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A fictional quad acts on his pre-planned suicide even after finding the love of his life (Me Before You). Two real-life disabled girls — one 5 and the other 14 — choose to die with the blessing of family members. Responding bravely, disability advocates battled widespread ignorance, melodrama and misinformation, telling the truth about living with a disability in an attempt to save lives. For their dedication, courage and persistence, NM is proud to honor them as People of the Year. By JOSIE BYZEK.
Now that we officially have a newly elected president, I want to look back to our departing POTUS and recount some of what I will miss about the man I voted for, twice. First, in case anyone cares, I did not vote for Barack Obama for political reasons. As I have written before, I tend to vote as an independent, so my thinking tends to focus on character.

President Obama got my vote because of his intelligence, his even temper, his ability to speak and write with great insight and clarity, his sense of humor, and his sensitivity to all minorities. If you think about it, when you look around, there is no shortage of minorities. Some say we are a nation of minorities. If you don’t buy that, then consider the latest minority, the one everyone loves to blame: old white guys. When all the other minorities team up and complain about OWG, that makes them the new minority.

Obama didn’t blame old white guys. In fact one of his most endearing traits was his ability to see people as individuals rather than members of any particular race, religion, political party or gender. No doubt this came from his own multi-ethnic background. His skin color and popular identity was “black,” but his ethnicity was mixed, and his soul was all-inclusive.

His intelligence inspired confidence in this voter. You don’t become editor of the Harvard Law Review by winning a popularity contest. And when you choose a president, you want someone who can take time to think things out thoroughly and make a reasoned decision that maintains order and sanity. It’s not about who can push the red button the quickest.

Not only was he intelligent in a common sense way, he could poke fun at himself, a most endearing trait, and a sign that at a deep level, he was no stranger to humility. Many professional White House observers think he may have been the funniest president ever. Here are three of my favorite Obama quips:

“i want to especially thank all the members of Congress who took a break from their exhausting schedules of not passing any laws to be here tonight.”

President Obama understood that the ADA was about civil rights, not “special rights,” and he was clearly at ease around people with disabilities.

“These days, I look in the mirror and I have to admit, I’m not the strapping young Muslim socialist I used to be.”

“Look, when I was a kid I inhaled frequently. That was the point.”

He was also approachable and aware of and sensitive to those of us with disabilities, beginning with his own father-in-law, who had MS. President Obama understood that the ADA was about civil rights, not “special rights,” and he was clearly at ease around people with disabilities.

One of my favorite videos is of his meeting disability activist Alice Wong when she appeared in the White House via telepresence robot for the 25th ADA Celebration. After chatting with Alice amicably, he did a little dance, and the robot and Alice followed his lead, to which he quipped: “How cool was that!”

Exactly. Our coolest president ever.

— Tim Gilmer

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What I Will Miss About Barack Obama

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“i want to especially thank all the members of Congress who took a break from their exhausting schedules of not passing any laws to be here tonight.”
As executive director of Neurotech Network, Jennifer French stays abreast of the latest in neurotechnology. A C6-7 quad since 1998, she has also distinguished herself as a Paralympian medalist in sailing and is the author of On My Feet Again: My Journey out of the Wheelchair Using Neurotechnology. She was the first woman to receive the Stand and Transfer system. Her latest book, co-authored with James Cavuoto, is Bionic Pioneers, a collection of 10 stories of brave individuals who either participated in a groundbreaking clinical trial or became a recipient of a newly-approved neurotech device.

Roxanne Furlong is a former associate editor of New Mobility who has been writing for the magazine for more than 12 years. She has also written in the agricultural, transportation enthusiast, how-to, business, and home and garden markets. She lives in Twin Cities, Minnesota, with her husband, Bill, and Sheila — their Dalmatian/ Spaniel, who was rescued from a high-kill shelter in Miami. Besides writing, she devotes considerable time to crafting and runs YourPaperPantry.ning.com, an international website for crafters and mixed-media artists. Her YouTube channel (RoxyFur) subscribers now number upwards of 9,000.

Originally from Houston, Christopher Salas moved to San Antonio as a teenager. He was injured in a car accident in 1997 but has never looked back. Besides being the founder and executive director of Rolling Inspiration, the United Spinal San Antonio Chapter, he is active in educating the public and advocating for those with disabilities. He has been a United Way Volunteer of the Year in the group category and has been inducted into both the Warm Springs wall of fame and Morgan’s Wonderland walk of fame.

Denise McQuade is a United Spinal board member who is employed as a Public Information Coordinator, Paratransit Division, for MTA New York City Transit. She is also former executive director for the Brooklyn Center for Independence of the Disabled and has worked on passage of human rights legislation, various public transit programs, passage of the ADA, and compliance issues.
Fix the Bug
Ben Mattlin notes that the newest version (“Dragon Individual Professional for PCs and MACs,” November 2016) “now automatically saves your user profile,” but Dragon Dictate for Mac has done that since version 3. This is hugely annoying since my speech dysarthria often results in bad sessions that I do not want to save. I have diligently called Nuance when I first bought version 3, and upon subsequent upgrades to versions 4 and 5. [Now with version 6] … it remains impossible not to “save” (i.e. the profile), when closing out of the program, and therefore one ends up saving whatever incorrect profile changes have been made during the last session. I have patiently called Nuance about this several times. If they can’t fix a simple bug like this, it seems more worthwhile to use the Mac’s inbuilt dictation software (especially “enhanced”).

Erich Pieper
via newmobility.com

If Only Medicare Would Pay
This would be wonderful if Medicare would cover a large portion of the cost (“The iBOT Returns …”). My son is in a chair and has Medicare, not Medicaid, and he has to pay out of pocket a lot of times because many things are not covered. This would truly be a blessing, if it were!

Joni Haubert Mitchell
via newmobility.com

Tribute to EDI Founders
Unfortunately, most of the original founding members of Measure E (the ballot proposition that made Easy Does It possible) have since passed away (“Easy Does It Provides Emergency Caregivers and Repairs,” November 2016). Tributes and recognition belong to the late Mia Rodolfo-Soisson, Michael Pachovas, Scott Luebking, Phil Chavez, Willard Harris, and several others.

