of the 138 people with SCI who responded to a poll I created responded that they, too, are sometimes in and sometimes out of their chairs when they dream. In contrast, most of the remaining 40 percent of respondents never use wheelchairs in their dreams. A big surprise for me was that only a few said they always use their chairs in their dreams.

Many respondents commented that despite enjoying otherwise full mobility while dreaming, they also run into illogical SCI-related stressors. Apparently, the dream world is full of seemingly-able sleep-walkers: dreamers with functioning limbs who still require help with basic tasks, can’t pee in inaccessible bathrooms, give themselves never-ending bowel programs, and — surprisingly often — must push or drag their wheelchair along as they walk.
A NEW NATURAL

Wes Holloway, a C5-6 quad, has a unique relationship with his vivid dreams. A fellow nighttime explorer with awkward mobility, Dream Wes never uses a wheelchair. Still, he frequently needs assistance or can’t pass a physical barrier despite ambulating on his own. “Sometimes, I’m walking up a hill without my wheelchair, but someone will lead me with a hand or come up from behind to push me,” he says. “Other times, I’ll be driving without my chair, but simultaneously being concerned I should have it and that what I’m doing isn’t safe.”

Despite a similar level of injury, Elizabeth Treston has no problems with mobility in her dreams. Her gait is normal and she goes and does as she chooses, nimbly and without hesitation. She has dabbled in dream analysis during her 40 years as a wheelchair user, but at this point, she doesn’t take dreams too seriously. Instead, she says, “In dreams, I’m just me. Except, I get to walk around, run, swim, and have great sex.” She coyly reveals, “When I’m dreaming, Steven Tyler and I are the perfect couple. Which is odd, because I don’t really have a thing for Steven Tyler. But believe me, we are a great match.”

For Andrea Dalzell, a paraplegic, dreams might as well be called walks, because that is what she does in all of hers. Without fail she is actively walking away from someone or something. She
NEW MOBILITY

In the weeks since I started this exploration, my own dreams have noticeably evolved with the influx of dream-related discussion and research. Last week, I fell asleep in hopes of consciously suggesting a reference to feeling conscious and awake but being unable to move for short periods while falling into or out of sleep. The sudden lack of control is not a dream at all, but an irregularity or lag in the sleeper’s ability to transition between stages of sleep and wakefulness. In dream sleep, our muscles essentially turn themselves off. So, for some, remaining or becoming aware while transitioning in or out of the dream stage can result in an unsettling momentary paralysis.

In stark contrast to waking up unable to move, for some paralyzed people it’s the sight of the more-mobile dream self that can be jarring. Dalzell says she occasionally dreams she is watching herself walk from above. “I’m acutely aware that my feet are there and I can feel everything. Those are the dreams I don’t like, because I can wake up very emotional,” she says. “I don’t know if it’s a subconscious yearning to walk, but I momentarily forget about my disability as I wake up. Things can feel so natural and real that I forget I can’t just swing my legs up and out of bed. I go to stand up, and I completely miss my wheelchair.

Beyond unpleasant wake-up calls and inescapable arachnids, post-SCI life also involves the inevitable dreams that are not dreamy at all. Before he was injured, Wacker had frequent nightmares about ghosts or monsters. “After my accident, I made peace with that stuff. Now, the anxieties I face in my dreams are things I worry about every day,” he says. “My biggest fears are about hurting myself by not being able to get out of harm’s way or falling out of my chair. [In my dreams] I may be out rolling around in the town with a beautiful girl and feeling a really vivid connection, but I will start to worry that my foot is dragging without me knowing it. If I see that it is, I will feel the hypersensitive sensation the same as if it was actually happening.”

Dalzell expressed something similar, noting that when she isn’t feeling well the perpetual forward motion she’s used to in dreams can slow or stop. “Instead of waking away from someone, I will be walking down steps or sitting on a mountain watching everybody else,” she says. “Sometimes, I’m playing with my feet, which sounds weird, but I will be playing with my toes or my feet will be moving much on dreams back then, he finds himself using the skill more frequently and while he didn’t find himself reflecting much on dreams back then, he finds himself using the skill more frequently now. “I’m able to take charge and do things that I can no longer typically do and I can experience different things that I find pleasurable,” he says.

Experts suggest that would-be lucid dreamers wake slowly to remain within a dream as long as possible. Upon waking, the use of a dream journal or voice recorder can be used to recall and re-examine dream experiences. Then, the focus becomes trying to re-enter a recent dream and look for clues that it is, indeed, a dream. By repeating the last two steps, recognizing dreams and re-entering that dream, there is potential to lucid dream at will and experience the independence and freedom the skill can bring.

**DREAM TRAINING**

For many, there are opportunities to manipulate their dreams into tools for both business and pleasure.

Dream incubation is the process of focusing your attention on an issue as you fall asleep in hopes of consciously suggesting the subject of your next dream or posing a scenario to act out as you sleep. The idea being that you can then recall the outcome or solution in the morning.

For the more advanced dream trainer, lucid dreaming takes things a step further by not just simply suggesting a subject of the dream, but consciously taking control of it. Lucidity in dreaming is a coveted skill, and mastering it generally takes training and practice.

For those of us living with mobility constraints, lucid dreaming presents a unique opportunity to fulfill otherwise unlikely fantasies. Like playing a first-person videogame, the dreamworld becomes a safe environment to experiment with alternate realities. All four of my interviewee noted the occasional ability to guide some of what happens in their dreams and exhibit some form of free will. Before his SCI, Wes Holloway worked on lucid dreaming in a psychology class and while he didn’t find himself reflecting much on dreams back then, he finds himself using the skill more frequently now. “I’m able to take charge and do things that I can no longer typically do and I can experience different things that I find pleasurable,” he says.

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Beyond dreams, post-SCI life also involves the inevitable dreams that are not dreamy at all. Before he was injured, Wacker had frequent nightmares about ghosts or monsters. “After my accident, I made peace with that stuff. Now, the anxieties I face in my dreams are things I worry about every day,” he says. “My biggest fears are about hurting myself by not being able to get out of harm’s way or falling out of my chair. [In my dreams] I may be out rolling around in the town with a beautiful girl and feeling a really vivid connection, but I will start to worry that my foot is dragging without me knowing it. If I see that it is, I will feel the hypersensitive sensation the same as if it was actually happening.”

