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Cover Photo by Loren Worthington
with Assistance from Estefania Cavazos
RELATIONSHIP PROBLEMS

I’m not a big fan of making adjustments to my wheelchair.

Like many of you, I spend 14-16 hours sitting in my wheelchair every day. The difference between feeling comfortable and making it through the day with no skin issues or fatigued muscles often comes down to adjustments of a few centimeters.

In my dream world, properly setting up all the components and configuring all the measurements would be a one-time deal — “set it and forget it,” to borrow from legendary TV pitch man Ron Popeil. Of course, that’s an impossibility. Parts break, bodies change, needs change.

Years go by with everything working perfectly, body and chair in harmony, each pushing the other to new places. The chair becomes an extension of you, and you find yourself wondering how you ever lived without it. You tell all your friends about this cool thing your chair helped you do, and you plan special excursions just for the two of you. Even though you know you can’t really afford those carbon fiber rims or the newest Frog Legs, you make sacrifices, because by god, you love that chair.

Then one loose bolt or one tiny crack in the frame changes everything. What seems like a small hiccup metastasizes into a slew of new problems. Your physical therapist does their best to fix things, but the problems persist. The smooth ride you’d savored for all those years grows bumpier and bumpier. Your pristine new chairs start wobbling, and hard as you try to keep going straight, your chair slowly drifts away from you.

Before you know it, it’s hard to even remember the good times. Gone is the feeling of safety your chair used to imbue. Now all it engenders is wariness. When you roll out of bed, you eye your cushion with doubt — is today the day you’ll betray me?

You catch yourself looking at other people’s chairs lustfully. Your chair doesn’t say anything, but you both know it’s over. Maybe you tear up a little thinking about the good times — that late summer’s roll through the park, that time you killed it together on the dance floor at Megan’s wedding. But distant memories are no salve for bumpy rides, and the simple fact is you can no longer see any future together.

“You catch yourself looking at other people’s chairs.”

Finally, you make the call. You tell your therapist you’ve exhausted all the avenues you can think of. Maybe there is someone else out there for this chair, but you two are done. You are ready to start trying out new chairs, particularly that cool new ultralight with the sleek design. You’ve even started dreaming about how you might look in it, and how nice it will be to throw its lighter frame in the backseat. Dealing with all the ups and downs of the last few years, you realize you’d forgotten what it feels like to be excited. Looking at this new chair has you feeling alive again!

At the seating clinic, your therapist looks at your paperwork. It turns out your insurance won’t pay for a new chair for another two years. And about that ultralight? Sorry, your plan doesn’t cover that.

You feel your heart drop. It sinks below your level of sensation to a depth you haven’t felt in years. Thoughts of duct tape fixes replace the beautiful future you’d dreamt of with your new chair.

As you slowly push your old partner back to your car, the dents in the rims remind you of all you’ve been through. You’ve been here before, you can do this. Only two more years...
When Seth McBride turned in the first draft of this month’s cover feature on online dating, he did so under the pen name of “The Married Guy Who Has Never Used a Dating App.” Looking back, he says his outsider status may have actually helped his reporting. “It gave me a good sense of the big picture because I had more distance from what people were going through,” he says. Reading through all the survey responses and interviewing people gave McBride a deeper appreciation of the complexities of the modern dating world. “People definitely need a strategy,” he says. “Reading all the surveys and talking with people showed that there were a lot of commonalities in terms of what worked and what didn’t, and those are what I tried to focus the article on.”

How do you go about comparing an award-winning foreign film (The Intouchables) and its critically-drubbed Hollywood remake (The Upside)? Our Allen Rucker set aside an evening, pulled up one on the TV and the other on his computer and broke out the popcorn. “Back-to-back is a wonderful way to watch movies because you can see what’s good and bad about both of them,” he says. “One felt like the writers knew what it’s like to be a quad, the other felt like they read a book about being a quad.”

Emily Rose Yates didn’t know anything about Risna Utami before starting this month’s profile, but she discovered a kindred soul. “Risna is dedicated to empowering women with disabilities, especially when it comes to sex and relationships, and that is one of the issues I’m most passionate about,” says Yates, who works for Enhance the UK, a nonprofit focused on changing the way society views disability. “To hear someone from across the world talk about sex and disability was great.”

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
A Lovely Reminder
Wow, what a beautifully written article (“"Doing Life: Pushing Beyond Fear," December 2018)! One day I would love to meet Kenny Salvini. He is one of my heroes. Thank you for this wonderful article that gives insight into your struggles and victories and what determination can accomplish.

Marna Peterson
Newmobility.com

Doing Great Things
What a wonderful story about Habitat for Humanity ("An Affordable Path to Home Ownership," December 2018). They certainly can do great things, especially for those that need wheelchair accessible homes.

David R. Coffield
Newmobility.com

Encouraging Progress
Way to go Habitat ("An Affordable Path to Home Ownership," December 2018)! These are encouraging stories of what can be done to include universal design features in an affordable house that accommodates people who use wheelchairs.

Rosemarie Rossetti
Newmobility.com

Gawker Addendums
How about these additions to the "Gawker Classification System," (Bully Pulpit, December 2018):

Hot Damn, He’s in a Chair: 7 — These individuals are checking you out, but then glance down and look away.

Over-helpers: 9.25 — These people tend to go out of their way to make a big production over helping you. For example, a guy driving a good 100 feet from me as I’m going in or exiting a store who insists on stopping everything to let me go by. If he would have gone by, things would have proceeded flawlessly.

Ashamed Parkers: 10 — This is a common species rocking a disabled placard from when Aunt Flo had hip surgery. When they see me exiting my vehicle with my chair in the access lane, suddenly they remember they are parking illegally. While most nod and hang their heads, the talented ones develop a limp! All-stars.

Joseph Barrett
Newmobility.com

Pretty Frustrated
I thought I was the only one that gets annoyed at the ignorance of people ("Gawker Classification System," December 2018). Over 20 years in a chair and it still gets to me at times. Thanks so much for sharing this with us! I have an addition, “You’re pretty! What are you doing in a chair?” Eye roll.

Melissa Veale
Newmobility.com

Priced Out
This is a great idea for people who have little functional movement below their shoulders ("New Tech Allows Users to Drive Wheelchairs With Facial Expressions," Newmobility.com, Dec. 28). The only two drawbacks are the difficulty for those who have spasms that create problems with facial movements and the cost of a $300 per month subscription. Really?

Deborah Gregson
Newmobility.com

Saska-licious!
[Kary Wright,] you are so creative ("A Berry, Berry Big Find," December 2018). Picking saskatoons is one of my favorite things to do as well, and when the harvest is as bountiful as it was this year and the year past, a person tends to get a lot of berries! What did you do with your berries? Jam? Pie? Ice cream topping? I ask this because I have bags and bags of frozen berries. Seems I am really good at picking them but not so good at doing anything with them!

Sue Wiberg
Newmobility.com

Kary Wright responds: Lately we have been dehydrating them, as the flavor in these “raisins” is so concentrated it is awesome. Then we add them to nuts for a trail-mix snack.

Oscar-Worthy
After reading Mike Ervin’s article “Very Special Effects” in the December 2018
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**NEW MOBILITY**, I had to dry the tears from the article after my uncontrollable laughter. I am a fan of many movies over my short time on our earth, 66 years. I’ve lived with my spinal cord injury for 51 of those years, after a high school wrestling accident. I’m a C5-6 quad cripple, using Mike’s vernacular. After seeing the few movies in 2018 that were worth watching, no more superheroes for me please. I would recommend that Mike inaugurate his movie writing, directing and acting career. I would like to go out on a limb and highly encourage Mike to headline as the main actor portraying himself. I’ve seen Tom Cruise acting like one of us SCI folks and believe me, he tested my patience. No expensive special effects are necessary. Mike, you would be nominated for an Oscar in the best writing, picture, director and actor categories.

**Stephen C. Grams**
St. Peter, Minnesota

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**People Don’t Get It**

Thank you, Seth McBride (“Mainstream Epistem Coverage and the Obsession With Walking,” December 2018). The majority of the public thinks using a wheelchair is abhorrent. Few understand the freedom it gave me to be independent again. It’s the old comment, “Oh my dear, I used one for four months when I shattered my leg skiing.” My politically incorrect reply is, “How is your bowel and bladder program now? Still using catheters to urinate and suppositories to empty your bowels?” (With overt sweet, sarcastic tone and smile.)

**Lois West**
Via Email

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**An Ounce of Prevention**

This is a good article but, more importantly, there should be mention of ways to prevent all of this ("Where to Turn When Wounds Won’t Heal," October 2018). Talk about an ounce of prevention is worth a pound (or tons) of cure! There are many little things that can and should be done to at least minimize the chances of getting a pressure sore. First off, and hopefully obvious, is to protect your skin at all costs. We all want to be active and live a full life, but also be mindful that certain activities are hazardous to your skin. Is it worth it? Make sure you factor in the “worth it” angle. Months in bed recovering from a wound is not really worth it in my book.

Also, once you experience a wound, your skin is never the same. You are much more likely to get another wound and sooner. Next, remember that your skin gets more fragile as you get older. Actions you took in younger years and got by with now become more risky to your health. Make sure you realize that your skin isn’t as resilient as you get older and act appropriately.

Third, the proper equipment, chairs and cushions are critical! Make sure you are using a cushion that provides the protection you need!

Lastly, everyday actions can incrementally work against our healthy skin. Small “traumas” every day can gradually break down our skin, especially as we continue to age. I have been using specially-constructed underwear from a place called GlideWear that provide a seriously slippery “anti-friction” seamless construction against my skin every day. I love them! Every time I transfer, the few movies in 2018 that were worth watching, no more superheroes for me please. I would recommend that Mike inaugurate his movie writing, directing and acting career. I would like to go out on a limb and highly encourage Mike to headline as the main actor portraying himself. I’ve seen Tom Cruise acting like one of us SCI folks and believe me, he tested my patience. No expensive special effects are necessary. Mike, you would be nominated for an Oscar in the best writing, picture, director and actor categories.

**Dick Crumb**
Newmobility.com

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**Corvette Confusion**

Great article (“Collector Cars,” Motivation, October 2018)! It would be really helpful if all of these folks would post videos and/or descriptions of their methods to get themselves and their chairs into and out of their vehicles. Most of them are kind of obvious, but having been in a Corvette, I can’t figure out where Jemal puts his chair.

**Jason Potts**
Newmobility.com

*Editor: Jemal says he generally puts his chair in the passenger seat, but it will also fit in the hatch if it’s disassembled.*
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THE NEW YORK TIMES DISABILITY SERIES GIVES DISABLED WRITERS A PLACE TO SHINE

In August 2016, The New York Times kicked off a new weekly opinion series dedicated exclusively to publishing essays by disabled writers. Its first offering was “Becoming Disabled,” by Rosemarie Garland Thompson, a foundational voice in the field of disability studies. She mined her personal experience to explore themes from societal perceptions of disability to the disabled community’s lack of a collective identity to whether being disabled is a physical condition or a mental construct. “The one thing most people do know about being disabled is that they don’t want to be that,” she wrote, making it clear from the beginning that the “Disability” series, as The Times would call it, was going to delve far deeper into the disability experience than mainstream media typically does.