Blane Beckwith
via newmobility.com

Wound Healed, Infection Gone
HBOT works (“Can Mild Hyperbaric Oxygen Therapy Help You? At What Cost?” November 2016). It saved my right leg that had a bad bone infection. I was facing amputation, and HBOT was the last resort. The infection disappeared and the wound that caused the infection healed up. It was like a miracle.

Rick Sorensen
via newmobility.com

Water Workout Is Best
For me water aerobics is a life saver! (“Total Body Fitness Videos Make Exercising Easier,” November 2016). I feel like the pool offers me a level playing ground so that I can participate at my own ability and level of endurance. I also love working out without being all sweaty. I have been doing aerobics for decades and I started doing water aerobics about 10 years ago. The water is gentle on arthritic joints and helps to allow me to assist my non-working left leg to be stretched and moved by my working limbs so that it doesn’t atrophy so badly.

Mary Doran
via newmobility.com

Bladder Stimulator Option
I liked your column on bladder meds, dementia and Botox [Bully Pulpit, October 2016]. Dementia issues (cognitive and executive dysfunction) are not fun. One option you did not include in your article is this: Medtronics Bladder Pacemaker Stimulator. It is not technically approved for neurologic conditions yet, but there is a test you can have done to see if you are eligible for it. I had a penile implant and trying to catheterize causes a lot of pain and I am trying to prevent it, because of the pain. My bladder is one-third the size it is supposed to be and still getting smaller, so catheterizing will come someday, with possibly bladder augmentation.

Tim LaPlant
via newmobility.com

Feedback
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21st Century Cures Act Signed, Protects Access to Mobility Equipment

On Dec. 13, President Obama signed the 21st Century Cures Act, a massive piece of legislation to help fund a wide variety of health initiatives, including Medicare’s coverage of mobility equipment for those with disabilities. Passed with overwhelming bipartisan support in both the House and Senate, the landmark bill aims to overhaul the health system by increasing funding for medical research, advancing the development and approval of experimental therapies and providing grant assistance to states to deal with the opioid crisis. Congress also included language to protect access to mobility equipment in Medicare.

The federal Medicare office had planned to cut funding for complex rehab technology, which includes manual and power wheelchairs, seating and positioning systems and other various adaptive technology necessary for those with physical disabilities. Passed with overwhelming bipartisan support in both the House and Senate, the landmark bill aims to overhaul the health system by increasing funding for medical research, advancing the development and approval of experimental therapies and providing grant assistance to states to deal with the opioid crisis. Congress also included language to protect access to mobility equipment in Medicare.

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“The cuts to CRT were scheduled to take effect on January 1, 2017, and the Reeve Foundation and our partners in D.C. have spent the last few months urging Congress to stop the cuts,” said the Reeve Foundation’s blog.

While passage of the bill did include an extension on the CRT cuts, the delay is temporary since the legislation only provides a six-month postponement. “Please just take a moment to thank your legislators for passing the 21st Century Cures Act,” the Reeve Foundation said. “Let them know that we’ll be working with them in early 2017 to enact policies to assure continued access to this specialized equipment.”

For more information or to get involved, visit unitedspinal.org and/or christopherreeve.org.

— MAUREEN GAZDA

Advocacy Groups Sue For Better Access to Red Rocks Concert Venue

A coalition of Colorado disability advocacy organizations filed a class action lawsuit on Dec. 1 against the city of Denver on behalf of six disabled Coloradans claiming that the city-owned Red Rocks Amphitheater violates the ADA by failing to provide “meaningful access” and seating for wheelchair-using patrons. The renowned concert venue, located in nearby Morrison, is built into a steep hillside that limits accessible seating to the front row and the rearmost row, but front row seats often sell out due to demand by nondisabled patrons.

According to Kirk Williams, a C7 quadriplegic and one of the plaintiffs, sitting in Row 70 [the rearmost row] “does not even compare” to sitting in Row 1. “You’re so far away that you can’t even see the performers. The sound isn’t as good. There’s a crowd behind you with the concession and beer sales, so there’s always a lot of background noise.” Williams says Row 1 seats sell out fast, only to appear minutes later on ticket resale site StubHub at inflated prices.

The lawsuit alleges that due to the city’s policies and practices, Row 1 seats are typically purchased by patrons without qualifying disabilities. “The most I’ve seen in Row 1 is four wheelchairs out of 50-60 seats,” says Williams. “But there will be a group of college guys dancing and doing cartwheels. That’s not why it’s here. It’s not a VIP section, it’s so people in chairs can actually see a show.” The lawsuit claims that Red Rocks, with overall seating capacity of 9,525, provides insufficient accessible and companion seating.

The Colorado Cross-Disability Coalition, the Civil Rights Education and Enforcement Center, and Disability Law Colorado have been lobbying the city to change its practices since 2015. The advocacy groups want the city to mark Row 1 as accessible seating and allow bouncers to ask patrons without a clear mobility impairment to move to a nearby row. They would also like wheelchair users with general admission tickets to be able to be reseated in Row 1 when space is available. Frustrated by what they perceived as the city’s unwillingness to change their seating and ticketing policies, the plaintiffs decided to file the lawsuit as a way to force the city into action.

The city released the following statement in response: “We will continue to work with groups representing disabled communities, in order to improve the experience of patrons with disabilities to the extent we are allowed by law, including the ADA, and the unique characteristics of venues like Red Rocks Amphitheater.”

— SETH McBRIDE
Since 1946, United Spinal Association has been there for members like you, ensuring that life on wheels is more accessible, affordable, and offers more opportunities for living fully.

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- $10 pays for metro card for a member advocate to meet with their elected officials in Washington, D.C. during Roll on Capitol Hill.
- $20 pays for a year’s printing and postage for a subscription to New Mobility.
- $30 provides a New Beginning Backpack filled with resources to someone living with a new spinal cord injury.