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**MAKING SENSE OF IT ALL**

While it doesn’t happen often, every once in a while, post-SCI life does barge in on Treston’s dream self. Like Dalzell, it is generally when she is ill or hospitalized. A recent example makes her laugh. “I have a colostomy bag that I call Sey-
friends and family are often main char-
acters, and what happened in a dream since my
accident. “Occasionally, I confuse what is real
and what is happening in a dream,” he says. “I have
the time to reflect on them more
now, but I find them pretty fascinat-
ing.” As a frequent dreamer, his dreams
are long and complex dreams I have teach
me. Intrigued, I consulted Google’s ex-
tensive collection of dream expertise and
interpretational guides to learn what it
means to dream that you are paralyzed.

It turns out paralysis has been a heav-
ily-explored theme since the beginning of
time. Back then, dream paralysis meant
a large spirit had chosen to sit on you as
you slept. Recommended solution? Keep
a knife near the bed for protection from
lazy giants.

The far less interesting modern inter-
pretation attributes paralysis to one’s in-
ability to act on a problem or solution in
real life. This explanation seems to cast
a pretty wide net, but it’s not wrong. If
nothing else, I’m certainly defenseless
against spiders.

Holloway says that he learns a lot
about himself through dreams. “Some-
times my dreams are exhausting, but the
long and complex dreams I have teach
me things,” he says. “Perhaps it’s because
I have the time to reflect on them more
now, but I find them pretty fascinating.”
As a frequent dreamer, his dreams —
even during short naps — are drawn
out and detailed. He can recall multiple
dreams from the night before [see side-
bar]. “Occasionally, I confuse what is real
and what happened in a dream since my
friends and family are often main char-
acters,” he says.

For Holloway, dreams are also cata-
lysts to further personal understanding.
“My day-to-day life can be boring, but
I’m pretty convinced that sleep is my
brain’s time to be active and allow me to
have experiences that I may not be able
to otherwise,” Holloway says. “I feel like
at night I’m getting a chance to code my
memories and get things formed in my
brain. Other times, I feel the opposite,
and dreams seem like my brain suggest-
ing I get out and do more.”

Wacker uses dreams to work out scen-
arios he is considering in his wak-
ing life. “I have many problem-solving
dreams and I find solutions and inspira-
tion in dreams all the time,” he says. “I
have come up with alternate strategies
for video games, ideas for projects, and
recently, I am able to work through cho-
reography for my performance routines
while I sleep.” He finds this very helpful,
but notes, “I have to make sure I get the
idea down or work through it right away
so I don’t forget what I learned.”

THE LONG LINE IN HEAVEN
Sleep is a time for our bodies to repair
and take a break from the physical bur-
dens of each day. Dreams play an essen-
tial role in maintaining a healthy sleep
cycle and given the added physical and
emotional tolls that come with SCI, it
seems reasonable to assume our dreams
carry extra importance.

After SCI, our dreams present a
unique environment to realistically
explore physical experiences, and for
some, feel the sensation of activities
we may not otherwise be able to access
while awake. Our dreams may not al-
tways make sense, but they present an
interesting opportunity to reflect and
interpret the images we receive to learn
more about ourselves. With the intro-
duction of dream training, there is po-
tential to increase our independence
and expand our minds as we sleep.

If I’ve learned anything discussing
this subject, it’s that we are all unique
in the ways that our unconscious
brains interpret our daily lives. Oh,
and if you can find an accessible bath-
room stall in dreamland, there will
likely be a line of other sleep-walkers
(or dreamers-with-paralysis) standing
around waiting for it too.
Srin Madipalli originally studied to be a research scientist focusing on genetics, before retraining as a corporate lawyer, only to discover he didn’t want to be one … and so went back to school to get an MBA from Oxford. He taught himself how to code and started and sold his first startup company before he turned 35. It’s the kind of resume Hollywood script writers usually save for the heroic lead who has been tasked with solving the insolvable problem and saving humanity. Maybe someday Madipalli will devise the cure to stave off a zombie apocalypse or a way to stop climate change, but for now his sights are focused on improving accessible travel, making it easier for people with disabilities to see the world and changing the way the world sees them.

Madipalli is the head of Airbnb’s accessibility team and arguably the highest profile and most visible face of accessible travel currently on wheels. With a valuation of $35 billion, over 150 million users and more than 6 million global listings, the San Francisco-based company is the unquestioned giant of the peer-to-peer rental industry. With listings in 191 countries and an explosive growth rate, Airbnb is uniquely positioned to shape
the experiences of travelers and hosts around the world. For travelers with disabilities, Airbnb could be a facilitator and an advocate, opening doors to new destinations and new cultures, or simply another obstacle.

Somewhat ironically, Madipalli’s ascent to his current perch began four years ago when he and a friend, both born with spinal muscular atrophy, founded a company to address the failure of the emerging vacation rental industry to accommodate the needs of people with disabilities.

Based in London, they called their company Accomable, and spent the next two and a half years devising ways to make accessible peer-to-peer property rentals more accessible. In November 2017, Airbnb acquired Accomable and brought Madipalli on to manage its accessibility efforts.

Seated in the atrium of Airbnb’s massive headquarters in San Francisco’s rapidly-changing SoMa district, Madipalli looks like someone who has found his place. With a zip-up hoodie featuring the company logo and his seemingly omnipresent smile, Madipalli exudes the laid-back vibe the building has been carefully crafted to encourage. When I ask if he feels any pressure with his role and the heightened visibility it brings, he is unfazed.

“I think the pressure comes purely from within myself,” he says. “This has been my life’s work. This is something I have dedicated years to. I started this to solve a problem for some of my closest friends, my family. I want to do justice for and help a community that I’m that I am a part of and very close to.”

TRAVELING ROOTS
In the last year alone, Madipalli, 33, has been all over Asia, Europe and the United States as part of his work. He estimates that he spends over a quarter of his time away from his San Francisco apartment and has a wealth of knowledge about where to stay and what to do for accessible fun around the world. But travel wasn’t a big part of his life growing up as a power chair user in London. “When I was younger, we hardly ever went anywhere,” he says. “Every now and then we would do the odd holiday, but it was such a struggle for mom and dad to do everything. It was complicated.”

As he got older and started managing his own support workers, Madipalli’s horizons expanded, but it wasn’t until the end of his short stint as a lawyer, around the end of 2010, that he got “the travel bug.”

Four months roaming around Europe, Africa, Southeast Asia and the U.S. hooked him on the allure of travel, but also reinforced the need for a better way. “I would turn up to a hotel and they did not offer the access they promised,” he says. “So many times I couldn’t find any information.”