Over the next two years, the series published essays by a mother with dwarfism who reflects on the passing of her disability onto two of her children, an incomplete spinal-cord-injured Rhodes Scholar whose professor suggested that he may have played the pity card to win the prestigious scholarship, and an eighth-grader with muscular dystrophy who authored a children’s book, only to have publishers reject it because the wheelchair-using main character was too happy.

There are dozens more like this, essays that pull you out of your own perspective and give you a view through someone else’s. Reading the archive of the “Disability” series is a lesson in the sheer size and diversity of the disability community — including those with mobility, visual, auditory and cognitive impairments — and also the breadth of talent and experience it fosters.

The Inner Workings
The series was born out of a 2016 meeting of The New York Times op-ed staff. Peter Catapano, an editor with the paper since 2000, pitched a series of essays written by and about people with disabilities. Through the course of his work at the Opinion Section, he’d managed various special projects featuring voices from specific groups, from members of the military to people with anxiety — “people who have unique personal experiences,” Catapano says. “I was really struck by the lack of voices in the mainstream media. Editorially, I thought it was something important to cover.”

Ben Mattlin is a freelance writer and the author of two books whose work has appeared in a variety of major media outlets, including New Mobility. He has written two essays for the Disability series, in addition to a number of other pieces for The New York Times. Mattlin, who was born with spinal muscular atrophy, sees the Disability series as a good example of the media’s slowly changing attitude toward disability and disabled writers. “I think it’s gotten easier,” he says of getting disability-related stories published. “In the old days, you really had to prove to people that there was a story besides the medical perspective. [The media is] a lot more open than it used to be, but it still has a long way to go.”

“I believe that having people with disabilities as integrated members of the newsroom and on staff is crucial. These things get better when they are involved in day-to-day operations.”

Mattlin is a bit conflicted about the premise of a special project on disability, wondering if it’s not “ghettoizing disability perspective.” That’s a valid concern, one anchored in the tendency to try to put disability in its own box, rather than view it for what it is — an interconnected piece of the human experience that affects all members and all aspects of society. “I feel like if I submit a piece to The Times, it’s assumed it has to fit into the disability column,” Mattlin says.

Catapano agrees that the disability perspective should be better integrated across the media, an issue that often comes down to employment. “I believe that having people with dis-
abilities as integrated members of the newsroom and on staff is crucial," he says. "These things get better when people with disabilities are involved in day-to-day operations."

New media outlets like HuffPost and Teen Vogue have done a good job of bringing on contributors with disabilities, but it will take more staff positions at media outlets from large to small that better reflect the demographics of disability in America before we start to pull disability out of its box. "Disability perspective is a human perspective," says Mattlin. "Our news is relevant to everybody."

The Bullhorn
This NM column spends enough time dissecting the various ways in which media botches coverage of disability that it's refreshing to have a series like this to hold up as a positive example. And what The New York Times has gotten right with "Disability" is as much about who is doing the writing as what they are writing about. Catapano describes the project as "a platform for people with disabilities to speak about themselves instead of having others write about them."

There have been writers with disabilities who have made a mainstream name for themselves and had their work published in the most famous media outlets in the country, but they are rare, and there has never been an instance where so many voices from the disability community have been given such a powerful microphone to talk specifically about issues related to disability. Their essays show that disability touches all aspects of society. For mainstream media outlets, a series like "Disability" should be one step in the march to include disability perspective in all manner of coverage.

"Disability" finished up as a weekly series at the end of 2018. It will continue publishing essays, though on a more intermittent basis. A book, About Us: Essays from The New York Times Disability Series, is scheduled to be released later this year. The New York Times has proven that there's already a vast talent pool capable of producing quality, disability-centric content and an audience to consume it. If other media outlets would like to make their coverage more reflective of the way disability affects the human experience, we're sure the National Center on Disability and Journalism would be happy to help.

Resources:
• National Center on Disability and Journalism, ncdj.org
• NYT "Disability" series, nytimes.com/column/disability
TYLER SCHRENK INVENTED HIS WAY TO INDEPENDENCE

Tyler Schrenk is the force behind The TSF, a foundation that provides assistive technology and support for quads like himself and others with disabilities to live in their own homes as independently and affordably as possible.

"The goal is to help pass along some of the knowledge I have learned to be independent because it made a huge difference in my life, changed my world and is something I can do to help other people," says Schrenk, 33. "It gives me purpose and helps me interact with the world again."

Under Schrenk’s direction, The TSF teaches how to use an iPhone to interact with a power wheelchair, an Xbox One with Kinect to control a television, a Wemo Outlet to turn lights on and off with a phone, and so on. The focus is on finding ways to use off-the-shelf affordable products to enhance independence. Schrenk offers tech support personally: “I’ll set it up locally or via Skype. I’ve helped people in Europe as well as the United States so they can use these tools once they have them.”

Schrenk has discovered ways to use everyday tech to solve huge problems, such as coughing independently. As a C1 quad, he’d been told he would always need a caregiver’s help to cough, but then he thought, “If I could control a lamp, why not a cough machine?” The components are an inexpensive smart outlet and an Amazon Echo. Keep the machine turned on and plugged into the smart outlet, and then use Echo to toggle it. Mount the facemask somewhere you can roll up to easily, and boom — you now can cough independently.

Follow TheTSF.org and search for Schrenk by name in YouTube to learn more about him, his foundation and his techniques.

THREE NEW WHEELCHAIR-FRIENDLY WINNEBAGOS

Already known for being wheelchair-friendly, Winnebago has topped itself. The RV giant has launched three accessibility-enhanced motorhomes: The Intent 30R AE, Adventurer 30T AE, and Forza 34T AE. These models feature standardized floorplans that are designed with wheelchair users in mind. The company hopes this will lead to enough sales to allow the costs to come down over time. Check them out at winnebagoind.com.

LIVE WELL

By Josie Byzek

ZUMBA WITH CARINA A. ORTIZ TORO

Carina A. Ortiz Toro, 35, says she is shy and has been her entire life. So how did she end up on stage leading Zumba classes as the only wheelchair-using instructor in the Caribbean? "In 2013, I went to a gym for the first time as an adult and started training and participating in the group Zumba classes," says Ortiz Toro, who has spina bifida and lives in Lajas, Puerto Rico.

Soon she was a regular at Zumba events and in 2016 decided she wanted to be on that stage leading the crowd. And by doing so, she made history.

"The day I went to take the instructor training, I found out that I'd be the first, and so far only, disabled Zumba certified instructor in Puerto Rico and all the Caribbean," she says.

Currently she guest-teaches during other instructors’ classes a few times a week and it’s going well. “Because I like to move a lot, people say, 'You almost kill me, but I love it!' There are some classes that are too slow or too fast and you get lost and don’t enjoy it,” she says, explaining that she aims for a happy medium. "I want people to sweat, but it’s not just exercise. It's having fun, having a great time — it’s a combination of both."

Ortiz Toro hopes to have a class of her own and is especially interested in possibly leading a class for fellow members of the Puerto Rico chapter of United Spinal Association and for people with all types of disabilities as well. Follow her at facebook.com/carina. ortiztoro.
For more information on how you can support United Spinal and become a corporate member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
Everyday Ethics takes a deeper look at the options we have when confronted with disability-related dilemmas that present more than one potential resolution. Often when a conflict is involved, our first impulse is to act solely in our best interests, because where disability is concerned, lack of awareness can lead to misunderstanding, misrepresentation of our real needs, or outright bias. But viewing these situations through a lens that weighs multiple viewpoints fairly can result in a more satisfying, lasting outcome for all involved — and that is the purpose of this column.

Q. I’m a caregiver for a C6-7 quadriplegic who has been living interdependently for about 10 years. I’ve been with her going on two years, and a week ago something happened that has caused me great concern. I’m not certain I did the right thing.

Claire had a doctor’s appointment that morning, so we started off with a shower, a routine we do regularly. While I was bathing her, she unexpectedly listed to one side, had to be supported, and suddenly seemed uncharacteristically weak. I even thought she might pass out. We were near the end of the shower, so I helped her get upright and into bed as quickly and carefully as I could. Usually she does what she can to help, but this time she lacked the strength.

Once in bed, she told me this sometimes happens when her bladder drains all at once and her blood pressure drops, but she still looked woozy and weak. I had never seen her like this before. She went on to say that she just needed to get something to eat and take a pill and she would be fine. But I couldn’t help thinking that had I not been there, she would have fallen off the shower seat. This especially concerned me because she was planning to drive herself to the doctor’s office, and her usual routine is that after she has been helped into her van, she drives herself; then when she arrives at her destination, she waits for someone to help her. I’ve seen her do this many times, but never in this condition. I couldn’t help imagining all kinds of dangerous scenarios.

I told her I would be happy to drive her to the appointment for no charge. She said all she needed to be safe to drive was food and a pill and I need not worry. By now she was in a hurry to get there on time. I repeated my offer to help, but she declined again. I asked her to look me in the eye and tell me she was OK, but she wouldn’t, and even made a joke about it.

After she took her medication and ate, I helped her into the car, giving more help than usual. She was slightly better but still looked weak. I felt guilty about letting her go, but I had to do what she wanted. I couldn’t force her to let me drive. As it happened, she got there OK and returned without help, and nothing happened. But I’ve been feeling guilty that I didn’t do more. Did I handle the situation properly? Is there something else I could have done? What if it happens again?

Our concern is certainly warranted, and the questions you bring up are worthy of careful consideration. This might be an appropriate time to look at your duties and responsibilities as a caregiver through a broader lens.

Independently functioning wheelchair users who hire caregivers often consider them to be personal attendants since their duties are mainly involved with helping, not overseeing or managing (as is the case with some elderly or cognitively impaired persons). Claire’s purpose in employing you is most likely to maintain her

“...It is not unusual for anyone, disabled or not, to downplay their need for help, whether out of pride, denial or momentary lack of judgement.”
independent lifestyle. But there is an unspoken ethical responsibility that each of you will do well to consider. While your duties may seem mundane, the well-being of your employer is a legitimate concern of yours. When independent living — often based on an interdependent relationship — is absent any concern for well-being (on the part of both parties for one another), it can resemble a dry routine that lacks deeper purpose, and at times may feel cold and mechanical. The best relationships are built on a careful balance of mutual concern, trust and respect for boundaries.

That said, it is vitally important that your concern for Claire’s well-being must never cross over into obsession or paternalism. She is the expert when it comes to matters of her health. However, you can be a kind of backup presence. For instance, she knows the signs and dangers of potential pressure ulcers, but she may not be fully aware of certain parts of her body. The two of you must have a prior understanding of how you may be able to help. The scenario involving weakness and low blood pressure is a similar matter. Now that it has happened, this is a good time to ask for further direction on how to proceed should it happen again.

But what if her behavior indicates she is not fully aware of the potential danger? There is a fine line between respecting her autonomy and voicing legitimate concerns about her decision-making when her physical health may be at risk. It is not unusual for anyone, disabled or not, to downplay their need for help, whether out of pride, denial or momentary lack of objective judgment. In this case, your dilemma was especially difficult because Claire seemed to know how to handle this situation, and even said that she had done so before, while at the same time your senses were giving you a conflicting impression. Bottom line: She had the right to exercise her will, both as an individual and an employer. But you were right in bringing up your concern.