Your donation helps United Spinal continue to offer our members resources and advocacy that make life better by providing priority access to personalized problem-solving for living with spinal cord injuries and disorders, a subscription to our award-winning membership magazine New Mobility, and other valuable benefits, including representation in local, state, and national advocacy.

Thank you for your commitment to our mission.
As a filmmaker, Murray Siple’s first love was documentaries. “Before the accident I went to art school and was making skateboard and snowboard films internationally,” says Siple, a 46-year-old C6-7 quad from Canada. A resident of Vancouver, B.C., he has always found inspiration in his environment. After his injury, he made a documentary about homeless men living near his house called *Carts of Darkness.*

But his injury definitely forced him to modify his directorial style. Injured in a car accident when he was 26 years old, he subsequently became paralyzed as a result of a doctor’s mistake. “The doctor misread the x-ray and missed my broken neck,” he says. “When the collar was removed, my neck broke more and caused permanent paralysis.” He now has a film crew that he brings with him in his van. “I create a script and return with the crew and direct them from my van on how we can recreate or encourage the same activities I learned of the subjects the day before while scouting,” he explains.

Because of the circumstances of his injury, Siple was also able to receive financial compensation. With the money he built a stunning one-level 2,700-square-foot universal accessibility masterpiece. “My home is 100 percent accessible in every way, yet we designed around the common features needed to make it this way so they are now part of the design and almost unnoticeable. Basically the accessibility dictated the design, which makes it extremely unique.”

Siple is as dedicated to his art as ever. When he was newly injured, he only briefly doubted if he could still direct. “I was still me — a filmmaker, and film directors sit in directors’ chairs. I knew that if I could still express myself, I could continue my life as an artist despite my physical limitations.”

Watch the full-length documentary, *Carts of Darkness* online: www.nfb.ca/film/carts_of_darkness/
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New wheelchair users quickly discover the world is an inconvenient place. Counters are too high, things are constantly out of reach, everything, it seems, is a struggle. Most of us find work-arounds or create tools to deal with these obstacles to living the lives we want. Some fixes are as crude as my piece of .75-inch diameter PVC pipe with a wine cork and a clothes hook in one end to flip hard-to-reach switches or to pull things closer. Others are more elaborate and complicated.

Here is a simple gizmo to get your adaptive juices flowing:

Skip Lonie is a carpenter. After a spinal tumor turned him into a T12 para two years ago, a big frustration for him was finding a way to carry his tools around conveniently without having them fall off his lap. A conventional carpenter’s belt wouldn’t work and besides, how could he carry a power drill, a circular saw or a sander and wheel at the same time? His solution is a Container Store metal basket hose-clamped to PVC pipe that slides over his arm rests. The basket stays stable on his lap while he wheels around his shop or Home Depot, the local Safeway or Walgreens.

As with most do it yourself projects, Lonie needed to change, modify and tweak the design a bit along the way. He found his original design too noisy and prone to break down, but after a few modifications he says it worked like a charm.

THE GIMP MACGYVER
At the other end of the adaptive gizmo spectrum from Lonie you’ll find Brian Johnston — aka “Brain” to wheeler pals back in the day. He is as close to a Gimp MacGyver as I’ve ever run across. He operates with a “there must be a way” mentality that allows this C5 quad of 40-some years to not only live totally independently, but also pursue hobbies and interests that would be demanding and challenging to the most skilled and adventure-some of nondisabled handymen.

He wanted to rebuild vintage minibikes and lightweight Harley Davidsons, so he found a way to adapt power tools and other necessities to meet his needs and capabilities, much like he came up...
with novel solutions and work-arounds to the endless problems quads deal with every day. He built a business around it in the 1980s, hawking his “gimplements” via a mail order business until he began an adventure in real estate — all while finding the time and energy to own and manage an apartment building. He reinvented the business in the 2000s but stopped offering many useful items due to waning demand.

When asked about his most useful and used items, Johnston began with what he sold as “Shut the Door.” The problem, as all wheelers know, is simply shutting a door behind you — a problem especially vexing for quads with limited strength, balance, flexibility and hand dexterity.

“I tried the usual: a shoelace around the door knob, then gripping it with my teeth, but then you’ve got this ugly string on the knob that’s always breaking, so I came up with the Thighmaster,” he explains.

The Thighmaster? “Well, that’s what all my girlfriends used it for.”

The device is placed against the wall the door opens to. When Johnston exits the door, pushing against the door compresses the spring, which then recoils back against the door, pushing it shut. Problem solved.

From there he moved on to his ankle cuffs. Having leg spasms in bed would pull his legs up into a fetal position. “I’d have to keep sitting up to straighten my legs out. Eventually they’d spasm again, and I’d have to sit up to straighten my legs out again. I first tried a 1-inch Velcro strap, a pull-up-your-pants dressing loop I came home with from the hospital. Velcro against the skin didn’t seem too smart, so I went to 2-inch webbing lined with sheepskin.”

The cuffs wrap around the ankles and attach to each other with a piece of rope that runs through a sailing cleat mounted on a small piece of wood that sits between the mattress and box springs. “My spasms are mild and just need a bit of resistance to calm them down. Pulling on the rope straightens my legs out, and the sailing cleat keeps them there. It takes maybe $15 of materials.”

We moved on to spray cans. “After I had some small bikes sandblasted, I didn’t want to wait around for someone to help me spray them. First I tried just using my finger and hand brace, but then couldn’t move the can up or down or side to side due to lack of balance. Then I tried using my teeth, but my lip would get in the way and turn my face different colors.”

“After some thinking and trial and error, I cut a flat piece of 1-inch steel with the torch, drilled a hole in it and ran a threaded metal rod through the hole to hit the sprayer button. I bent the piece of steel a couple times — once so I could clamp it to the can and another for the trigger mechanism. Then I bent the threaded rod, welded a washer to it and put a spring between two nuts on the metal rod to the trigger. I attached it to a spray can with a hose clamp. Then I could use my hand brace and spray.”

Got all that? Me neither. Once you see a photo or two of the final product, it all begins to make sense.