Madipalli returned to London to get his MBA and started learning to code. Looking to test his skills on a project he’d personally find useful, he and a friend set out to build something that would make travel easier. That effort became Accomable. “It was ultimately born from us asking, ‘What were the challenges that we faced?’” he says.

The site went way beyond simply allowing hosts to check whether a residence was wheelchair accessible. Instead, it allowed them to check off specific accommodations, like roll-in showers, ramps and steps. It also required photo or video documentation...
of listed accessible features. Madipalli helped raise a reported $500,000 to support a growing staff and a rapidly expanding userbase that topped 1,000 listings by the fall of 2017.

When Airbnb moved to acquire Accomable, Madipalli saw it as the natural next step. “We started off wanting to create what an ideal travel platform looks like if you had an accessibility need, and at Accomable, we got that started,” he says. “We had proof of concept and some early users, but at Airbnb we can take that to a much more exciting, global level. We have a much larger team, many more resources, and we can actually take our know-how and expertise to a more scaled and global platform.”

**A DISCRIMINATION PROBLEM**

The victory for Madipalli and his team could also be seen as a shrewd move for the Silicon Valley giant as it struggled with questions about discrimination. In 2016, published accounts of hosts turning away and in some instances confronting, guests based on race were backed up by a Harvard Business School study. The study found users with distinctly African-American names were roughly 16% less likely to be accepted as guests than those with distinctly white names.

Airbnb responded to specific incidents with bans and other tactics, but made headlines in June 2016 by hiring Laura Murphy, the former head of the legislative office of the American Civil Liberties Union in Washington, D.C., to lead a review of its discrimination policies. Her report, released in September, led to a number of policy changes, including a new nondiscrimination policy that specifically addressed disability with nine prohibited host actions.

In her opening, Murphy wrote that the company’s genuine commitment to improvement had removed the skepticism she had before signing on: “Airbnb is engaging in frank and sustained conversations about bias on its platform. More noteworthy, however, Airbnb is putting in place powerful systemic changes to greatly reduce the opportunity for hosts and guests to engage in conscious or unconscious discriminatory conduct.” She also noted that CEO Brian Chesky told her, “Airbnb will never be able to fulfill its mission without seriously combating discrimination on its platform.”
Eight months later, in June 2017, another study, this one from researchers at the Rutgers School of Management and Labor Relations, found Airbnb users with disabilities were less likely to be preapproved and more likely to be rejected outright. “The rise of internet-based platforms for some services threatens to perpetuate and possibly increase their exclusion. Many of the newly-available services are not fully accessible and may create more opportunities for both intentional and unintentional discrimination,” wrote Mason Ameri, the lead researcher.

The study found that only 25% of guests with a spinal cord injury were preapproved, compared with 75% of guests without disabilities. Even hosts who advertised their listing as “wheelchair accessible” were more likely to approve a guest without a disability (80%) than a guest with a spinal cord injury (60%). The authors pointed to Airbnb’s odd relationship with the ADA (see ADA sidebar) as part of the problem and urged the company to bolster its education and outreach efforts.

Airbnb officially acquired Accomable just over five months after that report was released. Madipalli understands how outsiders could see acquiring a disability-focused company led by a wheelchair user to be a public relations gesture but, like Murphy, is confident the company’s intentions are true. “At the end of the day Airbnb would not have agreed to the acquisition unless I could look people in the eye and say we are actually making genuine effort here.”

Airbnb clearly sees Madipalli as an asset, too. “Srin is a force of nature whose leadership has made travel more inclusive and accessible for everyone,” says Airbnb head of public policy and public affairs Chris Lehane. “Airbnb’s mission is to create a world where anyone can belong anywhere and Srin’s in-home accessibility work has been critical when it comes to creating the opportunity for our guests to be able to belong everywhere.”

THE TEAM

Madipalli’s efforts include the outreach and education the Rutgers report called for but go well beyond that. As the product manager at the head of Airbnb’s In-Home Accessibility Team, Madipalli has 16 staff spread across engineering, research and sales. While five Accomable employees transitioned to Airbnb, one of them left and three work from London, leaving Madipalli as the only original employee on this side of the pond.

His new group is young, diverse and eager to make Airbnb as accessible as possible. They also clearly enjoy working with Madipalli. “Srin’s passion is the number one factor of our team,” says Nanako Era, a researcher on the team. “I’ve been able to learn a lot from him … the way that the team grows and how passionate he is about accessibility and travel,” adds Lydia Marouf, strategy and operations manager.

His team is working to improve Airbnb’s In-Home Accessibility Team, Madipalli has 16 staff spread across engineering, research and sales. While five Accomable employees transitioned to Airbnb, one of them left and three work from London, leaving Madipalli as the only original employee on this side of the pond.

WHAT ABOUT THE ADA?

If you’re wondering why ADA enforcers aren’t cracking down on repeated instances of Airbnb hosts discriminating against people with disabilities, well, it’s not so simple. Like fellow peer-to-peer giants, Uber and Lyft, Airbnb exists in a murky realm between public and private spaces that nondiscrimination laws have not caught up to yet. The ADA covers public accommodations, like hotels and some larger Airbnb hosts, but it doesn’t apply to private homes or lodgings that are owner-occupied with fewer than six units available for rent.

In a press release accompanying the Rutgers study, the researcher who oversaw the study wrote: “The growth of the so-called sharing economy can benefit many people, but it is largely an unregulated gray area. These new platforms may allow individual hosts to avoid anti-discrimination laws, which may lead to more exclusion and discrimination against people with disabilities. We need a broader public policy discussion of how to increase accessibility and expand lodging options for travelers with disabilities.”
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nb’s interface from both the host and guest sides, while also growing the number of accessible options the company has. The most obvious examples of their impact are changes that follow in Accomable’s footsteps — like replacing the “wheelchair accessible” checkbox with 27 different filters, allowing hosts to better represent their offerings and making it easier for guests to find needed features, such as roll-in showers or grab bars.

They are also working to better understand the needs and concerns of customers around disability. "For current hosts, we’ve found that a lot of people have their own interpretation of, for example, what step-free access means. They think that if there’s a 4-inch threshold, that's still fine,” says Era. "For people with disabilities who are interested in hosting, there are a lot of concerns. … For example, they have a lot of medical equipment at their home, and they don’t want that to be damaged by guests coming over. [And] if they start getting income, does that affect their Social Security benefits?"

Not all those questions have easy answers, but Madipalli’s team is working to address them. They have crafted extensive educational materials to teach hosts how to properly photograph their homes to best help guests with disabilities, and they plan to require hosts to provide photos or videos of any options they select. “Our approach is, first get better information, and once you have better information, then present it in a more discoverable way,” says Madipalli.