Did you go too far? Perhaps. Repeatedly questioning her may have verged on paternalism, but you did the right thing by giving in to her judgment. However, that might not be the best course of action if it happens again. In this instance, three things happened that most likely influenced your final decision, perhaps subconsciously. She did what she said she must do — eat and take medication; she joked about the situation; and she showed improvement, however slight. In other words, she was on the right track.

But what if she had passed out and had an accident en route to the doctor’s appointment? Or what if no one had come to help when she arrived, or she had fallen in the process of getting out of her car? In discussing how to handle future incidents, you could suggest that she might call ahead, tell them she will be late, then rest until she is better.

Still, the question of what causes the weakness in the first place remains unresolved. Is it your place to mention this? Respectfully, you might suggest that you take her blood pressure at times when similar weakness shows up; the two of you could then discuss what to do with that information. There are a number of potential causes of sudden low blood pressure. Besides urological issues, it could be related to her medication, or there might be a link to dehydration. Whatever triggers this condition, the best outcome of all would be to pinpoint the cause, perhaps with help from a doctor, and take action to correct it.

 Whatever you do, know that your responsibility is to help, not manage, always with her well-being in mind. This kind of approach will not only relieve your guilt, but be of valuable service to Claire — and the end result will be a strengthening of your relationship.

Send your ethical dilemmas to Tim Gilmer at tgilmer@unitedspinal.org.
Since being shot 12 years ago, Christopher Johnson has learned to focus on solutions and be comfortable in situations where others might be uneasy. Those skills have helped him become a successful real estate agent, medical dispatcher and a leader of the Greater Boston Chapter of United Spinal Association.

Johnson is a licensed EMT and has spent the past nine years working for Boston Emergency Medical Service as a dispatcher, answering 911 calls and providing assistance while an ambulance is in route. His most rewarding calls are the ones in which he instructs a caller through the process of safely delivering a baby. These life-and-death situations are where his skills and expertise are most vital. "I've done quite a few baby deliveries over the phone," he says. "On one call, the newborn had a nuchal cord, where the umbilical cord is wrapped around the neck. The caller was extremely calm, and I was able to instruct her to gently remove it. It worked out."

Johnson's life as a paraplegic began on the other end of a 911 call. After sustaining a gunshot wound, he required emergency care and assistance to survive. During his recovery, Johnson learned that his spinal cord injury would not be the most difficult hurdle to overcome. Figuring out how to move forward and live again was the most grueling challenge. Johnson says he remembers spending a lot of time sitting with his friends and family, reminiscing about everything prior to his accident. "Remember when we did this, remember when we went there," he says. "I recall literally telling myself, 'I'm tired of saying remember when. I have to get out there and create new memories and find things I can do.' So that's what I did."

At the suggestion of Kenneth Mumford, a fellow gunshot survivor who ran Boston's Wheelchair Sports and Recreation Association, Johnson joined the New England Blazers wheelchair basketball team. He then interned with an outreach and advocate training program through the Boston Public Health Commission and, after going through EMT certification, found a career as a dispatcher with Boston EMS.

He likes the job, providing instruction and talking people through stressful situations and sometimes being able to give people "a second opportunity to live." One thing he's taken away from nine years as an EMT? "Just try to remain calm no matter what. Don't panic. Regardless of your situation, panicking never helps," he says. "Instead of focusing on the problem, focus on the solution."

That solution-based approach helps Johnson push his boundaries on a regular basis — whether it's taking up scuba or diving into a second career. Johnson often works the graveyard shift.

**How We Roll**

**Medical Dispatcher/Real Estate Agent**

**Christopher Johnson**

Saving Lives

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**Favorite Vacation Spot:** Rincon, Puerto Rico. It’s a beautiful island with beautiful people and Rincon is a very peaceful place.

**Can’t Work Without:** Most dispatchers use a foot pedal to transmit over the radio. I have something like a space bar that sits on a platform that I can use with my hand.
shift as a dispatcher, and he recently decided to get a day job as well. About a year and a half ago he got his real estate license. When he started that process, he said friends in chairs would ask him, “How are you going to show properties if there are stairs or whatnot?” Johnson knew it might not be easy, but that he’d figure it out. “I have a friend of mine come along to pull me up the stairs, or if it’s a narrow or windy stair case, they’ll carry the chair up and I’ll bump up the stairs.”

The first year was rough, as he gained experience and learned the ropes, but Johnson sold four properties and has a fifth under contract. “It’s been going well,” he says. When asked if he recommends either real estate or dispatching to other wheelchair users, he brushes the premise of the question aside. “I would recommend that anyone in a wheelchair do whatever they want to do,” he says. “Choosing a career path that’s not necessarily wheelchair-friendly is just a matter of what you’re willing to put yourself through. I’ve always told anyone, whether your disabled or not, ‘Become comfortable with being uncomfortable. That’s where you’ll begin to see yourself grow.’”

Johnson first got involved with United Spinal Association as a peer mentor before moving to an outreach advocacy position where he helped pioneer a program to help connect people with SCI to whatever resources they may need to live in the community.

“I would go out into the community to meet at-risk individuals who may have fallen through the cracks of the healthcare system. One of our main hospitals, Boston Medical Center, had just shut down its spinal cord injury floor and a lot of people were getting sent to nursing homes and kind of scattered about. I helped a number of people to get out of nursing homes. There was another lady who was in a nursing home and she didn’t have a wheelchair she could operate on her own. We were able to secure a grant and get her a power wheelchair. We were also able to help secure housing for a couple of other guys in Boston. Beth Weaver, the director of the chapter, was extremely instrumental in working with me and eliminating red tape so these individuals could get the services and the products they needed. We try to just meet them in the community where they are and be a resource and help them not to feel alone in their situation.”

WHEN I'M NOT WORKING:
When I’m in Puerto Rico I’ll do water sports — kayaking, jet skiing, snorkeling. At home, I play basketball and I love fishing, mainly down in Cape Cod.

WHY I JOINED UNITED SPINAL: My mentor Dave Estrada asked me to come visit a kid who was a gunshot survivor. Unfortunately, he wasn’t really wanting to take anyone’s advice. I thought I was just visiting this one kid, but they asked me to be a volunteer mentor and I did.
As a 20-year-old newly-minted para, I learned how to drive with hand controls on the day I was discharged from the hospital in South Central Los Angeles. My older brother picked me up in a humongous 1965 Red Chevy Impala with first-generation hand controls manufactured and installed by a toothless veteran in his Burbank garage. I transferred from the passenger side, slid behind the wheel and pushed on a large lever attached to a telescoping rod that connected to the brake. The accelerator was activated by a smaller squeeze-style lever attached to the larger one. A wire ran from the squeeze lever to a small pulley on the floorboard and looped back to the gas pedal.

When I fired up the engine and squeezed the small lever, my brother and I nearly went airborne screeching out of the hospital parking lot. In those early days, windows were useless to me. I was in heaven just cruising the L.A. freeways with my hair flying and the acrid air stinging my eyes. If I needed to freshen up with a clean-air bath, I drove the Pacific Coast Highway, pretending I was the captain of my boat-like Impala. Either way, the reward was in the journey. There is nothing like rediscovering the freedom of movement after losing it.

Last year, 2018, took me back to the hospital days of 1965. Six months of bed confinement led to shoulder problems and loss of strength that robbed me of my ability to transfer into my minivan. Up until then I’d been fortunate in not having to purchase an adaptive vehicle with lowered floors and a lift or ramp. A stock vehicle had always worked for me.

I graduated from those early Chevy rides to stock minivans when they first came out in 1984. Then came my supercrip days as a community college instructor/freeway flyer/farmer. I would transfer several times a day in and out of a Ford F250 Supercab and pull my 50-pound Stainless Sportster folder into the cozy rear seating area and somehow wedge it behind the front passenger seat.

Later, as I aged, I lost the ability to make that Supercab transfer, so I stuck with stock minivans. Years passed. Decades. Heart surgery, then below-the-knee amputation compromised my strength and mobility further. Then came the latest complication, flap surgery. When I finally got the OK to get out of bed in June 2018, after nearly seven months mostly spent in bed and with no driving, I could no longer transfer into my stock minivan.

**In Search of the Elusive Solution**

After several weeks of being ferried around by my daughter in the cramped quarters of her Ford Focus, I considered my options. Everyone except my wife advised me to get an adaptive van with a ramp or lift. But no way could I afford $50,000-$60,000 for a new one — at 73, I need every penny for living expenses and retirement. Even used adaptive vans cost upwards of $20,000, and they are likely to be very well-used. So I considered a Turny seat, a seemingly simple front seat that rotates outward, slides out of the doorway and drops down for an easy transfer. Simple or not, they cost $10,000 — more than my wife paid for a used 2013 Ford Fiesta with low miles.

There’s a cheaper version that costs about $5,000 — essentially a padded transfer board that flips up at the side of your car seat and moves up and down via an electric motor. But when I visited someone who had one, I saw right away that my car door doesn’t open wide.
enough to allow me to get into position to even attempt the transfer, plus the transfer board was not all that sturdy. Next idea, please.

How about widening the door opening? I got that done, but it still wasn’t wide enough. OK, how about putting a set of low-rider hydraulics on my van so it will kneel to my geezer transfer level and I can slide right in? No soap. They don’t make them for the front of my van, and even if they did, they’d cost thousands. The question always came back to the same dilemma. How much money was I willing to spend to get something that could either raise me up five or six inches or lower my van down to my sitting level?

Being an inveterate cheapskate, I started thinking low tech. What if I could just make some kind of really sturdy, blocky cushion that I could squish into the space between the front seat and the door, so I could split the big transfer into two small transfers — the first to the new cushion, positioned slightly higher than wheelchair seat
level, and the second to the car seat? I raided my hall closet filled with dead wheelchair cushions, got out a pair of industrial-strength scissors and a roll of duct tape, and went to work.

Sorry, necessity may be the mother of invention, but some inventions just aren’t ready to be born. The space in between the seat and the door was too cramped to stuff a halfway decent cushion of any size in there. I ruled out the seat extension approach and went back to my drawing board in hopes of designing a platform with a minimal ramp that would elevate me just enough to make the transfer and still be portable. And not only portable — I wanted to be able to independently load whatever solution I devised into the van by myself while sitting sideways in the seat after transferring.

Eureka!

In a fit of genius, I envisioned a portable platform with minimal tire ramps that would assemble and reassemble in small sections. No section would weigh more than seven or eight pounds. That meant I would have to find a lightweight but strong building material. Carbon fiber would be perfect, but once again, too spendy. Styrofoam might work, but a quick trip to the nearest Home Depot brought me back to my senses. I could rip the stuff into pieces with my bare hands.

What about 3D printing? No, the printed parts would be too large and still might be heavy and unwieldy. On the other hand, wood would work if it was light — maybe — and it was something I could do myself. So I sketched out a simple design for a two-part platform made with one-by-four white pine and covered with 3/8-inch plywood. In my online search for a lightweight ramp, I found a pair of sports car mini-ramps for garage work that were made of hard plastic, but they would only raise my chair up about three inches.