“It works for anything that sprays — paint, WD-40, bug spray, air freshener, you name it,” he says. He even made one for a fire extinguisher.

Nothing stops this guy. When he tired of repairing his hand brace, he simply made a replacement built to last.

**THE ULTIMATE DIY POWER ASSIST**

Johnston’s pièce de résistance is his DIY power assist. “I used E-Motion wheels for years, but they’re really heavy and I wanted to rest my arms more. I didn’t have $6,000 or $7,000 for a SmartDrive. A buddy who works for a trash collection outfit said he came across motorized Razor scooters from time to time, and he got me one. It was in pristine condition,” he recalls.

For less than $100 and a case of beer, Johnston created his own wheelchair power assist.
“I designed a mount and figured out a way to connect the motor to the wheel. I used a simple knob — like the volume on a stereo or a wall dimmer switch — to control the speed. The scooter was 24-volt, but when I tried it on my chair, I could go 15 mph. I don’t need to go that fast, so I rewired it for 12 volts. Now the batteries should last twice as long, and they let me get up to about 8 mph.”

He says it works great. His first test ride was five miles of varied terrain, including several challenging hills, with no signs of slowing down. Then he put it in a vise on his work bench and turned it on at about a third of the speed. When he checked after eight hours, the batteries were still showing 12 volts. Eventually it ran for the better part of a day. It’s all switch operated. He just needs to turn it on and guide the wheels. He didn’t get started until mid-August, so wasn’t able to do much testing out of the house, which is where he plans to use it.

“It’s perfect,” he gushed. “If I was to build it from scratch, it might take about $150 for everything — motor, batteries, all the hardware. I spent less than $100 and a case of beer to Danny for finding it. Sure beats $6,000. I wish I could make and sell them. People have offered me stupid money for one, but it’s just too much liability, too much trouble, too many lawyers. I’m afraid to share the plans with people because of liability.”

For more of Johnston’s gimplements, go to Idea Mobility at ideamobility.com/. You can see the Brain Wheel in action atyoutu.be/nKbUljk3XVM.

Gimplements are born out of need and a willingness to negotiate with disability. They can be quite crude — the clothes hook on the end of a plastic pipe — or sophisticated, as with Johnston’s Brain Wheel. What they all have in common is that they meet a need and allow the user to live on their own terms.

Gimplement Basics

**Meeting the Need**

For myself, I stick to simple gimplements — more like Lonie’s tool carrier-basket. I like to read in bed for an hour or more before turning in at night. I bought an adjustable bed, only to find that in the sit-up mode I was too far away from my night table to reach my tea or light switch. Moving the table forward put it about three feet away from the wall as well as created other problems. The solution came by way of roller tracks used for roll-out shelves or drawers. I mounted a track on each side of the table, built a new tabletop and attached it to the roller tracks. Now I can simply reach back and pull the table top forward and voilà! — problem solved.

Gimplements are born out of need and a willingness to negotiate with disability. They can be quite crude — the clothes hook on the end of a plastic pipe — or sophisticated, as with Johnston’s Brain Wheel. What they all have in common is that they meet a need and allow the user to live on their own terms.

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Unlike most cold-climate wheelers, Dave Kott can’t wait until the first snowfall at his Minnesota home. It’s then that he can put to the test his newly improved, homemade snow plow that runs with the use of actuators, similar to his Wheelchair Reacher. Now, if you just envisioned one of those handheld reacher/grabber gizmos, you need to think on a much larger, holy-smokes scale, because his inventions are destined to change the way we get things done from the seat of our chairs.

Modeled after how an excavator works, Kott’s Reacher can lift, move and haul items up to 40 pounds. That means everything from picking up a dropped screw in his workshop to hauling trash barrels down his driveway. A toggle manipulates actuators that work the unit, which is fitted with a claw at the end. The actuators are similar to a vehicle hydraulic actuator that opens and closes a hatchback, but is motorized. The wooden base, using old wheelchair wheels, will soon be made out of metal.

ROAD TO FRUITION

A master plumber, Kott was running a successful contracting business when he sustained a C5-6 complete injury in a 2006 dirt bike accident. He has made small steps in the 10 years since, working toward a new livelihood.

“I started the plumbing up again but didn’t like just managing things,” explains Kott. “I began taking general classes toward an engineering degree but decided that wasn’t the road. Because I really liked the drafting and computer-aided design work I had done, I switched to that to build things.”

Unable to move his fingers and with limited hand use, Kott knew he needed adaptive shop tools to create his ideas. He and a friend developed simple adaptations — including a handle on a saw and a piece to hold wood while drilling — to allow him to work more on his own.

“It started there and I kept picking at things and moved further along and eventually was able to do more and more on my own,” he says. “All the while I was trying to figure out what I wanted to do for a living. I knew it wasn’t sitting behind a desk. I wanted to be in the shop, but was like, ‘Who’s going to hire me in their shop?’”

He designed his Wheelchair Reacher in his head five years ago and waited until he could afford the Fusion360 software and cutting system needed to bring the mechanical device to reality. In early 2013, Kott sold his house to move in with his girlfriend but was sidelined by a pressure ulcer that took two years and surgery to heal.

In mid-2015, Kott used $18,000 of equity from his house sale to purchase a CNC plasma-cutting table, which includes a computer, plasma torch and cutting table. This setup enables him to design what he envisions onscreen, and with a tap on his keyboard, send data to start the cutter.

Kott also creates and sells fire pits at art fairs and does custom artistic signage and decorative elements for the home. He recently began working with a snow plow company — making parts for its plows — and eventually wants to expand to hire employees. He envisions a scale version of the Reacher that would fit onto a power
chair arm and run off its toggle. He has a part time employee now and would like to grow his business.

“This is a very broad industry, but that’s the challenge of it,” Kott says. “It’s going to be a lot of trial and error, learning the best applications for customers.”

Kott is excited to try out his new snow plow, but, as with any mechanics, knows there may be bugs to work out.

“There’s always some things that may break or not work, but I can fix anything as I go,” he says.

As for stressing his Permobil C300, Kott says in seven years he’s only had to replace one gearbox, as he keeps everything under the chair weight limit.