As part of educating existing and potential customers, Madipalli and other team members have embarked on a global educational tour, holding events with disability groups, government and community leaders, and anyone interested in accessible travel. He has been to over 30 cities and eight countries since he joined Airbnb. "For a lot of people, this was the very first time that they were aware of the issue of accessibility,” says Madipalli. “In one place, the translator had to stop me and say, ‘Look Srin, I need a few minutes to explain what the word accessibility actually means,’ because there isn’t even a direct translation.”

ROOM FOR IMPROVEMENT

As a frequent traveler and regular user of peer-to-peer rental services, Carole Zoom is exactly the type of stakeholder Madipalli and Airbnb are looking to appease. Zoom, who has covered travel for New Mobility, guesses she has used Airbnb and its competitors — VRBO, Homestay and Home Exchange — 30-40 times. She knows and thinks highly of Madipalli but is reserving judgment on Airbnb’s commitment to actual reform. "They’ve made a commitment to Srin and to the Accomable model,” she says. “Personally, at this stage, I feel like it’s more about financial gain for them than it is about true nondiscrimination.”

One bad experience with Airbnb raised her awareness of the many issues the company had around disability access. After a long day of travel and hours setting up her medical equipment in a studio she had booked for a month through Airbnb, Zoom, who has muscular dystrophy, and her husband went to bed.

After midnight, the building manager pounded on their door and informed them, “You have 10 minutes to get out of here!” It turned out the building did not allow sublets. In the middle of the night, in a city she didn’t live in, Zoom was being told to pack up her ventilator, travel gear and scooter and find an accessible place to stay. Eventually, police showed up and all parties agreed Zoom and her husband would leave by 10 a.m., but Airbnb’s response highlighted some of the company’s oversights and problems.

The “wheelchair accessible” rental Airbnb suggested as a replacement turned out to be inaccessible and illegal. Zoom says Airbnb urged her to take the booking anyway because they had no other accessible listings. To add insult, when Zoom decided to cancel the tentative booking, the host gave her a negative review, downgrading her overall rating. Still, she says she will continue to use the service.

“There are a lot of great things that can come from using Airbnb’s lodging” she says. “But unfortunately, I had about the worst experience you can have short of being kidnapped in the middle of the night by the police. … The emergency backstop when something terrible happens is not in place, and there’s nobody to respond.”

Zoom has a number of ideas to improve Airbnb’s services, including establishing better connections with independent living centers and local disability service providers and locking down a plan of action for incidents like the one she experienced. She also hopes the company focuses on developing some form of enforcement to hold hosts accountable.

“‘There’s got to be some piece to what they’re going to put out for people with disabilities, for us to really trust that they are in this with us,” she says. “Right now, it feels like they’re in this with us only insofar as they can make money off us.”
ties as viable guests or hold prejudices against them, it’s all for naught.

As people with disabilities are a large and growing segment of the travel market, it makes sense Airbnb would want to have a healthy footprint in the market. “If you do the business right, that in itself will help people travel,” says Madipalli. “And if people can travel, that in itself is what creates the wider social benefit.”

Madipalli points to the infrastructure Brazil built to prepare for the 2016 Rio Olympics and Paralympics as an example. “Loads of businesses had started putting ramps in because of the Paralympics and that in itself got more people in the local area out and about,” he says.

At this point, the majority of Airbnb’s efforts to effect social change are mostly limited to education. When asked about a possible rewards program, or some means to incentivize hosts to use the accessible filters or make their residences more accessible, Madipalli said Airbnb is considering its options but suggested the filters offered their own reward. “Adding this stuff is going to help you get more bookings,” he says. “And I think that is going to be an important driver.”

Helping hosts get more bookings is good for the bottom line, but if Madipalli is to truly help Airbnb achieve its stated goal of creating a world where people “belong anywhere” he is going to have his work cut out for him. If anything, the challenge of what he described as “a once in a lifetime opportunity” seems to drive him. How committed Airbnb is to opening doors for people with disabilities remains to be seen, but all indicators are that Madipalli’s intentions are genuine.

Prior to joining Airbnb, Madipalli founded a closed Facebook group, Accessible Travel Club, to discuss accessible travel. Even with his relentless travel and work schedule, he still remains very active, posing and answering questions with the nearly 7,000 active members. He makes it clear that this is a side effort, not part of his work at Airbnb, but his commitment and passion for helping remove the obstacles around accessible travel are obvious.

How and whether Madipalli is able to channel that excitement and use his myriad skills to impact Airbnb will be interesting to watch. He says he envisions his current work as a three-to-four-year plan, but he knows new challenges will pop up. “I’m hoping that we can be a more vocal advocate for a positive message for disability,” he says. “I think people often feel that disability is treated as an afterthought, and actually seeing that the person leading this work at such a large brand like Airbnb is somebody with a disability is important.”

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On March 27, Zappos Adaptive and the Runway of Dreams Foundation hosted an adaptive fashion show to highlight the exciting present and future of adaptive fashion. Hundreds of fashion aficionados, industry insiders and members of the disability community lined an outdoor Las Vegas runway, while thousands more watched a livestream online. The event was the collaboration’s first high-profile effort to open a dialogue about fashion designed for customers with disabilities.

“Disability doesn’t change how you want to present yourself to the world,” says Mindy Scheier, founder of the Runway of Dreams Foundation. “The idea is simple but has gone largely unrecognized by the fashion industry. It’s time for brands and designers to embrace people with disabilities as an important part of our culture.”

Since 2014, the Runway of Dreams Foundation has engaged the disability community to better understand its diverse needs and create a call to action for the fashion industry to listen and use it as a resource for developing stylish, adaptable pieces that work for all bodies. Zappos launched its adaptive line in late 2017 to provide disabled customers and their families with clothing, shoes and accessories designed to make their lives easier.

As the warm spring sun set, one by one, 30 models with all types of disabilities took to the catwalk and demonstrated the power of clothing that works for them and their unique needs. In three acts, the models sported looks from adaptive brands that showcased daywear, active wear and more glamorous wear for a night out on the town. Actor R.J. Mitte served as the celebrity host of the event. Mitte, who has cerebral palsy and has appeared in major campaigns for Gap, walked the runway for fashion elite Vivian Westwood.

“Disability or not, every type of body needs clothes that fit comfortably and make you feel good,” says Mitte, adding that the fashion industry often “forgets about flexibility and makes clothing for models. I don’t need things that work for the runway. It’s about functionality and having things available that I actually want to wear.”