No problem, I could glue two-by-four blocks to the plastic grid-like underside of each ramp and raise them to 4 ½ inches. The platform would still be...
5 inches, just a small jump from ramp to platform. But the grid on the underside did not provide sufficient surface for glue to hold the wood. OK then, what about Velcro! Yes, of course, good old Velcro always works. And it did!

I bought the materials and the mini-ramps at a cost of about $150. I sawed and nailed and Velcroed and voila! — I had my lightweight portable platform/ramp, capable of raising me up five inches and being loaded independently, by me, into my minivan.

But the maiden voyage was troublesome. Taking the thing apart and getting it situated in the back of my minivan in a way that allowed plenty of room for me to pull my wheelchair in, casters first — just roll it in and lock the brakes — was strenuous and time-consuming. It took about 30 minutes the first time I did it, and afterward I felt like taking a nap. Now what?

Could it be that the real problem was not my damaged shoulders or my loss of strength or my pocketbook after all? Could it be … oh my God, could it really be … I was a 73-year-old geezer who just couldn’t face the music?

Wife to the Rescue

A week later, sulking at the kitchen table while I stared at my laptop, my wife thrust the classifieds in front of me with a circled ad: “2003 Dodge Caravan with wheelchair lift. 93,000 miles. Runs good but kind of jerky, $6,000 or best offer.”

I called immediately. Why not? Maybe it was time to bite the bullet and get a cheapo adapted van. Maybe I could live with the jerky part. It would make life easier, save my shoulders, my dignity and my independence and not cost an arm and a leg. To my disappointment, the owner did not return my call. So I went back to my low-tech semi-portable platform with mini-ramps. If I could just gain a little strength, maybe I could make the contraption work after all.

The phone rang two weeks later. The owner of the cheapo van had been out of town. Would I like to drive by and take a look at it? “Of course, of course, I’m on my way.”

I transferred into my minivan with...
the help of my low-tech semi-portable platform/ramp. My wife loaded all four pieces into the back of the minivan for me, and off we went. When I got there and saw the van from a distance, my heart leapt. It looked pretty good, or at least in OK shape for only $6,000. I couldn’t find a good place to park, so I pulled off on the shoulder with my van sloping off on the passenger side and parked in a grassy area — the kind of compromise we all have to settle for when the perfect parking spot just can’t be found. I got out OK, no problem. Getting out is always easier than getting in.

The van, with all the sliding doors open, looked inviting. But the lift worked sporadically, there were bundles of wires running all over the place, the interior was trashed when you inspected more closely, and the bottom of the car was rusted out. My wife turned her nose up at the vehicle and minced no words: “It’s a piece of crap,” she insisted. “I would never own it. A homemade conversion.

The owner took one look at our faces and immediately lowered the price to $3,000. The drastic reduction only proved the owner knew my wife’s assessment was justified. Sorry, no deal.

To top off my disappointment, when I attempted to transfer back into my minivan using my DIY semi-portable platform/ramp on an uphill grade due to the sloping surface, I didn’t have the strength to pull it off — and fell to the floorboard. My wife helped me, I got in, and we drove home in silence.

Acceptance

The next day I called our local adaptive van dealer and made arrangements to order a Bruno Valet Plus Turny seat that would cost me $9,865 installed. It took a long time to seriously consider robbing my retirement fund to come up with the bucks, but deep down, I knew at my age I wasn’t getting any stronger and my shoulders needed a break. Maybe, after going without an adaptive van all these years, I deserved a spendy automatic seat that would make life easier. Best of all, maybe it would restore my independence.

I had the seat installed right after Thanksgiving. It’s programmable, so the movements and angles necessary to clear the cramped door space worked out just right. By the Christmas holiday I felt like a new man cruising the countryside, rubbernecking, going where I wanted, when I wanted. Sweet, sweet independence!

I know it’s probably an illusion, but I actually feel younger now. It’s amazing how restored independence affects your feelings of well-being and overall outlook. The road ahead looks a lot more inviting these days. I might even go on a road trip to prove to myself that I’ve reversed the aging process. Even if I don’t succeed in turning back the clock, I’ll have a good start on getting my money’s worth.
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These are just a few of the responses to a survey we sent out, asking people to share their experiences of dating with a disability. Reading through the 141 surveys we received, it quickly became clear that dating as a wheelchair user is as variable and individualized as every other part of our lives. One theme emerged though: regardless of age, level of function or past dating history, more and more people are turning to online dating services to meet people and spark a romantic connection.

Online dating offers more potential relationships than ever before, but brings its own unique set of considerations and challenges — from addressing disability in your profiles, to dealing with ghosting and other byproducts of anonymity, to tackling access concerns when moving a relationship from the web to the real world. To help you minimize the worst aspects of online dating and maximize its advantages, here’s what we’ve learned talking with wheelchair users who have been playing the online dating game.
To Show or not to Show?

While how much of your disability you showcase in your online dating profile may seem like a big question, it’s really not much of a debate amongst the people with whom we talked. The consensus: potential partners need to know you use a wheelchair, and they need to know on first glance at your profile. Anything else, more often than not, leads to problems down the road.

The only person we talked with who doesn’t share his disability on his profiles does so because he was getting contacted “by too many weirdos.” That’s certainly a concern [see sidebar]. For most though, dealing with the weirdos is annoying, but less of a concern than starting to develop a relationship with someone, only to have it end because of the unexpected introduction of disability.

Emily Ladau is a 27-year-old writer, editor and communications consultant who lives in New York City. When Ladau started in the online dating world, she struggled mightily with disclosing that she has Larsen’s syndrome, a congenital disability. She traces her struggles back to the media she consumed as a kid. “Disability is never portrayed as a characteristic of a desirable person. I’d never really seen it represented in media. I’d never seen myself reflected back at me in the teenage romance novels I was reading, or the movies that I would watch,” she says. “I definitely did not see myself as someone who was worthy of a relationship.”

Because of what Ladau now refers to as “internalized ableism,” she struggled to put her whole self out there, disability and all. “My hope was that I could hide it, and kind of build on other connections and a spark in personalities before disclosing my disability,” she says. “I would hide everything about my disability and I would sort of break it to the person all at once. And when you do it that way, when you treat your disability like it’s a big issue, that’s exactly how the person’s going to perceive it on the other end as well.”

For Ladau, growing comfortable with making her disability a visible part of her online profiles was a gradual process. Once complete, Ladau says things were a whole lot easier.

Corey Lovato, 31, a C6-7 quad who works as a staff attorney for the Arizona Center for Disability Law, went through a
similar progression, though for different reasons. He had a girlfriend when he was injured at the age of 19. They’d only been together a few months, but the relationship ended up lasting 3.5 years before they eventually broke up. When he reentered the dating world, that relationship had given him confidence that there “was at least one person out there who was interested,” he says.

Lovato ended up going on a few dates, first with a girl he’d known since high school, then with someone he’d met at a bar. They didn’t progress to serious relationships, but it showed him that using a wheelchair wasn’t “an immediate deal breaker.”

When he first started using dating apps and online services, Lovato says he didn’t include anything about using a wheelchair in his profiles. “I just thought, it doesn’t matter, so why should I put it on there,” he says. But he had enough experiences with people stopping communication, or offering some lame response about how inspirational he was when they found out he had a spinal cord injury and used a wheelchair, that he started putting his disability front and center in his profiles. That means a picture where his wheelchair is clearly visible as his first profile picture. It also means an explicit mention that he’s a wheelchair user because he broke his neck snowboarding, as well as an answer to an awkward but inevitable concern. “The biggest question people have is whether or not you can have sex,” he says. “So I just wrote that in there, ‘The important parts for a relationship still work.’”

The straightforward approach works for Lovato — he’s had success finding dates on the free website OkCupid, and he met his current girlfriend on the paid service Match.com. They’ve been together about seven months and spend a lot of time doing typical young couple stuff: going to see live music, going to events and festivals around Phoenix and taking road trips all over the West. When asked about advice for passing the first impression test and connecting with potential dating partners, Lovato thinks a lot of it boils down to confidence. “People are attracted to confidence. Once I figured that out, things started going a whole lot better for me,” he says. “If you’re confident in who you are, even if you’re sitting in a wheelchair, people will respond to that. If you’re self-conscious … if you don’t want to go talk to people because you’re worried about what they will think because you’re in a wheelchair, then yeah, you’ll get more negative responses. And it’s not necessarily because of your wheelchair, it’s because of your attitude about it.”

That’s solid advice, even if it’s coming from a young, straight, normatively good-looking attorney. But with the realities of the online dating world, building and maintaining confidence can require a lot of resiliency.

Dealing With Rejection, and Ghosting
Even for those like Lovato, who have success with online dating and dating in general, rejection is just something you have to learn to deal with. “Some people aren’t going to want to date you because you’re in a wheelchair, and that’s just something you have to accept,” says Lovato. “It’s going to hurt when you run into one of them, because it’s going to bring up all those doubts that you have.” But, he says, “Most of the time they don’t have any idea what your life is like, so it’s really not a reflection on how dateable you are, it’s a reflection of what stereotypes they’ve accepted.”

Caitlin Reilly, a wheelchair user for 27 years, met her ex-husband via online dating back in the late ‘90s when it was still in its infancy. Reilly says that she’s spent more of her life as a wheelchair user than not, and feels comfortable with her disability — it’s a part of her life that she knows how to manage. But when she and her husband got divorced and she reentered the online dating scene about two years ago, the experience dredged up doubts that she hadn’t felt in a long time. Reilly says she’s been ghosted — a now common practice where one person suddenly cuts off all communication — several times in the past two years. “There was one guy I went out with like three different times, and it was kind of getting serious quick and he just totally disappeared off the face of the earth,” she says. It brought her focus to her dis-
Lucian Smith, a wheelchair user and now retired accountant who lives near Philadelphia, recently got a divorce. Afterward, a friend signed him up for a Match.com profile and shortly after setting everything up, Smith was surprised by a match that came through. “She was really pretty, I’d say out of my league,” he says. “And she was in Philadelphia with a dance troupe, dancing in the Nutcracker ballet.”

Smith and the woman met up for a date in downtown Philly. Smith says she was as beautiful as she’d appeared in her profile, smart and seemed very open to the idea of dating a guy in wheelchair. “We had a great time,” he says. They made plans for a second date. Things went just as well at the start of the second date. Then, after they’d finished eating, the woman pulled a fiancé visa application out of her purse, complete with passport and supporting documentation. She told him that if they filled out the application and he signed it, when she returned to Russia with the dance troupe, he could get a visa and come back. Then they could be together and get married. “I was like, ‘Really? I don’t think I can do that on my second date after 13 years of marriage,’” says Smith. “As soon as I hedged on it, she was gone … I never heard from her again.”

Smith says he talked to a Russian woman he knew from work who told him that Russian women are often told disabled men are good targets “because they’re desperate.” A match requesting money “for airfare” or trying to get you to fill out a visa application most likely isn’t doing so because of unending devotion to you.