Soon, after the first good snowfall, he will go from using a wooden plow base that attached to his chair with store-bought gate latches, to a new metal unit fitted with latches he created himself that automatically attaches when he drives up to it. Using a 42-inch Craftsman plow blade, instead of engaging the tilt on his wheelchair to dump as with the previous prototype, he’ll toggle the new unit to lift up as he moves forward to dump the fresh, white snow.

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Everybody has to go. For those of us with neurological conditions like spinal cord injury, multiple sclerosis, or even complications from a stroke, you can often feel tethered to the toilet. In fact, bladder and bowel control consistently rank among the most important functions to regain among people living with spinal cord injury, according to a study led by Dr. Kim Anderson-Erisman of the Miami Project that surveyed nearly 700 cohorts.

Understanding bladder and bowel options starts with knowing how the systems work. The urinary system consists of an upper tract and a lower tract. The upper tract includes the kidneys and ureters — the ducts that drain urine from the kidneys. The lower tract consists of the bladder, sphincter and urethra. Think of the bladder as the body’s holding tank for urine, while the sphincter is the door and the urethra is the pathway. In a normal functioning system, when the bladder is full, a sensory signal sent to the brain says, “Hey, you need to go.” Once you are in an appropriate position to release, a signal is sent from the brain through the spinal cord telling the sphincter to relax and open the door, allowing urine to pass through the urethra. But for those of us with neurological conditions, the process doesn’t work like that.

For spinal cord injury, neurogenic bladder dysfunction is dependent on the level of injury. Those with lower level injuries can have a flaccid bladder, meaning the bladder does not contract when it is full. High level injuries tend to have a hyperactive bladder (the bladder is overactive with contractions, while the sphincter is underactive). Complications from not managing a neurogenic bladder can lead to frequent urinary tract infections or damage, renal injury or failure, autonomic dysreflexia or simply a stinky mess. These complications are nothing to brush off. They can lead to serious health complications and even death.

Coming up with a way to manage your unique bladder management method means focusing on preserving the system, minimizing complications and matching your lifestyle. Conventional methods of emptying the bladder are intermittent catheterization, credé (pushing manually on bladder), valsalva maneuver (straining), indwelling catheters and external or condom catheters. Oral or patch medications such as alpha blockers or anticholinergics — like Ditropan, Detrol or Vesicare — can help. (For more on the benefits and risks associated with anticholinergics, see “Anticholinergic Medications and Dementia: Clarification, Perspective, Options,” August 2016.) Reflex voiding can be an option, or even surgical procedures like bladder augmentation or continent urinary diversion.

For the bowel system, food is digested through the intestines and makes its way to the colon. Nerve signals are sent to the brain, alerting when evacuation is necessary, and the process begins voluntarily involving the rectum. For those with neu-
logical injuries, it is not so easy. For T12 injuries or above, reflexic bowel dysfunction is common. However, since anal reflexes stay intact, defecation can be triggered by stimulating the rectum (using a finger or device) to open the anal sphincter so stool comes out. For those with T12 injuries or below, an areflexic bowel is common. In this case, the rectum loses its reflexes and stool can leak out.

Similar to the bladder system, the bowel system has no singular approach that is adequate; a combination solution is usually needed. Finding the right evacuation method — such as manual removal or digital stimulation — and keeping on a schedule are first steps for a bowel care program. Also finding the right medication and/or device can help make the program less burdensome and reduce the overall program time.

Medications can be in the form of oral medications, like stool softeners (Colace or Docusate), bulking agents (Metamucil or Benefiber) or hyperosmolar agents (Milk of Magnesia or Miralax). There are also suppository medications like colonic stimulants or bisacodyl (Magic Bullet or Dulcolax) or mini-enemas (Enemeez). There are full enema or flushing systems to help get the job done, too — like Peristeen transanal evacuation system or the PIE pulsed irrigation system — that use water to help clean out the pipes.

Keep in mind one of your best means to keep bladder and bowel systems healthy is a good routine and proper nutrition. Authors Kylie James and Joanne Smith offer some great advice in their book, Eat Well, Live Well with Spinal Cord Injury. For example, good bowel nutrition requires not only plenty of fluids, but also gearing your diet toward high fiber foods like whole grains, oatmeal, beans, legumes, nuts and fiber-friendly fruits and vegetables (apples, berries, apricots, spinach, broccoli or sweet potatoes.) These options have been around for a long time.

What’s New?
In 2013, the FDA approved the use of onabotulinumtoxinA, otherwise known as Botox, for the treatment of overactive bladder. Injections are made directly into the bladder to relax the bladder muscle. A study published in 2015 showed that those with thoracic or lumbar injuries responded better than those with cervical level injuries. The typical effective time between needed injections was eight months, and some people were able to discontinue their oral bladder medication completely.

Implanted electrical stimulation that directly activates the bladder is another option that is currently on the market for people living with spinal cord injury. The system is surgically implanted with an external control unit for the user to select options for voiding the bladder, evacuating the bowels, or for males, getting an erection. The down side of this device is not only the surgical risk, but also that it requires a dorsal rhizotomy, or cutting the sensory nerves of the sacral spinal cord. In Europe, the device is sold by Finetech Medical as the Brindley device. In the United States, it is no longer available. Other neuromodulation devices are available on the market in the United States and can be considered under the advisement of a trained urologist.

Sacral nerve stimulation requires an implanted device that sends electrical pulses to the sacral nerve and is offered by Medtronics (InterStim) or Axonics (SNM systems). Both de-
vices have an option to test the system on a trial basis before getting the full system implanted, giving you the ability to see if the device will work for your particular situation.

Tibial nerve stimulation (a method of modulating bladder reflex pathways) is a conditional treatment that typically delivers around 30 minutes of stimulation to the tibial nerve in the lower leg. Systems like Cogentix Urgent PC or Medtronic NURO system use percutaneous electrodes to control the bladder. Home-use implanted tibial nerve stimulation systems are currently in development by Nuviant Medical, StimGuard and BlueWind Medical.