As an online retailer with revenues in the billions, Zappos has influence in communicating what it is looking to sell and what customers are looking to buy. This gives it leverage with big established brands.
ZAPPOS ADAPTIVE ORIGINS

Zappos’ commitment to adaptive fashion all started with one grandmother’s phone call to customer service. The grandmother was struggling to find no-lace shoes that allowed her autistic grandson to put his shoes on by himself. Noting that situations like hers are common, Zappos set out to create adaptive shoes and clothing. It immersed its employees in research and education, and engaged in conversations with people who have all types of disabilities. The result is a dedicated hub for sourced products that are functional, fashionable and meet all types of needs.

and also allows it to greatly impact some of the smaller brands seeking to innovate in the adaptive marketplace.

“What we need is traction,” says Mitte. “And Runway of Dreams and Zappos Adaptive have done something that isn’t only going to impact the fashion world but will have benefit in making people feel and look good.”
Two years ago, Lauren DeBruicker gave up her career as a partner in a high-powered Philadelphia corporate law firm to be an assistant U.S. attorney. As a C6 quadriplegic, DeBruicker was part of the estimated one-third of 1% of law firm partners in the United States who have a disability. She had achieved the type of professional success people dream about, but found herself wanting something more meaningful.

“Lauren’s unique experiences as a practitioner, advocate and public interest champion prepared her perfectly for this role,” says longtime friend and colleague Charlene Keller Fullmer. “She reached the pinnacle of a private firm career with a demonstrated track record as an accomplished litigator. Her service on numerous boards has affected change and raised awareness. Now, each day, her lawyering in a variety of complex cases makes a difference in the lives of citizens of the Eastern District of Pennsylvania.”

A true Philadelphian — from her upbringing, through her education and into her sports fandom — DeBruicker is a tireless advocate for all those around her, but her personal experiences have made her an especially empathetic voice.
for the region’s underserved disability community.

“Despite living a fairly privileged life, in which I have been blessed with support and resources, I still know what it’s like to be told to use the service entrance and eat in the back by the kitchen. I know what it’s like to go years without basic, preventative medical care because I can’t find a doctor with an exam table I can get on. I know what it’s like to go vote on Election Day and having to leave my polling place without having cast a real, non-provisional ballot because I couldn’t get to the voting booth,” DeBruicker says. “Now when I see something and say, ‘someone ought to do something about that,’ I can actually be that person. I have the tools and resources to bring about change.”

A Competitive Spirit

DeBruicker grew up in the suburbs of Philadelphia before heading to Stanford University for her undergraduate degree. During her drive from Pennsylvania to California for the start of her sophomore year, she was paralyzed in a car accident when the person driving fell asleep at the wheel. From that September to the following March, she recovered and rehabbed, before going back to school to pick up where she left off.

By the time she finished undergrad, DeBruicker had identified a career in law as a good fit for her skills and the new realities facing her as a quad. “I knew I wanted to be good at what I thought good lawyers were good at doing — speaking clearly, writing persuasively, addressing issues from different perspectives,” she explains. “I figured I could go to law school and learn these things, and maybe then I could go into the practice of law — because it was one thing I knew you could do sitting down — or maybe I would take those skills and do something else productive with them. Either way, it seemed like a good idea.”

DeBruicker moved back to the Mid-Atlantic region and enrolled at University of Pennsylvania’s law school. She graduated with a Juris Doctor in 1998 and began practicing at Duane Morris, a well-known firm in Philadelphia. DeBruicker had interned with the firm one summer while still in law school and says she expected the new job would last a few years. “Working in a big corporate law firm is very intense, but you learn a lot. There is a lot of ‘how much work can you get done, how many hours can you bill,’” she explains. “I knew that going in — I wanted that. I was ready to prove that I could do the work at that level and practice law at that level.”

Keller Fullmer worked with DeBruicker at Duane Morris and says her attention to detail and persistence helped her thrive early on as an associate. “In a matter of weeks, she became nothing short of an expert in a particular medical device — mechanics and all — after bringing a patent infringement and employment case against a major medical
device distributor, all the while effectively managing client expectations and extracting the best evidence to secure a successful resolution.”

Whether in or out of the courtroom, DeBruicker impressed her colleagues. “Lauren packs a punch with an iron fist in a velvet glove,” says Fullmer. “With her steady and unassuming demeanor, she skilfully disarms opposing counsel to the benefit of the client. At first, she may be underestimated by adversaries, and that works to her advantage.”

DeBruicker developed some of that punch as a Division I lacrosse player. She still plays wheelchair rugby and Keller Fullmer, now assistant United States attorney and deputy chief of affirmative litigation, points to DeBruicker’s athletic roots as a source of her resolve (see sidebar): “This mental mindset is fierce and fiery and is present on the field, courtroom, gym and board room. A true athlete, this competitive spirit and drive has enabled her to excel not only in wheelchair rugby but in all aspects of her life. It prepared her to tackle adversity and overcome obstacles.”

Instead of complaining about obstacles that arose because of her disability, DeBruicker looked for ways her disability benefitted her and then focused on how to maximize any advantages she might have. She found that being able to sit and speak at eye-level in front a jury, instead of lecturing them from a podium or pacing around the room, often gave her the upper hand. That was not the only advantage her disability lent her.

“I think people see that I clearly have enough on my plate in real life that I don’t have time to waste my time or theirs about something that isn’t important,” DeBruicker says. She focuses on facts and common sense. “Because if those two things aren’t on your side, you’re probably not going to get as far as you want to, regardless of what the law is or how righteous your position may be.”

Committed to Community

Despite having a full plate at work, DeBruicker has consistently found time to support causes she believes in. Mayor Jim Kenney appointed her to the Philadelphia Mayor’s Commission on People with Disabilities in 2016 and reappointed her in 2018. In that role, she acts as a resource for the city’s administration on how policies impact the disability community, and she brings issues that are affecting the disability community to the administration. Philadelphia’s large disabled population ranks among those with the highest poverty levels in the nation, making the commission’s job even more crucial.

According to DeBruicker, “Many cities have offices of disability services or other offshoots. Philadelphia’s is so small compared to other [large cities] where they have multiple people on staff. The commission feels the importance to volunteer and help out where they can.”