Caitlin Reilly has also learned a few things about dealing with scammers on online dating services. “They pull at your heartstrings,” she says. “One guy was a widower, really handsome and he also lost his daughter in the same accident as his wife. So me, bleeding heart, I’m like, ‘Oh my god.’” They started messaging and then texting back and forth. Then one night she got suspicious when she asked him to video chat. He claimed it wasn’t working on his phone, and they had a phone call. “He told me he was from Texas originally, so I expected him to have a southern accent. But he clearly had a British accent.” She cut it off right there.

Reilly says other things to watch out for are military profiles — those purporting to be war heroes. You’d be amazed how many guys claim to be on a secret mission in Afghanistan. Obviously, guy in the military doesn’t equal fraudster, but if they use it as an excuse for being vague about their life, it’s worth watching out for.

If you’re worried about a potential date being a scammer, make sure you talk to them over the phone or in a video chat before you meet up. Always make sure an initial meeting is in a public place. And this should go without saying, but never send money to strangers over the internet.

Lastly, there’s a whole world of people who fetishize disability. If you have a photo that prominently features your wheelchair in your profile and/or mention your disability, there’s a good chance you’re going to get messaged by some of them. It’s a much larger topic than we have space to cover here, but “Hot Wheels: The World of Wheelchair Fetishists and Disability Devotees” offers an in-depth look at this subculture. Available at: bit.ly/2RsUpWq

Oh, and the prostitutes. There are definitely prostitutes who target disabled folk online because they think we’ll be more likely to pay for sex. Moving on …
ability. “Can they not handle it?” she asked herself. “I’m not normally like that, but it definitely brings back insecurities.”

Ghosting is particularly hard to deal with because you have no idea why it happens. One minute things are progressing and the next, this person you may have been developing feelings for has vanished. Outright rejection can be easier to deal with because it’s conclusive and you can move on. Ghosting gives the imagination free rein. And because society so often frames disability as a negative, ghosting makes it all too easy to get lost down that rabbit hole.

Consider this though: ghosting has become so prevalent as a cultural phenomenon that the Oxford English Dictionary added an official definition in 2016. In the same year, the dating website Plenty of Fish released a survey showing that 80 percent of millennials, who the site defined as between 18 and 33 years old, using the site had been ghosted. So maybe it was your disability, or maybe you had a booger in your nose or you talked too much without bothering to listen or you really love anime or you drink too much or … whatever. The point is, people deem others unfit for a relationship for all sorts of reasons, some stupid, some not. People ghost because for some, awkward conversations are just too much to deal with these days. That’s certainly not a satisfying answer, but if you want to use online dating services, ghosting is probably something you’re going to have to deal with.

Disability Double Down

What do you think about dating someone else with a disability? For some, the response is, “No way, I already have enough disability in my life.” For others, having a relationship in which the other person also has a disability can be fulfilling in a way that dating a nondisabled person never would be.

If you have a disability, you most certainly shouldn’t feel like dating within the disability community is your only option. But at the same time, you shouldn’t rule it out. For a longtime, Ladau says she didn’t want to date someone with a disability because she didn’t want to call more attention to her own disability. “Which is so silly,” she says. Then she met a wheelchair user and they really connected on a personal level. “I was a little hesitant at first, but I realized, if I want someone to accept me and date me … how come I can’t extend the same thing for somebody else?” They ended up dating for two years, and Ladau says that having that level of mutual disability understanding was “a rewarding and unique experience.”
The even more common corollary to ghosting in the online dating game is the simple non-response to an initial message. Elizabeth Bruch, a sociologist at the University of Michigan who recently analyzed large scale data sets from a popular online dating website, found the reply rate to the average message was somewhere between zero and 10 percent. If you’re new to online dating, and you send out messages to a few matches and don’t get a response, it can be crushing. But when you follow the data, actually hearing back from your first few messages would be abnormal. For those who are just entering the game, or struggling to connect with anyone, Bruch and other experts recommend a simple strategy: persistence.

The Unpaid Internship
If persistence sounds like hard work, you’re not wrong. There are so many people on online dating sites these days, that finding someone with whom you have a mutual attraction, chemistry and all the other intangibles that can make or break a relationship takes a lot of effort. In person, we can use all of our senses to get an immediate and often strong first-impression of the relative worthiness of a potential mate. But online you have to comb profiles, send and respond to messages, make phone calls and coordinate meetups, just to get to the point where you find out whether they have body odor or trouble maintaining eye contact.

For Andrew Gurza, a queer man with cerebral palsy, a disability advocate and the host of the sexuality podcast Disability After Dark, reaching the “getting to know someone” stage of things is proving to be more effort than it’s worth. Gurza is open and even playful with his disability, using lines like “Your number one disabled lover” or “Bear (slang for a large, hairy guy) in a chair” in his online dating profiles. But he says that openness often brings ableist messages along with it. “I’m constantly asked, ‘What can you do sexually?’ I’m constantly told that I shouldn’t be on the app because I’m disabled, why would anyone want to be with me,” he says. “It’s so much work getting past all that crap to actually spend time getting to meet somebody.”

Gurza says that as a young, queer man with a disability, “The idea of going on a date with anybody when I was a teenager was exciting but impossible.” In college, he explored and had plenty of sexual encounters, but nothing that developed into a relationship. “In my experience with queer men, sex seems to be on the table a lot faster than connection does.”

Online dating was supposed to be a means to find a connection with someone, but in that regard, it hasn’t proved worth the effort. In the past year Gurza has decided to back away from it. He’s not going to “give up on finding love, because that would be tragic and sad, but to give up on the need to be in a relationship and to go on dates.”

Reilly has also struggled with the amount of effort it takes to make a real connection with someone when you meet online. Reilly has a job, she’s a program specialist for the Supplemental Nutrition Assistance Program of the federal government, and a life. Dating is different in her 40s compared to her 20s. “I get a ton of responses, and I don’t know how to say this in a nice way, but it’s a lot of losers just looking for hookups,” she says.

Reilly’s had a few short-term relationships that came from online dating, and estimates she’s been on 20 dates in the past two years. To help keep her from wasting her time or getting scammed, she makes sure that if she’s going to meet someone, she has at least talked with them on the phone, preferably a video chat. “I wasted a lot of time on people that I think I could have ruled out had we talked on the phone,” she says. “I’m at an age where I know what I want, and I’m not going to waste my time if they don’t seem worth it.”

Between the ghosting and the hookup culture and the
A World of Apps

It can be a bit overwhelming choosing which of the plethora of online dating apps to use. Of the mainstream dating services, popular free options include Tinder, Bumble, Plenty of Fish, OkCupid and Coffee Meets Bagel. Match.com and eHarmony are the most commonly used paid options. “The best dating apps of 2018” from the website Digital Trends offers a good overview of the features and usability for the most popular services. Available at digitaltrends.com/mobile/best-dating-apps.

For the queer community, Her and Grindr are two popular apps, while OkCupid gets good ratings for inclusivity. Teen Vogue gives a good breakdown of some of the current options in their article “Best Dating Apps for Queer and LGBTQ People,” available at: teenvogue.com/story/best-dating-apps-queer-lgbtq-people.

In addition, there are a number of services that cater specifically to people with disabilities. Whispers4u, Dating4Disabled, Special Bridge and Disabled Passions are a few options that Vantage Mobility breaks down in its article “Expert Dating Tips for the Best Disabled Dating Websites.” Available at bit.ly/2TNwI1K.

amount of effort it takes to get to a first-date, only to have it go nowhere, the experiences have taken a toll. “I’m really discouraged by the whole process,” she says. “But I’m not going to give up, because I feel like I’ll eventually meet someone.”

So You Have a Date, Now What?

With online dating in general, and dating with a disability in particular, there can be so many layers to get through that it can feel like, “’Wait, now what?’ once you actually wind up on a date. Ladau has had dates go off the rails because of accessibility issues. One time, she and guy planned a second date at a painting class. She researched locations and found a restaurant that was reputed to be accessible. Once they got there, they found out that the restaurant was accessible, but the painting class was upstairs. They spent an awkward meal listening to happy banter of the class going on without them. Ladau eventually got the company to refund their money, but she never heard from the guy again. After that, she says, “I would try to show up early to a date because if there were accessibility issues I wanted to scope it out and come up with a game plan before the other person even arrived.”

Both Reilly and Lovato say they haven’t really had any issues with accessibility on dates. Lovato usually picks the location because it’s often still the guy asking the girl out. “Not always though,” he says. “If she picked, I had the fact that I’m in a wheelchair on my dating profile, so she’d know we needed a place I can get into.”

How proactive to be about accessibility is up to you. If you have very specific accessibility needs, or there’s a high potential for access issues in the town or city in which you live, you may want to vet locations before showing up for a first date. Access issues are unavoidable over the course of a relationship, but you may not want that to affect first impressions. At the same time, dealing with inaccessibility is just another part of life, and showing a potential partner that you know how to deal with it and find a workaround can be a good thing for potential partners to see.

Ladau spent a long time trying and struggling with online dating, dealing with rejection and moving through relationships of varying seriousness. She’s now out of the dating game, in a stable, happy relationship with a guy she met on Tinder. With that experience, she offers some particularly helpful words for moving from the online realm to the real world. “Too many times, I would build up these relationship fantasies in my head of what would happen as soon as someone showed the slightest bit of interest or told me that the wheelchair wasn’t a problem, and getting carried away like that is incredibly harmful,” she says. “Don’t settle … just because somebody does accept you for who you are and that you’re a wheelchair user doesn’t mean that you have to date them. If it doesn’t feel right, break it off.”

After Lovato broke up with the girlfriend who’d been with him through his accident, he worried about starting the dating process as a wheelchair user. “I also had this fear in my head like, if she leaves, will anyone else ever be there?” he says. But putting himself out there quickly dispelled that notion. “The best thing about online dating is that the net is so much wider, you find so many more people. But the worst thing about online dating is also that the net is so much wider. You get so many people who are just not good matches, you have to sort through a lot more people until you find someone you actually click with.”

Ladau says the advice she wishes she’d heard from people is simple: keep trying and be realistic. “You have to pull a lot of weeds before you find the flower,” she laughs. “That’s really cheesy, but it’s true.”
SEXUALITY AFTER SCI:
Creating a Lasting, Transformative Resource

BY IAN RUDER

Over the last half of 2017, members of United Spinal’s New York City and Hudson Valley Chapters devoted hundreds of hours to planning and starring in a series of videos to educate people worldwide about sexuality and spinal cord injury.

Working hand-in-hand with Wheeling Forward, and under the leadership of professionals from Mount Sinai Rehabilitation Hospital in New York, the group created 16 well-produced, high-quality videos covering topics ranging from debunking myths about sex and SCI to fertility to sexual positions. Those videos, along with videos chronicling two thoughtful sex and SCI seminars and a number of other sex and SCI-related resources, are now available for free in perpetuity at Sexuality After SCI, online at sexualitysci.org.

In its first year online, over 6,000 unique visitors from more than 116 countries visited the site. “I never even thought it would really get out of the United States,” says Angela Riccobono, the senior clinical psychologist at Mount Sinai, and the woman who envisioned the project. “There have been visitors from countries like Rwanda, Serbia, Russia, Croatia, Korea, Saudi Arabia, Iraq, Iran, places like that where they are so restrictive. … It just blew my mind that it had this global sort of outreach.”