There are also pelvic floor stimulators (external devices that provide stimulation to the pelvic floor muscle to improve the voluntary opening and closing of the urethra). With these devices there has been expanded use specifically for neurogenic bladder dysfunction, and there are active clinical trials exploring more qualification data as well. When choosing any option that is currently on the market or in trials, Dr. Graham Creasey, surgeon at the Palo Alto VA Medical Center and Stanford University, advises, “Leave your options open, think long term and be aware that things can change.”

On the Research Front

With all these options, there is still much activity on the research front to find better solutions, particularly in the medical device realm. The Craig H. Neilson Foundation has put efforts toward further research, and the National Institutes of Health specifically identified bladder and bowel control as a key area for development in their five-year research plan. So,
what is actually happening on this front? A list of human clinical trials can be found through clinicaltrials.gov, but here are a few highlights:

A company called Spinal Singularity is developing the Connected Catheter. Led by Derek Herrera, who lives with paraplegia, the company is working on a device that is an extended use, internally inserted, smart catheter. It has a pressure sensor to notify the user when the bladder is full and needs to be drained. The device has a valve to open and close the urethra upon command by the user. It is designed to minimize unexpected leakage and the need for an external leg bag. It is currently under development with clinical trials in the United States projected later in 2017.

Other ongoing trials are looking at the impact of gait training on bladder function, and also epidural stimulation or even electromagnetic stimulation. Then there are mechanical interventions. Magnetic valves, such as the FENIX system, are being developed to go around the urethra or colon to maintain urinary or fecal continence. Women may benefit from devices such as the Eclipse system, which involves a vaginally-inserted pressure balloon that pushes up against the rectum to maintain fecal continence. These systems may be more appropriate for individuals who do not have intact pelvic reflexes on which electrical stimulation devices act.

Another encouraging and related area of development in technology is dorsal genital nerve stimulation, which stimulates the dorsal penile nerve in males or the dorsal clitoral nerve in females. There have been some small studies conducted in Europe. One study conducted by a team at the Institut Guttmann Neurorehabilitation Hospital in Spain found that 10 out of the 12 participants used DGN stimulation to decrease undesirable bladder contractions and in turn increase bladder capacity. Another small study at Radboud University Nijmegen Medical Centre in the Netherlands demonstrated in seven of the eight participants with SCI that DGN stimulation suppressed involuntary contractions.

At Case Western Reserve University in Cleveland, Ohio, researchers are developing a device in clinical trials using external surface electrical stimulation to block the reflexes of voiding contractions. Drs. Dennis Bourbeau, Kenneth Gustafson and Steven Brose recently completed a short-term chronic test of genital nerve stimulation in study participants with SCI. This particular study enrolled 24 participants with neurogenic overactivity, spinal cord injury and pelvic sensation. The results showed that 23 of 24 individuals tolerated the stimulation at levels needed to block reflexive bladder contractions or increase capacity of the bladder. Plus, the stimulation did not cause autonomic dysreflexia or intolerable spasticity.

In another study conducted by the same research team, participants (also with neurogenic overactivity and SCI) used the external GNS device in their home settings with the option of continuous stimulation throughout the day or on demand stimulation. After one month of use, they reported a significant reduction in leakage events throughout the day. Although reporting to be satisfied, participants also reported a primary concern was the bulkiness of the system. With these results, researchers
are now looking to develop an implanted device to stimulate the same nerves and hope to not only reduce urinary and bowel incontinence but improve sexual function.

The ultimate goal of research is to improve quality of life for people with SCI or other neurological disorders. “If our approaches are successful, we hope to improve confidence, independence, and dignity for these individuals as well as significantly reduce costs and burdens related to care,” says Bourbeau.

Finding the right options for managing bladder or bowels is not just a health issue but a lifestyle one, too. Sometimes the right solution for you may be a combination of treatments. It is really important to find a doctor who is willing to work with you to help you find that right fit — so you can break that tether to your toilet.

Resources

- Bladder and Bowel Articles (archived columns and features from New Mobility): search “bladder” or “bowel” along with other keywords on newmobility.com
- Bladder and Bowel Foundation: www.bladderandbowelfoundation.org
- Eat Well, Live Well with SCI: www.eatwelllivewellwithsci.com
- National Foundation for Continence: www.nafc.org
- Neurotech Network Bladder Management Fact Sheet: www.neurotechnetwork.org/factsheets/factsheet_urinary.html

- Options for Bladder Management: www.msktc.org/lib/docs/Factsheets/SCI_Bladder_Health.pdf
- Research and Reports from the NIH: Neurogenic bladder in spinal cord injury patients: www.ncbi.nlm.nih.gov/pmc/articles/PMC4467746/
- United Spinal Association (archived webinar and resources):
  - Bowel Management: www.spinalcord.org/video-solutions-bowel-management/
  - Bladder Management: www.spinalcord.org/video-solutions-bladder-management/
- Uro Today: www.urotoday.com

Companies

- Axonics SNM: www.axonicsmodulation.com
- Congentix, Urgent PC: www.cogentixmedical.com/
- Fenix: Torax Medical: www.toraxmedical.com
- Finetech Medical: finetech-medical.co.uk
- Medtronic, NURO system: www.medtronic.com
- Peristeen: www.coloplast.co.uk/peristeen-anal-irrigation-system-en-gb.aspx
- PIE Medical: piemed.com
- Spinal Singularity: www.spinalsingularity.com

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FROM THE MOVIE ME BEFORE YOU TO THE UNTIMELY DEATHS OF 5-YEAR-OLD JULIANNA SNOW AND 14-YEAR-OLD JERIKA BOLEN, OUR SOCIETY’S MESSAGE OF “BETTER DEAD THAN DISABLED” IS AS INSIDIOUS AS EVER. THOSE DISABLED ACTIVISTS WHO RESIST THIS MESSAGE ARE OFTEN MET WITH SCORN, EVEN DEATH THREATS, YET THEY STAY STRONG IN THEIR FIGHT TO DEFEND THE LIVES THAT ARE SO OFTEN DEVALUED BY OTHERS. THIS YEAR, WE ARE BREAKING FROM OUR TRADITION OF NAMING ONE PERSON OF THE YEAR TO INSTEAD HONOR THE ACTIVISTS WHO WE ARE COLLECTIVELY CALLING THE RESISTERS: CARRIE ANN LUCAS, TK SMALL, EMILY WOLINSKY, DIANE COLEMAN, DOMINICK EVANS, TARI HARTMAN SQUIRE, ELLEN STOHL AND SO MANY MORE. LEAD ON!