DeBruicker’s commitment to people with disabilities is also visible through her involvement with Inglis House, a local organization founded in 1877 that serves people with physical disabilities. Inglis broke ground on its first accessible complex in the 1970s and has been working to expand the availability of accessible housing, particularly for people with limited or low income in the Philadelphia area. Several friends encouraged DeBruicker to join the board, and she agreed after getting a better understanding of Inglis’ mission and goals.

“I learned that [Inglis] wasn’t just a nursing home with the
After eight years, her time on the board will come to an end this year. Fellow Inglis board member Won Shin has nothing but praise for her leadership and her unique point of view. “She understood, and continues to understand at the highest levels, what it means to advocate for someone,” says Shin, a fellow quad and friend who is the executive director at the Philadelphia office of the global business management firm, Ernst & Young. “Take those skills and combine them with her superior intellect, gracious and confident communication style, and the fact that [she] uses a wheelchair, and you have a board chair that impeccably represented Inglis and those we serve every day.”

The People’s Work

After 18 years at Duane Morris, DeBruicker decided she was ready for a new challenge, one that combined her interest in community service with her legal work. Working as a member of the Civil Division of the U.S. Attorney’s Office fit the bill. She started in December 2016.

As a lawyer for the United States and its citizens, DeBruicker enforces all civil laws, including the Americans with Disabilities Act, and represents the U.S. in other proceedings. She also ensures people who are billing the government do so in accordance with the law. “I feel like I’m doing more of the people’s work,” she says. “It’s doing right by the taxpayers. It’s making sure that what the law promises in rights and access is actually what people experience on the ground.”

Not only does she feel strongly about her work, but others within the office do too. It’s the right combination of fit and focus. One of her most successful projects to date involved working with Philadelphia restaurants to implement compliance programs and resolve violations of access issues under the ADA.

While the skills to be a strong lawyer and advocate may have come naturally to DeBruicker, the demands of her work have not always been easy. She says a pressure sore forced her to realize she could do anything, but not everything.

“I came out of the gate like, ‘Look I can do anything anyone else does,’” she says. “Sometimes it’s hard to advocate for yourself, but if you think about not asking for yourself and instead asking for the benefit of the next person to come along, you can make it easier for [someone else] down the line.”

Reflecting on the last two years, DeBruicker feels she made the right choice. “This feels like a broader purpose, not just pushing corporate money around. I’m in a position to do some good.”

The Other Court

As a former high school and college athlete, DeBruicker now gets her hits in playing wheelchair rugby for the Magee Eagles. She has been playing for almost 10 years, but feels like it’s a new part of her life. “I’m still not very good at it. I should probably know a hell of a lot more of what I’m doing by now,” she jokes.

While she loves the exercise and competition, the camaraderie that comes with being around people who have similar experiences is hard to beat. “It’s nice to be around people that get all the jokes — sort of the same gallows humor,” she says. Though there is one thing that reigns supreme: “At the end of a long day of depositions to go and smash into things is pretty therapeutic.”
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“light, strong, and portable”
Having been a functional paraplegic and manual wheelchair user for several years, I was used to coping with the semi-regular revolt of my body parts. I’d learned to live with sporadic UTIs, slipping tendons in my thumbs and a cranky patch of skin under my left bum cheek that occasionally likes to become a wound — usually when I’m away from home with no supplies, of course. Then one day I was blindsided by a problem I couldn’t just roll through, the one that turned my life upside down — menopause.

Now, you men who read the “M” word and kept reading, know that you are awesome. No wonder the women in your life love you! Stay with us, gents, and hopefully you will learn some things to make those ladies’ lives a little easier. And ladies — my sittin’ sisters — I know you’re still here, because you’ve either ridden “the beast” or heard dark tales of your hormonal future. Sadly, wheelers can’t always count on guidance from medical professionals regarding the “M” word, so we have to rely on each other. I talked to some menopausal wheelers who were willing to share their experiences and tips to help you get through your menopause.

Meno-what?

First, the basics — what exactly is menopause? Technically speaking, “menopause” is the point in time when a woman’s menstrual periods have stopped for a full year. It happens because a woman’s ovaries stop producing estrogen and progesterone, usually after age 45. Prior to menopause is a time called “perimenopause,” aka menopausal transition, when your periods become irregular and you can experience a wide array of symptoms resulting from fluctuating hormones. Together they comprise what we’ll call the “menopause experience.”

The bottom line on menopause is that it brings lots of hormone changes, usually over several years, and those changes affect everyone differently. Take the contrasting cases of Kathleen, a T2 para, and Lynn, whose dual C5-T8 incomplete and complete injuries result in functional paraplegia.

“You feel like you are on fire,” remembers Kathleen, a 59-year-old from California. “I didn’t mind it in the winter, when the additional warmth was not bad, but in the summer, it became quite uncomfortable.”

Lynn’s experience couldn’t have been more different.

“I had heard so many women talk about being hot all the time that I was actually looking forward to it,” says the 59-year-old from Canada. “That, sadly, was not my case.”

Regardless of your menopause symptoms, what your body goes through and the symptoms you experience are all part of the normal female aging process. Hormones regulate everything in your body, and it doesn’t take much of a change in them to alter your physical, mental and emotional state. All kinds of things can change.

“My periods got out of whack, which was not normal,” reports Norma, a T10 para from Ontario, Canada. “One of my last periods was over 38 days long and very heavy at times. It was really scary!”

Other symptoms of the menopausal experience may include changes in your bladder — often leading to more UTIs — and also depression, osteoporosis, insomnia, mood swings, heat regula-
tion issues, weight gain, increasingly dry skin and more. If some of these symptoms sound familiar, that’s because many symptoms of menopause overlap with other conditions commonly experienced by wheelchair users.

Unfortunately, there are very few studies on the experiences of menopausal wheelchair users. If it seems like your doctor doesn’t have good information to give you, that’s because there really isn’t much good information to give.

**Doctor, Doctor, Gimme the News**

I’m officially menopausal now. When I went through perimenopause, I didn’t know any menopausal wheelers, and I couldn’t find information to help me through the process. I felt isolated, alone and, sometimes, more than a little crazy. My doctor said what was happening was “perfectly normal” and the process would go on for two to 12 years. I love it when my doctors can give such concrete information on my health.

One thing that struck me when talking with menopausal wheelchair users is that most had one thing in common — their doctors never mentioned menopause to them and weren’t very helpful when the topic was raised.

“I feel like it’s dismissed by my doctors,” says Kathy, a 49-year-old quad from Northern California. “I’d like to have been more informed by my doctors ahead of time. I wish someone had given me more information on what to expect and if there are strategies to prevent or combat some of the symptoms.”