Debbie Poli, a board member of the New York City chapter, credits Riccobono with the vision and follow through. “Without Angela, I don’t think the site would be as successful as it is,” says Poli. “She has tremendous insight and a lot of experience dealing with people, their emotions, and the recovery from spinal cord injury.”

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Gary Karp (left) and renowned sexologist Mitch Tepper were presenters at the “From Injury to Intimacy” conference.

The group created 16 well-produced, high-quality videos covering topics ranging from debunking myths about sex and SCI to fertility to sexual positions.

A Need Arises
Riccobono has worked with thousands of people with spinal cord injuries as they’ve passed through Mount Sinai’s acclaimed model systems rehab unit over the last 25 years. While many aspects of SCI rehab have evolved thanks to new technologies and techniques, one area remained frustratingly stuck in time: sex after SCI.

Riccobono points to an old sex-ed video produced by Kessler Rehabilitation Center. “The video is horrible, but it was the only tape out there,” she says. “It doesn’t make you feel like going out and having sex.”

Riccobono says the aged videos are one of many signs that it is time to improve the way we talk about SCI and sex. “We have people with new injuries come in and we teach them a bowel routine, but we won’t talk about what it’s gonna be like when they go home and get in bed with their partner,” she says. “You have people who think their sex lives are over after their injuries, and they’re afraid to ask anything, they’re so uncomfortable. And then you have doctors who aren’t bringing sex up because they don’t know what to say, and it’s awkward and uncomfortable.”

From her experience running a weekly SCI support group, and a well-attended conference in 2015 called “From Injury to Intimacy,” Riccobono sensed the community would support a more robust program. In addition to hosting an expanded conference, she envisioned creating a lasting set of resources. She received a Nielsen grant to cover the costs.
and quickly got to work figuring out how to maximize its impact. “The idea behind the grant was not only to educate people with spinal cord injuries, but to do it in a way that’s never been done,” she says.

The hospital hosted two conferences on sex and SCI in the spring of 2017 — one for professionals and one for people with SCI. High turnout and enthusiastic responses reaffirmed Riccobono’s instinct that there was an unserved need for further sex education in the SCI community.

The Plan Comes Together

The original plan had been to record the conferences and post the videos online as a permanent resource, but everyone involved wanted more. “It just wasn’t enough,” says Riccobono. “I wanted to develop a website that people with spinal cord injuries and healthcare professionals could go to, and to make this a complete resource.”

Riccobono roped in leaders from New York’s SCI community and started planning what an educational video series should cover and what it should look like. “What was really important to us is that we have real people in an attractive setting — not in a clinic, or a hospital bed,” says Riccobono. “The people in these videos are real, attractive, sensual people. And I think it’s quite loving.”

A majority of the people featured in the videos came from the New York City and Hudson Valley Chapters and the two filmmakers were the children of a longtime sponsor of the NYC chapter. Everyone involved worked hard to ensure the videos were factually correct, well-planned out and helpful. “We had everything on a story board and planned out because we knew we couldn’t just wing it,” says Poli. “It was too important and we’d put in too much time and effort.”

The project’s success has Riccobono excited about future endeavors to keep the momentum moving. Doctors, therapists, support groups and individuals have contacted her with various ideas and requests, and the videos and site are already being used as teaching tools in institutions around the country.

Poli makes sure to thank the many organizations and individuals that helped make the project a reality, but comes back to Riccobono. “The one thing that every single person that goes through Mount Sinai Rehab comes away with is that Angela is the person that changes everything for them. She’s just so caring and insightful.”

Now people all over the world can share in those same benefits. Visit sexualitysci.org to find out more about Sexuality After SCI.
I was born with spina bifida — basically an in utero spinal cord injury — in the early ’70s. Like many others with mobility limitations, I have had to deal with what I call the “side dishes of disability.” In those days, we found ourselves in many learn-as-we-go situations. One of the recurring side dishes that popped up consistently for me was renal health. At one point in my childhood, it seemed I had a different type of UTI on a monthly basis.  

Back then, everyone was preoccupied with creating a germ-free environment, so my doctors prescribed a different antibiotic each round. Eventually they decided that my system was being compromised by the constant rotation of antibiotics. Since I would always carry low-grade bacteria by nature at all times, unless it “bloomed,” the best thing for my body was to allow it to create its own antibodies.

Time passed. Then, in the spring of 2012, I tangled with acute renal failure after being prescribed the wrong blood pressure medication. The error shut down my entire system. I was born with only one kidney, so the risks were exponentially higher. It was an extremely frightening experience.

Taking Care of Our Kidneys

BY BETHANY A. HOPPE
With a new diagnosis — chronic kidney disease — and the fact that I am constantly seated, I knew I would now be facing serious, ongoing renal issues. I decided in that moment that the outcomes predicted for me weren’t acceptable, and if there were anything I could do to improve my circumstances or regain my health, I would do it.

I immersed myself in research, statistics, methodologies, case studies, and the world of medical diet restrictions concerning CKD. I turned to those wiser and more experienced than myself and found the most often-repeated directive specific to kidney health, reduction of UTIs and avoidance/delay of dialysis was renal-friendly dieting. What I’ve learned over seven years through researching and practicing renal-friendly dieting has been my saving grace. This is what I want to share with you. To date, I have avoided kidney dialysis and stayed off the path to a transplant list.

A Kidney-Friendly Diet

Our kidneys, those two bean-shaped vital organs no larger than your fist, filter approximately 200 quarts of blood each day — almost enough to fill a bathtub. This all-natural filtration system removes waste and toxins from your blood, creates urine and sends the purified blood throughout the entire body. However, if you are a wheelchair user, being seated most of the day and unable to walk is not the greatest gift to your urinary tract.

According to the National Kidney Foundation, one out of three American adults is at risk for kidney disease, a reality exacerbated by our typical diet, where the bulk of the food intake is over-processed, highly salted, high in sugar, high in protein and depleted of quality nutrition. Also, the balance of potassium, sodium and protein dramatically impacts renal health because they’re difficult to filter when the kidney is weakened or compromised. A solution is renal-friendly dieting.

I am not a urologist, nephrologist or home health worker, so I have no following of people who have taken my advice. But I have found what works for me, and it seems that many people follow the kind of diet that I use and have encountered beneficial results. A renal-friendly diet is one that is low-to-no sodium, low potassium and relatively low in protein. Because of the diet, I have sacrificed tastes I adore and been counted out when it came to some traditional foods I valued and grew up with. I had to re-learn how to cook with alternatives that resembled my Scandinavian heritage.

Your kidney function, blood pressure and overall health will improve almost immediately if you cut added salt from your diet. Filtering the waste products generated when your body processes proteins. The more protein you eat, the more work for your kidneys — leading to potential overworking when compromised.

If your kidneys could choose whether they were carnivorous or vegetarian, they would choose to be veggie. Our bodies, however, need certain things in proper amounts that vegetarian or vegan diets might not be able to deliver on their own without supplements.

If you look at the soft part of your palm and visualize that as the amount of meat you should eat every day, you’re on track. The average American eats nearly three times that amount. Blood tests that screen for or monitor kidney disease measure the amount of protein found in the blood, called creatinine. When you have chronic UTIs or CKD, protein levels must be cut by more than half, and it’s recommended you eliminate red meat. If you’re close to dialysis, consider vegetarianism.

According to Dr. Robert Galarowicz, author of All Natural Kidney Health & Kidney Function Restoration Program: Everything You Need to Know to Improve Your Kidney Health, Avoid Dialysis and Live a Better Quality Life, we should opt for plant-based proteins such as beans and tofu as much as possible. Dr. Gal-

Your kidney function, blood pressure and overall health will improve almost immediately if you cut added salt from your diet.
arowicz is my virtual go-to renal health guru. Through his books and website, he has provided me the most comprehensive research, the most applicable strategies and the easiest menu guidelines in all my years of research.

The Importance of Water
Like many solutions to the issues that disabilities present us with, taking care of one problem potentially creates or overlooks others. I had to seriously consider my unique dietary and disability needs before going into this lifestyle change. Please consult with your physician, nutritionist or specialists who are experts in handling specific complications before embarking on any dietary change. For example, limiting protein — a crucial element in fighting CKD — is in opposition to the recommendation of eating large amounts of protein to combat pressure sores, and a nutritionist or specialist will know best how to navigate these complexities.

It is easy to see the cycle that can lead to problems. An overload of protein, added salt, and high levels of potassium equals renal stress, which results in crystallizations that can attract sticky bacteria, which become bladder sediment, and that often morphs into infections. Infections leave scars and compromise your kidney health, potentially leading to CKD. CKD impacts hormone regulation, blood pressure, heart health, sugar regulation, metabolism and the body’s ability to fight off other illnesses.

In addition to eating a renal friendly diet, I found staying well hydrated optimizes health. Dehydration expedites the process of developing chronic urinary tract infections and thus speeds up this cycle. This is especially true for those of us who are constantly seated and unable to get any “walking motion.” Urine held in the bladder can collect sediment due to inactivity, which can lead to crystallization and a friendly environment for UTI-causing bacteria. Drinking lots of fluids can help keep your bladder flushed and minimize crystallization.

Living Healthy
Proper diet and water intake are keys to good kidney health. If you decide to make a significant lifestyle change, work with your doctor and know that with any dietary change, your body will take a couple of weeks to acclimate.

The fact is our greatest wealth is our health. It took years for me to understand that disability can be greatly mitigated by true wellness. Limitations can become less bothersome when you create and maintain your health with self-care, proper diet, and exercise at whatever level possible, from the inside out. This includes spirituality and mental health in addition to how you regenerate your physical being with great food and fresh water every day.

That may sound a little like motivational hype at first, but research and science and my own personal experiences have proven otherwise.
This January, Risnawati "Risna" Utami became the first person from her native Indonesia to sit on the United Nations Committee on the Rights of Persons With Disabilities. As one of the committee’s 18 members, Utami, a lawyer and activist, is arguably one of the most powerful women in the world when it comes to international law and disability rights. Her rise is a testament to more than 20 years of passionate work on behalf of women and people with disabilities and her refusal to give in to the low expectations of the society where she grew up.

RISING ABOVE
Born and raised in Indonesia, Utami was all but disregarded as a disabled child in her community after contracting polio at the age of 4. Utami describes the Indonesian culture she grew up in as "not accepting of women with disabilities whatsoever." As the only daughter in her family, Utami saw those dynamics play out in her own household. "My father was initially ashamed and embarrassed," she says. "My mother convinced him that I’d be OK someday, which was true." She credits her mom with providing a strong female role model for her to follow. "My mum is a strong figure for me — in the way she raised me, encouraging me to be the woman I am now."

Even with her family’s emotional backing, financial and social obstacles made things difficult. Utami’s parents were unable to afford a wheelchair for many years during her childhood, forcing her to use a brace. "I’m lucky because my family has supported me, but very few women have that opportunity," she says.