It started with Me Before You. Sam Claflin, the star of this past summer’s blockbuster hit, Me Before You, hosted a Twitter chat on May 23 for his fans so they could #AskSam questions about his new movie. As most know by now, Sam played Will Traynor, a wealthy, good-looking quad who found love and then killed himself because he didn’t want to live as a disabled man any longer.

“I hope that your character doesn’t make me cry in the movie,” Tweeted Clara Salvatore, echoing many fans. “I cried when I read the book.”

Then Tweets came asking, “what’s your favorite quote?” and “what’s your favorite scene,” and of course, the ubiquitous “how did playing Will make you feel?”

Then the mood started to shift as people with spinal cord injuries and other disabilities showed up:

#MeBeforeYouthanks for setting#Disability Rights back by 30 years,” — Leena Hague

I have #MeBeforeYou Will’s disability. Stop killing me on film! #liveboldly, fight cripple snuff films. — John Kelly

#MeBeforeAbleism because no child should EVER have to hear “I would rather kill myself than have a disability.” — Ayanna Justine

It was as if a disability rights Bat Signal went up somewhere, calling all those with disabilities resisting the “better dead than disabled” message that is so ingrained in our culture to come on out and fight back.

In a way, that’s exactly what happened. “We found out about the #AskSam chat the night before it took place, and only had hours to try to recruit as many people with disabilities as possible to take part,” says media advocate Dominick Evans,
who has spinal muscular atrophy and lives in Wallbridge, Ohio. “Activists in the United Kingdom were also protesting the film — it was written by a British author with a British cast. We combined our efforts and I think this was the first time we had an international community of people with disabilities activating on Twitter together on an issue.”

The advocacy efforts were so strong that soon messages of resistance popped up on television, traditional newspapers, online news sites, and poured out into the streets as British activists protested the movie’s May 25 posh premiere in London. “‘This film is offensive to disabled people, the vast majority of whom want to live — not die,’” said British actor Liz Carr, a wheelchair user well-known for her role on the UK’s Silent Witness.

Many cities across Britain, the United States and as far away as Australia saw disabled activists leafleting the movie, from big cities like New York to small ones like Harrisburg, Pennsylvania. Collectively the protests were so successful that Forbes published an article on May 31 with the title, “Will Protests Against Me Before You’s Disability Representation Affect Opening Weekend Profits?”

There are not many movies about, or even featuring, wheelchair users, and a high percentage of the ones that do exist end with the death of the disabled person — think Million Dollar Baby. This doesn’t match reality, in which most people with spinal cord injuries or other mobility impairments live well with their disabilities. The unbalanced view in the media about how disability is experienced can have real-life consequences, warn the resisters.

That’s why they fight so hard.

SENDING UP THE ‘RESISTANCE SIGNAL’

Resistances don’t just happen. They have to be built, nurtured.

Media guru Tari Hartman Squire knows this very well, having been part of the disability rights movement since the ‘70s. Squire has successfully helped disabled actors be cast on screens big and small, and she’s coached organizers on how to frame their issues in ways that mainstream media will pick up and repeat.

These days Squire is active with DisBeat, a national communications initiative to provide the media with accurate information about disability issues. The group didn’t seem to be having much success in early 2016.

“In the context of this year, we were hit with the State of the Union not even mentioning disability, and then #OscarSoWhite — again, no mention of disability — and we circled the troops after that,” says Squire. “And by the summer it became clear that disability being ignored in the media was a pattern. So when Dominick Evans and Diane Coleman made DisBeat aware of Me Before You, we thought, yeah, this could be an organizing opportunity.” Coleman is executive director of the anti-euthanasia group Not Dead Yet.

Those protests that erupted? “Not Dead Yet took the lead and we were the vessel linking press to different activists,” says Squire. “Diane Coleman and John Kelly and Dominick Evans and Carrie Ann Lucas came up with such great marketing materials that were so crisp and right on.” These included banners declaring “Me Before Euthanasia” that were made available to activists, as well as some original tactics. “Sandra Connor in Australia along with our intern came up with bookmarks so people who didn’t feel comfortable leafleting could go in a bookstore, put the bookmark in the Me Before You books and slip away. Then people who bought the book would find it, and learn about Not Dead Yet. It was great guerilla marketing. Because it was so beautifully executed, the mainstream press started paying attention.”

That headline about disability protests possibly affecting the movie’s bottom line? “That never happened before,” says Squire, who credits activists Mark Johnson, Stephanie Hydal, Lawrence Carter-Long and New Mobility contributing editor Ellen Stohl for explaining to reporters the effect movies like Me Before You have on the lives of real people.

In Buzzfeed’s June 9 article, “The ‘Me Before You’ Backlash Was Bigger Than Anyone Expected,” Stohl, a C8-T1 quad who teaches at California State University, Northbridge, talks about how she wanted to die after her injury.

“I thought my life was over,” said Stohl, a teenager at the time of her injury. “I was still a virgin, [I thought] I was never gonna have sex, I could never be an actress, I could never have a husband, a career, a life. I really did believe that when I woke up”
I was upset about this movie in particular because it really promoted the theme “better off dead than disabled” — not only that the person with a disability is better off, but everyone else in that person’s life as well. This common stereotype is very dangerous.

When I was injured at age 19 in 1982 I felt life was not worth living and that I’d be a burden on my family. I was lucky that my mom and my family fought against my desire to just die instead of leaving the choice to me or, God forbid, supporting my choice.