Wheelchair users and their doctors can spend so much time dealing with other issues that reproductive health is often neglected. And many female wheelchair users, especially quadriplegics, have difficulty even finding facilities that can physically accommodate them in order to get preventive gynecological care.

“It’s difficult because it seems I’m always at my doctors for a variety of things, and menopause seems to be at the bottom of the list. So it never gets dealt with,” says Lynn.

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**Fun with Symptoms**

Lynn doesn’t hesitate when asked about her worst menopause symptom. “Night sweats!” she exclaims. “I’d wake soaked with a puddle of water between my breasts, needing my husband to turn on the fan. Once I dried, I’d be freezing and would need to wake him to turn the fan off. We soon installed a fan with a remote control and I began to sleep with the remote on my chest so I could turn it off and on, almost in my sleep.”

Temperature regulation is a very common symptom. Hot flashes were also at the top of the list for Kathleen. “I had the concern of getting too hot and then having problems with dysreflexia, which raises blood pressure excessively,” she says. “I got through it with a fan next to me, a ceiling fan and, at times, a cold washcloth on my face and neck. I didn’t want to be prescribed any medication because that just causes other problems, and my solutions helped me.”

Anyone experiencing difficulty regulating body temperature who also has issues with autonomic dysreflexia, MS-related heat sensitivity or other temperature-related complications could face serious discomfort. As Kathleen and Lynn demonstrate, a little planning ahead can help alleviate the issue.

All of that waking up in the middle of the night results in sleep disruption. Many wheelers have issues with sleep quality without the complications of menopause. Between pain, spasms, medication and neurological problems, a good night’s sleep can be elusive. Waking up due to hot flashes, night sweats and other menopause-related issues can drive an already tired wheeler right into the wild world of exhaustion.

“I’ve always had a little bit of a problem with insomnia, but it seems to have gotten worse,” says Kathy. “But the frequent waking is really the most aggravating thing now.”

Whether they’re exacerbated by a lack of sleep and/or hormones, mood swings and depression are very common. We thought PMS was bad, but many of us didn’t really understand the power that hormones have over our mood until menopause. Memory issues and inability to concentrate can also be issues for many of us.

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Everyone experiences menopause and all its effects differently. Joyce, a 64-year-old C5-6 quad from Florida, didn’t notice any symptoms of menopause when it happened 14 years ago.

“I went through menopause, but it was super easy,” she says. “The only way I knew that it was happening was that my period stopped when I was 50. I didn’t feel anything!”

But Joyce has recently experienced bone breakage due to osteoporosis. She doesn’t know if it was from decades as a quad, decreasing bone density from menopause or some combination of the two. The lack of medical information has been an issue for her.

“For the osteoporosis there is no real data,” says Joyce. When doctors suggested she take medicine for it, she found a complete lack of information on possible issues or benefits for a quad taking the drug. “There’s no research to tell us if it’s even going to help us. It’s crazy.” [See “Para/Medic: Fracture Risk and Treatment Options with SCI,” April 2016]

One thing we do know is that wheelers have an increased risk of osteoporosis and that menopause increases that risk even more. Exercise can help — it can also level out your mood, decrease depression, combat weight gain and more. Women are especially at risk of vitamin D deficiency during and after menopause, and it can also affect your mood. Talk with your doctor about whether exercise, dietary changes, calcium supplements, hormone replacement and/or medication may be right for your body and lifestyle.

Weight gain is another symptom of menopausal life. It can be exacerbated by joint pain, which may limit movement, as well as by other health concerns. Kathy lists weight gain as one of her primary issues, and degenerative joint disease limits her ability to exercise. She has been working with a nutritionist and dieting for a year and a half but has not been able to lose weight.

Another issue for wheelchair users undergoing the change is skin integrity, as skin tends to become drier during menopause. It’s more important than ever to do daily skin checks and moisturize.

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**Para/Medic: Fracture Risk and Treatment Options with SCI**

“Para/Medic: Fracture Risk and Treatment Options with SCI,” April 2016
Menopause can also lead to bladder changes that increase your chances of UTIs and/or incontinence. I suddenly started getting more UTIs even though I had not changed anything in my bladder care. Hormone treatment was an option presented by my urologist, but since hormone treatment can increase the chance of breast cancer, which I had already experienced, I declined. I changed my bladder meds, increased my liquids and started using an essential oil called clary sage — and my UTIs decreased.

**Where Do We Go From Here?**

So, what’s a wheller to do? Your first step is to get educated. Understanding how your body works can help you understand and address menopause symptoms as they arise. Your doctor may not bring menopause up, so make it a priority to talk with her about it and discuss what options may be best for you and your health, whether that be medication, meditation or marathons.

“I think we have to be the ones to initiate talking to our doctors about things that we are going through,” says Kathy. “We have to initiate the menopause conversation — you have to be assertive because your doctor is not going to bring it up.”

Your education needs to include those around you as well — anything you go through affects those close to you and understanding the facts will help them cope.

“Men or partners should be educated on it as well,” recommends Norma. “I have heard menopause compared to puberty and all the talks that go around it — those talks should happen around menopause as well. It is normal and not a taboo subject.”

Don’t be afraid to try different techniques to combat your symptoms. Fans were the cooling tool of choice for many of our wheelers, but I found that applying clary sage essential oil externally twice a day kept my hot flashes at bay and seemed to help my bladder symptoms. Talk to your physician, menopausal friends and family to learn about strategies that may work for you — everyone is different, so keep trying until you hit on what works.

And go easy on yourself. Menopause is a normal part of life that you have limited control over — just try to find strategies that make you feel as healthy and happy as you can.

Kathleen sums it up best, “Get adequate sleep and love and enjoy the changing new you!”

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**Resources**

- “How Does Menopause Affect Women with MS?,” everydayhealth.com/multiple-sclerosis/symptoms/menopause-women-with-ms
- “Menopause and the SCI Woman,” mobilewomen.org/2016/04/menopause-and-sci-woman.html

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Lately I am less willing to go to friends’ and new acquaintances’ homes, mainly because so many of their bathrooms are not accessible or the rooms are too crowded with furniture and other obstacles. I feel uncomfortable when I’m visiting because of being limited in my choices of where I can and can’t go in my wheelchair. In my younger days I would go visit anyway, probably because I was more adventurous and had not yet grown weary of the continuous hassle of inaccessibility. Now, after decades of running into the same problems repeatedly, it seems I usually decline when invited or make up some excuse, like I’m too busy or not feeling well or need to go to bed early. Afterwards, though, I don’t seem to be able to avoid feeling bitter and resentful about my friends having wheelchair-unfriendly homes. But instead of speaking up, I swallow my feelings.