That support helped Utami thrive academically. She graduated from Sebelas Maret University, an Indonesian university, with a degree in law in 1997, but her credentials only did so much to counter discrimination. "It was very difficult to find a job," she says. "People focused on my wheelchair and disability, and the stigma in Indonesia was difficult to overcome." After two years searching for work, Utami started volunteering for a local nongovernmental organization that focused on disability. "It fit perfectly with my law degree, and it was a great opportunity for me to learn about the disability rights movement and civil rights movement," she says. "I’d never met or interacted with other disabled people before — you don’t see other disabled people in Indonesia. I thought, wow, I can go deep and learn more about the disabled world and make a difference here."

NGO LIFE
In 1999, Utami applied some of what she learned to help start the Talenta Foundation, an NGO that focused on the participation of people with disabilities in Indonesia’s political arena. During the six years she worked there, Utami wrote prolifically about the intersection of gender and disability, including a book about the importance of reproductive rights for women with disabilities. Utami submitted the abstract of the book to the International Association for the Study of Sexuality, Culture and Society and was selected to present at the organization’s 2005 biannual conference in San Francisco. Around the same time, Utami ap-
plied for a scholarship with the Ford Foundation International Fellowships Program. "I didn't know until I'd returned to Indonesia that I'd been accepted, and out of 4,000 people, I was the only disabled woman!" she says. The scholarship funded further opportunities for her to study sex education in rehabilitation centers and reproductive rights for people with disabilities.

Just as Utami’s work was beginning to be noticed, she decided to relocate to the United States to further her education and pursue a childhood dream. "As a child, I always dreamt of going abroad, pursuing education and speaking English," she says. "I just loved watching the TV series Little House on the Prairie, about a family living on the American frontier, struggling to realize their dreams while taking on the great unknown — and then the dream came true for me!"

Before starting her work with NGOs, Utami had only spoken a few words of English. Now, just a few years later, she found herself moving to Massachusetts to earn a master’s degree in International Health Policy and Management from Brandeis University.

“HOME SWEET HOME”
In May 2008, Utami returned to Indonesia to start another NGO aimed at helping people in her hometown of Yogyakarta. The organization, named OHANA Indonesia, aimed to provide disability rights, policy advocacy and technical assistance for local governments on dealing with disability.

At the heart of OHANA Indonesia is a series of programs designed to get properly fitting wheelchairs to people in need and to empower wheelchair users. The effort involves training technicians to fit and work on wheelchairs, coordinating with foreign providers to secure equipment and organizing social events to bring wheelchair users together and destigmatize disability. Christiaan Bailey, an outspoken advocate for adaptive sports, who is also involved in many international NGOs, has worked with Utami on her efforts.

“I’ve personally witnessed her program start from an obscure idea and grow into a regional endeavor, then to a national initiative, onto an international movement, and finally, come to its zenith in a seat at the United Nations, shaping disability policy for the whole world,” says Bailey. “Her infectious smile, quick wit and consummate passion for helping others has served as a great source of empowerment for not only myself, but countless thousands around the world.”

Bailey says Utami has a zeal for
her work that can’t help but rub off on those around her. “Risna’s life is about making a better life for people with disabilities,” he says. “Not just in her town, city, state or country, but everywhere. As long as she’s out in this world, fighting the good fight for the rest of us, I’ve got her back.”

**INTERNATIONAL IMPACT**

Additionally, and perhaps most importantly, OHANA opened the doors for Utami to explore the issues she was passionate about on a global scale. “It enabled me to create national and international networks and has led to me working in the United Nations and traveling to conferences in places like Brussels, Germany, Mexico and Ecuador,” she says. “Working together and presenting at huge places like these and being able to influence people to change law and regulations and create disability programs in places like Indonesia is so important.”

Utami takes obvious pride in representing her country, and more specifically its women with disabilities, on a global scale. She thinks it is important that women with disabilities are regarded as sexual beings and are granted adequate sexual and reproductive rights and responsibilities to reflect this. She is equally adamant about the importance of people in the disabled community pushing for change elsewhere, sharing their work and findings and encouraging progress on a global level.

Her passion has made her an outspoken leader in the push for the Convention on Rights of Persons with Disabilities on both a local and a global level. The United Nations adopted the Convention in 2006 to empower people with disabilities and provide human rights guidelines and goals.

Utami has led the Indonesian Con-
sortium for Disability Rights, which has 45 organization members representing eight provinces, to push for CRPD implementation at the local and national level. On the international level, her work has helped get more than 160 countries to sign and ratify the treaty (the U.S. has signed, but not ratified).

“Risna is a formidable leader, stellar advocate, and kind and compassionate human being,” says Elizabeth Lockwood, a representative at the U.N. “It is a joy to work with Risna, not only because of her depth of knowledge, expertise and experience, but more so because of her welcoming and warm nature.”

Lockwood, who has worked with Utami at the U.N. since 2014 to advocate for people with disabilities, says it’s obvious why she is so successful. “Risna has always been aware of the importance of her determination and positivity, and what a vital role both have played in her success to date,” says Lockwood. “Her kindness and willingness to put the needs of others before her own is also immediately present in the way she speaks and writes.”

**U.N. PRECEDENTED**

Those qualities and skills were rewarded last June when Utami was nominated and elected to be Indonesia’s first-ever representative on the Committee on the Rights of Persons with Disabilities, a body of 18 experts who monitor implementation of the Convention. Her four-year term started Jan. 1. “Risna is an excellent addition to the Committee on the Rights of Persons with Disabilities on which she will continue to advocate for equality and human rights for all persons with disabilities,” says Lockwood.

Utami is thrilled to represent the long-voiceless women with disabilities of her country. “Disabled women in Indonesia are more passionate and advanced than the men,” she says. “I’m so proud of this. This progress for women has led to my government nominating me to be a candidate for disabled people in the United Nations.”

In addition to her new role, Utami continues to lecture on disability, accessibility, public health and human rights at Gadjah Mada University, Duta Wacana Christian University and the Sunan Kalijaga State Islamic University, all in Yogyakarta. She also writes prolifically and travels the globe for various speaking engagements. Her experiences have only deepened her dedication to her work.

“You can’t find many people like me in Indonesia,” she says. “It’s sad, but it makes me even more passionate to improve the education and quality of life of disabled people there.”
The Toyota Mobility Foundation announced the five finalists in its Mobility Unlimited Challenge at January’s Consumer Electric Show, held in Las Vegas. The three-year-long challenge kicked off last year when engineers, innovators and designers from around the world were invited to submit their ideas for products designed to improve the lives of people with lower-limb paralysis. Eighty entries were received from teams in 28 nations, and the judges themselves were drawn from seven countries.

Making the final five are an AI-enhanced manual wheelchair that knows when to assist braking and propulsion, two variations of exoskeletons, a fleet of power assist devices for rent à la urban bike-sharing and a refined FES sleeve to ameliorate foot drop. Each has received $500,000 from the Toyota Mobility Foundation and Nesta’s Challenge Prize Centre to keep developing their entries. The final winner will be awarded $1 million and will be announced at the September 2020 Paralympics Games in Tokyo.

Two of the 11 judges are wheelchair users, including United Kingdom journalist Sophie Morgan, 32, a T5 para since she was 18. “At the moment, if you have lower-limb paralysis, you mobilize with a wheelchair — and that isn’t necessarily the best way for people like me to be able to get around,” says Morgan. Her wheelchair-replacing dream device would be “a robotic exoskeleton that I could wear underneath my clothes and control through thought. I’d be able to walk around amongst people and they’d never even know that I am paralyzed!” Her perspective may help explain why two exoskeletons made the finalist cut, while only one wheelchair did.

Here are the finalists:

**Phoenix Ai Ultralight Wheelchair by Phoenix Instinct**

Designed by Andrew Slorance, the brains behind both the Unstoppable luggage system and the Carbon Black wheelchair, this new offering melds smart technologies with a sleek ultralight manual wheelchair.

What does that actually mean? The chair has smart sensors installed that shape its functionalities to what the user is doing. So if you lean forward or backward, the chair recognizes the motion and responds appropriately. Slorance says this smooths the ride, eliminates drag and prevents tipping. It detects whether you’re going up or down a hill and adjusts braking so you don’t backslide or reach the bottom faster than you’d like.

“When a user is going downhill, they’ll no longer have to grip onto the pushrims for dear life,” says Slorance, a para based in the U.K. “You can decide to either use it intelligently or use it manually, so the user could decide how much braking they want to apply, or they could let the chair decide for them how much braking they want to apply on that slope.”

The final product will weigh around 18 pounds, including an integrated power assist, and will be a custom build. In response to *New Mobility* Facebook followers concerned the back is too low to be practical, Slorance reassures, “The backrest will be available in different heights, and there will be an option for an after-market backrest too. We are very aware of the need for users to be able to use their preferred pressure relief cushions, and the seat will be designed to accommodate this.”

**Moby by Italdesign**

Moby is the cycle share equivalent for lightweight manual wheelchair users, says Italdesign. When it’s up and running, you will be able to book a Moby power assist device via an app, make your way to a hub located in the major city of your choice, click into it, and enjoy being powered until you’re ready to turn it in at the closest hub to your destination. Italdesign also says it’s “a semi-autonomous electric device with integrated systems that help users to avoid any collisions with fixed or mobile obstacles and it is designed to help them to...
on the market? For starters, it has more tech built in than
other versions. In theory this will allow the suit’s wearer to move more naturally.

“Quix will have actuation, sensing and controls that the existing, including our current Mina v2 prototype, exoskeletons do not have,” says IHMC’s Peter Neuhaus. It offers four actuators per leg. One is located where the leg moves sideways from the hip, one where the hip moves the leg forward, one at the knee and one at the ankle. This will allow customers to side step as well as walk forward.

Also, it’s designed for the user to be able to tell where their feet are — and that’s a big deal. “As for sensing, we will have sensors under the feet that sense the magnitude and location of the ground reaction force,” says Neuhaus. “Basically, how much load is on the foot, and is it toward the toes, heel, or in the center?” Another sensor will be continually examining upcoming terrain to check for obstacles that may need to be stepped over, onto or around, and, “finally, we plan to add assistive balance control to help the user stay balanced without the need for crutches.”

The rendered images show a person walking without crutches, but even with the extra sensors, that idea seems far-fetched. “This is a very ambitious goal, and might not be possible technically, or possible for all users,” Neuhaus acknowledges. “At a minimum, the Quix should reduce the crutch force and reduce the frequency that the user needs to put the crutch on the ground for balance assistance.”

If all goes as planned, once Quix hits the consumer market it will be priced in the same range as high-end power chairs.

**Qolo by Team Qolo, University of Tsukuba**

The Qolo is an exoskeleton/wheelchair hybrid. Leaning forward engages actuators to move you from sitting to standing, and while standing the Qolo can bump over obstacles a little under an inch tall and handle slopes up to 10 percent steep. An actuator is the part of a machine that makes it move.

You don’t need a joystick to steer Qolo, but rather you lean in the direction you’d like to travel. That’s both one of the coolest features, and also one of the most disappointing, as it means only people with trunk control can use the Qolo as it’s currently designed. Also, there doesn’t seem to be space for a decent wheelchair cushion.