Recently a situation came up that brought the issue to a head.

A longtime friend invited me to his home to celebrate his 25th wedding anniversary. Several couples had been invited, and a dinner was to be held in their backyard area with one long table to set out on the lawn, as usual. They prefer the same setup for any special occasion, and their circle of friends has grown to expect it. I knew the table would be too low for me to roll under, as always, which would mean an awkward eating situation with me spilling food in my lap. Plus the thick grass makes rolling in my manual wheelchair almost impossible. If I had to cath, I would have to make do with an empty bottle in some out of the way corner of the yard with no running water. Worst of all, if I needed to use a bathroom, I would have to be hauled up a difficult staircase in my wheelchair by two people, a risk I am no longer willing to take.

Even though I had been a groomsman in their wedding and wanted to be there for them, I could not honestly bring myself to RSVP because I knew it would all add up to one more long uncomfortable evening. When my friend called and asked if I would be able to make it, I said I was sorry, but the whole setup just isn’t comfortable for me any more — it’s harder and harder to have a good time. I should have told him I’m no longer willing to risk the humiliation of having another bowel accident at a social gathering, but I left it at that. My friend called back a couple of days later and offered to set up a card table that would sit higher at the end of the long table. I thanked him but declined. The flimsy card table never has worked that well and I had even inadvertently knocked it over a few times. I just couldn’t do it one more time.

Afterwards I felt guilty declining their invitation — until my girlfriend reminded me they could have easily offered to move the long table to the nearby concrete deck or inside, where the legs could have been propped up a couple of inches, or they could have offered to move the celebration to a different location, like an accessible restaurant or someone else’s home.

It has been two weeks and I haven’t heard from them, but it seems we crossed an invisible line and there is no going back. Did I do the right thing, or should I have swallowed my pride and gone to their celebration feeling like a second-hand friend?

Welcome to the land of private ownership, where homes are regarded as personal castles and no law can change the right of a homeowner to ignore or deliberately choose not to follow principles of universal design. We are stuck with it, unfortunately, and how our friends respond to our needs — or don’t — too often threatens the limits of our friendships, both in how far they are willing to go to accommodate us, or how much or for how long we are able to tolerate feeling left out or slighted.
At this point the real issue is how much you value their friendship and what you are willing to do about it. It seems your true feelings have been building up over time, and you have kept them mostly hidden. If you want the friendship to continue, reach out to them soon and explain fully how difficult it has been for you for some time now, and that it isn’t getting any easier. They may not have realized just how inconvenienced you have felt, how aging has made your disability harder to deal with, and how difficult it has been to articulate how something as common as an inaccessible bathroom can lead to a kind of humiliation that few people truly understand.

If you want to take the high road, you might offer to treat them to a special dinner at a nice accessible restaurant in honor of their belated anniversary. Or you could float your girlfriend’s suggestion to relocate the table to their concrete deck for a shorter get-together — but only if you are willing to accept the lack of a bathroom. You might rather go “all out” and help them research and develop other restaurant options for future gatherings where a choice of venues could appeal to their other friends as well. You do the work; they make the choice. In this way, you will be demonstrating your willingness to keep a valued friendship intact as well as establish your need for independence and autonomy.

But what if they are unwilling to take you up on your offer because they prefer to eat in the comfort of their own surroundings? That would leave you with a very difficult choice. But before closing the door to future dinners, would you be willing to host them and their friends in the comfort of your own home? If so, then offer. If they still prefer to always play the role of the default dinner party host in their inaccessible home, then perhaps the time has come to let them go their own way.

We don’t like to admit it, but friendships change over time, and it isn’t unusual for good friends to gradually fade out of each others’ lives. Whatever you do, it is always best to be honest with each other, no matter how your differences may have altered things. In this way, a difficult decision can function as a maturing experience for both of you, something of value. Also, remember that it is still possible to maintain friendships that don’t always center exclusively around social gatherings. Of course, expecting your friends to make any major architectural change in their home to create accessibility for you alone would be asking too much. Their castle will always be their castle, but it doesn’t have to be the only choice in the kingdom. Perhaps over time, if you stay in contact, they will consider in their advancing age that making architectural changes is the smart thing to do sooner rather than later — for everyone’s sake.

Send your ethical dilemmas to Tim Gilmer at tgilmer@unitedspinal.org.
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NATURE’S CONFERENCE CALL

On a business trip to New York City, a coworker literally grabbed my wheelchair and said we were heading out to lunch. In about two city blocks, we ended up at an Italian restaurant with a couple of steps out front. The wait staff brought out a ramp and I rolled in. So far, no issues, except I never got the chance to use the bathroom before leaving work.

Sure enough, halfway through lunch nature calls, and there is no way I’m making it back to the office. I checked the restrooms and they were not accessible. I couldn’t fit through the men’s room door at all, but I could fit into the ladies’. One of the wait staff stood outside to make sure I wasn’t interrupted, but I still couldn’t reach the bowls inside any of the stalls. Luckily, I have a urinal bag in my backpack, just in case of an emergency like this. The next problem was where to empty it, since I couldn’t reach any of the toilets.

With the attendant knocking on the door to let me know my time was up, my focus shifted to the sink. As George Costanza famously said after it was discovered that he regularly pees in the shower, “It’s all pipes, what’s the difference?”

THIS WHEELIE HAPPENED

My very first meal out after leaving rehab was lunch with my mom in a crowded restaurant. We were both pretty nervous initially, but things seemed to be going well as the food arrived. I began rocking my casters up and back, practicing the little wheelies I had only started to master that week.

Mindlessly, I got a little overzealous, thinking my trusty tip bars would have my back. They didn’t. Not only did I flip myself completely over, but I managed to upend the table with the force of my legs in the process. As I hit my head on the floor, food and dishes rained down around me.

The bustling restaurant went dead silent. Everyone turned our way. From the tile floor, I could see my mom’s face, completely white, and obviously worried that I’d bought myself a one-way ticket back to rehab. Behind her, a piece of blackened catfish slowly slid down the wall. I started laughing.

Aside from a slight bump on my head, I was fine. Our waiter looked more relieved than either of us, clearly glad he wouldn’t have to dispose of a body in addition to clearing the table. In fact, in his hurry to get us out the door and move on, he forgot to bring us the bill, and we never paid. Most of the food did end up on the floor and walls, but still — a free lunch ain’t all bad.

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