“We want to remove the chair from ‘wheelchair,’” says Team Qolo’s Kenji Suzuki. “Our device gives users the choice to sit or stand, using cutting edge technologies.” The streamlined Qolo is a jump forward in terms of how intuitive it is to use, plus those large front wheels add stability. Hopefully the final version will be usable by more than just people with trunk function ... and build in some space for an appropriate seat cushion.

**Evowalk by Evolution Devices**

People with foot drop caused by multiple sclerosis, cerebral palsy, stroke and other nervous system conditions, this one’s for you. The Evowalk is an FES sleeve similar to the FES battery packs we’ve seen strapped to people’s calves that make it easier for them to walk more smoothly and farther. The difference, we’re told, is Evowalk is sleeker, less obtrusive and more customized.

“Our main advantage is that we use an artificial intelligence algorithm to train our device on each individual user’s walking patterns in order to personalize stimulation,” says Evolution Devices spokesperson Juan Rodriguez. “This leads to improved comfort and better outcomes.”

These innovations could mean the user’s leg does not need to swing out quite so wide to compensate for foot drop. This in turn means less energy expended, which could translate into a longer distance traversed or another activity enjoyed. For people with MS who have fatigue issues, any edge is appreciated. And it’s nice that, for once, how a product for people with MS looks and feels is considered as important as its functionality.
There is probably no one in America in or around a wheelchair who won’t find something to complain about in The Upside, a Hollywood film starring Bryan Cranston and Kevin Hart that saw wide release in January. It is the story of a white quadriplegic plutocrat and a streetwise black guy who becomes his caregiver and soul-saver — the latest in a nascent but growing genre, the disability-buddy movie. It begins as an almost exact frame by frame remake of the much-lauded French film of 2011, The Intouchables, winner of five César Awards, the French version of the Academy Awards, and globally, the most financially successful French movie of all time. If the makers of the remake had stuck with the exact same shot-by-shot story beyond the opening two minutes, it would have been a fascinating piece of cultural appropriation — and maybe a better movie. Instead, they ventured off into an “Americanized” story, much of which falls flat.

Watching them back to back, I tried to dispense with two standard movie-viewing clichés. The first is that any American remake of any European film is never as good as the original. OK, this is a cliché mostly among film critics and snobs, since most American moviegoers have never heard of the foreign predecessors to their beloved Hollywood hits. Quentin Tarantino’s famous blood-fest, Reservoir Dogs, was a stealth remake of a Japanese blood-fest, City On Fire, but who knew and who cares? That ear-slicing scene was new to me and probably to you, too. Even American remakes of American movies can be a huge improvement. Best example: Scarface — a remake of a 1932 film with the same name.

The other cliché is that nondisabled actors playing disabled roles are far inferior to disabled actors in the same role. In matters of technical performance, this is no doubt true, and of course, technical performance influences emotional performance and vice-versa. Occasionally, a gifted nondisabled actor, almost like alchemy, can transform themselves into a character with a disability. Think of Daniel Day Lewis in My Left Foot.

If current trends continue, up-and-coming disabled actors will soon get the chance to prove their case. But here we have two acclaimed nondisabled actors, French star François Cluzet in the original, and Cranston in the remake, portraying a quad’s life. From my own half-assed perspective — I’m a T10 para and only know some of what a quad deals with — both actors are brilliant, but in much different, and telling, ways.
Cluzet’s character, Philippe, drawn from the true story of French champagne magnet Philippe di Borgo, plays his disability card as a hard-to-read stoic, both philosophical and temperamental. He knows he is only in control of his interior life, i.e., how he reacts to things. Almost all of his emotional expression is in his eyes. He can smile, especially when his bud Driss (played by Omar Sy) tells crippled jokes, but he never shows anger, hostility, bitterness, or fear, even when he is suffocating in his own bed. As I watched this subtle, complicated performance, I both admired the restraint of the character and saw its level of make-believe nobility. Sure, all us crips want to see ourselves as graceful and resilient — no tears, no excuses — but we rarely are.

Cranston’s character, Philip with one less “p” and no “e,” is angry, frustrated, and much more out there in every way. In one pivotal scene, egged on by his pal, Dell (Hart), he experiences an orgy of delight watching Dell destroy a room full of expensive birthday gifts, his way of saying f-you to the world. At times he seems like someone you know, like yourself.

Unlike the Cluzet character, he isn’t quarantined from the pain of being a social oddity. In another key scene, he has a lunch date with a woman with whom he has developed an epistolary, or by letter-only, romance. After just a few minutes of pretending that fork feeding your completely immobile date is normal, first-meet stuff, she admits she can’t handle the situation, walks out and never comes back to apologize.

Both films, in general, make the disability experience too pain- or hassle-free for anything approximating reality — no spasms, infections, hateful moods, suicidal depression, falls, spills, or accidents. The remake tries way too hard to dramatize Philip’s circumstances. A self-consciously squeamish scene where Dell learns to use a catheter, turns a potentially honest/funny moment into something painfully overplayed and distasteful. Sticking a tube into a paralyzed penis, speaking from vast experience, is not worthy of all this mania.

Disability is only half of both films — the parallel stories of the caregivers, both black, is also told. In The Intouchables, the character, Driss, is completely believable, alternately charming and prone to violent outbursts, and not, as one critic pointed out, “the magical, mystical Negro” who teaches a white guy how to live. Fittingly, Sy won the 2012 César Award for Best Actor for his performance.

His Driss was much more entertaining and enlightening than Hart’s Dell. Hart is one of the most successful stand-ups on the planet and here he isn’t acting as much as playing Kevin Hart. Maybe it’s simply because I have no idea how West African immigrants live in contemporary Paris that I found Driss’ French life much more engaging than Dell’s American version, a tired ghetto trope about an estranged husband and father who redeems himself in the third reel.

George Lucas once said that a movie either worked or didn’t work. A movie that works can be flawed but still have force and resonance. A movie that doesn’t work can have flashes of brilliance and humor, but simply doesn’t allow you to enter another reality or perceive the world from another human’s perspective.

Using that criteria, I found something that resonated in both of these movies, though The Intouchables will likely be watched 20 years from now and The Upside probably won’t. If you are looking for a film about life in a chair that you can mercilessly trash for all the errors and omissions and fraudulent emotions involved, see the American version. Here the cliché holds true — it ain’t as good as the original, not by a long shot.

Omar Sy brings complexity to the caregiver role in The Intouchables.

The Upside has some of the exact same scenes as The Intouchables but little of its broad appeal.

Omar Sy brings complexity to the caregiver role in The Intouchables.

The Upside has some of the exact same scenes as The Intouchables but little of its broad appeal.
THE SECRET TO MY LONGEVITY

By the time the end of June rolls around, I will be either 63 years old or dead. I’m betting hard on the former. I don’t know if Las Vegas would give me very good odds on that, but screw it. Las Vegas thinks Celine Dion is a genius, so what the hell does it know?

You know how in illustrations of biblical times there are often hunched old men with long white beards who are walking around on gnarled canes? Well, in biblical times those guys were probably about 30 years old. I’m twice their age. The same is true of those grizzled prospectors in the Wild West. And how about those people featured now and then on the local news who are 110 years old? A 63-year-old, lifelong cripple has got to be as old as they are, at least in terms of wear-and-tear. And the local news reporter always asks the 110-year-old person the secret to their longevity.

If anybody asks me the secret to my longevity, I have a clear and simple answer: “Hell if I know.” It’s true, I don’t have any business being here. I don’t do any of the stuff cripples are supposed to do to stay healthy, like physical therapy or exercise. I know I really should do those things, but I can’t motivate myself. It feels too much like doing homework to me. I don’t even do any of the stuff people who aren’t crippled are supposed to do to stay healthy. I sure as hell don’t drink eight glasses of water a day. Are you kidding me? Eight glasses a day? How can anybody do that? I’d be peeing like a horse every 20 minutes if I did! What kind of quality of life would I have if I spent it in the bathroom? And I sit on my butt all day, every day too. I’ve heard all those reports about how doctors say that prolonged sitting is harder on your body than wrestling a coked-up gorilla. So why haven’t my vital organs joined together in solidarity and gone on strike? I have no idea. Who would blame them if they did?

I also continue to eat and drink pretty much whatever I want. The other day I had a dessert of cheesecake and whiskey. Sometimes I even eat White Castle cheeseburgers. It’s my way of thumbing my nose at death. But I do avoid some things that I know will bring me stress. Like for instance, I avoid joining any diagnosis-based cripple support groups. In these groups, cripples inevitably talk about their physical aches and pains (I’d much rather talk about our political aches and pains). And listening to it all turns me into a hypochondriac. I feel like my body’s going to fall apart any minute now, so I get all stressed out and go see a doctor. And then seeing a doctor stresses me out even more.

Once I went to see a pulmonologist, and he gave me a bunch of breathing tests where I exhaled into a tube with three little balls in it. The strength of my puff was supposed make the balls shoot up to the top of the tube, but I could only blow the balls about half way up before they dejectedly fell back down. The doctor gave me this mournful look, as if my body was going to fall apart right there in front of his eyes.

But that was 10 years ago and I’m still breathing. But is my breathing just symbolic? How much of the oxygen I take in actually gets up to my brain? That is a subject upon which reasonable minds can disagree.

Maybe listening to jazz is the secret to my longevity. I listen to a lot of jazz. Jazz is good for the soul. Jazz fans are cool and calm. You never hear about jazz fans rioting because they went to a concert and the musician didn’t show up. I think listening to jazz activates the same pleasure centers of the brain as having a dessert of cheesecake and whiskey.

That’s the only reasonable explanation I can come up with for why I’m still chugging along. Or maybe I have a freaky weird immune system and the more White Castle cheeseburgers I eat, the stronger it gets.
“What if I said you are the single most important breath in my space.”

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When getting to know someone new or training a caregiver, I always make a point to tell them that when they spot something amiss with my appearance to let me know and/or just go ahead and fix it. So, if I have a gap between my jeans and shirt or there is something in my teeth, they should treat it the same way they would if it happened to them. That said, I have a few longtime before-injury-guy-friends who, especially in the beginning, either didn’t notice or didn’t care if something was off.

Unbeknownst to me, I’d be rolling around town with my hair sticking up, or even worse, my bra would sometimes shift enough during lift transfers to make it look distinctly like I had four boobs. The worst, though, was seeing my reflection after a long day of beers and fun at the ballpark. Before the game, my friend and I shared a messy turkey and avocado sandwich.

Years later, I clearly remember the large blob of bright green guacamole that had apparently been peeking out of my right nostril all day.

Greenhorn

UNCLEAN GETAWAY

A few weeks after being released from rehab, I visited my local Honda dealership to select a van that would eventually be equipped with a hydraulic transfer seat. Halfway through a day of test drives and price negotiating, I was startled by the rumblings of an unexpected and explosive bowel accident. Mortified but optimistic, I hoped no one else was the wiser. I made up an excuse and did my best to make a quick exit. To my dismay, nerves and inexperience caused me to misjudge my transfer and I ended up on the ground in a rapidly expanding and foul-smelling mess. Defeated, I had to recruit two well-dressed young salesmen to help lift me up and into my car as poo fell from my pant leg. I left a mark on the parking lot, those dealers and the cloth seats of my old car that day. In the end, I did return to buy a van and even upgraded to the easier-cleaning leather seats.

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