Even after the first few years, people with new injuries do not know what life will be like, and with the rampant negative preconceptions about life with a disability, it is easy to see why they think living with a disability is a life not worth living. We do not see enough role models in the real world, so society does not realize that life with a disability is a life worth living and can be full, meaningful, and have tremendous quality and joy.

This movie struck a chord because I look at my amazing daughter and know that if I did what the main character did, she would not be here today. I know the world would be less beautiful if she was not a part of it.

I thought I wanted to die after my injury, but that was because I could not see the possibilities. I was blinded by the negative stereotypes and preconceptions. The main character in Me Before You was also blinded by these false representations, but even when he was given the opportunity to see, he chose to close his mind and opt for death.

What a devastating message wrapped up in a heart-wrenching romantic film to make it easy for the public to swallow and believe.

[after the accident]. She attempted to refuse a life-saving blood transfusion while she was in the hospital. During a Me Before You protest in 2016, sitting several yards away from her 12-year-old daughter, she related this same story to two people who stopped to listen.

“Thank God,” Stohl said, raising her hands for air quotes, “my mom didn’t respect my choice.”

What made Stohl’s statement, and all of the Me Before You advocacy, so successful was that activists told simple truths about their own lives, coupled with protests and skillful utilization of social media.

It seemed as if the message of “better dead than disabled” was finally being corrected to “our lives are worth living.”

**A REAL LIFE ‘ME BEFORE YOU’ STORY**

While advocates were making headway resisting the death-affirming message of Me Before You, a 14-year-old girl with quadriplegia from spinal muscular atrophy decided she no longer wished to live.

On June 3, Jerika Bolen’s mom, Jen, created a GoFundMe page called J’s Last Dance to raise money to throw her teenaged daughter a prom, since if all went as planned, her daughter would enter hospice with the intent of dying at the end of the summer. Here’s part of what Jen wrote:

“She has let me know now that she needs to be free of her broken body. She has a couple last wishes that I would love your help with. She wants a to have a ‘prom’ … one night of music and dancing and fun. She wants a disco ball and black and lime green decor and to be surrounded by lots of friends she has been unable to see for a long time. … After that she will come home and begin her journey to Heaven.”

The GoFundMe goal was $25,000 but raised $36,482, and Jerika got her prom on July 24. Then, true to her word, she entered hospice either near the end of August or the beginning of September and died on Sept. 22.

New Mobility first became aware of Jerika in July, after her story was picked up by USA Today subsidiary Post-Crescent, which serves the Bolen’s hometown of Appleton, Wisconsin. That story was picked up by national outlets who collectively presented the situation as if Jerika was terminally ill (she was not), in excruciating pain (possibly, but if so, others with similar disabilities wonder why palliative care failed her), and — the kicker, for many nondisabled people — dependent on a ventilator (it was a bipap machine that she used at night).

Even after her death, The Washington Post published an obit with this misleading headline: “Terminally ill 14-year-old fills final summer with friends and a ‘last dance’.”

In retrospect, advocates never had a chance against the prevailing “tragic but brave, better dead than disabled” narrative that saturates our culture. But watching so many fierce adults with disabilities rise up to try to save Jerika’s life was like watching a pride of momma lions stride across a savannah.

But first came Julianna Snow’s death.

“Heaven Over Hospital: 5-year-old Julianna Snow dies on her own terms,” read the CNN headline about the child’s June 15 death. Like many stories about her, this one said she was “dying” of Charcot-Marie-Tooth, a type of neuromuscular disability. Snow wasn’t dying at all, but like many kids with neuromuscular dystrophy, had to be hospitalized from time to time.

CNN latched on to the melodrama and printed this from Snow’s mom Michelle Moon’s July 15, 2015 blog entry:

**Michelle:** Julianna, if you get sick again, do you want to go to the hospital again or stay home?

**Julianna:** Not the hospital.

**Michelle:** Even if that means that you will go to heaven if you stay home?

**Julianna:** Yes.

**TARI HARTMAN SQUARE MEDIA MAVEN**

A longtime media advocate, Squire prefers to work in the background where she connected advocates to reporters. As a resister to the “better off dead than disabled” forces, Squire connected activists to reporters writing about Me Before You and Jerika Bolen. Her latest endeavor is DisBeat, which you can learn more about at www.adalegacy.com/disbeat/initiative.
Prior to June 15, to try to save Snow’s life, Emily Wolinsky had created the DearJulianna.com campaign, in which adults with NMD wrote letters to Snow talking about their lives to show her and her mother that life with a disability could be rewarding. As a result, “I was vilified by the media,” says Wolinsky. “Even CNN and People magazine made me look like a terrible person for even suggesting Julianna could have had a long, fulfilling life.”

Wolinsky learned the hard way what happens when a person with a disability publicly resists society’s ingrained attitude that the untimely deaths of people like her are to be celebrated.

Which brings us back to Jerika.

SHE MADE IT PUBLIC, NOT US

“Because of my work with Dear Julianna, people associated me with these types of issues, so I got notified of Jerika and her mother’s plans by one of the women from our Facebook support group, Living with Muscular Dystrophy,” says Wolinsky. “She sent me to GoFundMe, saying it looked really weird. It looked kind of like a private family fundraiser to me. I wasn’t happy to read it, but I didn’t know this family, this story, so I said I’m not going to get involved.”

Then came the article in Post-Crescent and Jerika’s story made the news on Wolinsky’s local TV station, and that piece ended up going international. “It’s one thing when it’s between you and your family, but when it turned into a telethon I got upset.”

Wolinsky says Jerika’s situation was different than Julianna’s, since Jerika and her mom were connected to the SMA community. “She knew a lot of us. She knew that life could be better,” says Wolinsky. “Julianna was 5 years old and was kept from that knowledge.”

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Wolinsky says Jerika’s situation was different than Julianna’s, since Jerika and her mom were connected to the SMA community. “She knew a lot of us. She knew that life could be better,” says Wolinsky. “Julianna was 5 years old and was kept from that knowledge.”

But a 14-year-old girl, also, is still a child. “The things she said — ‘All I do is come home, do homework, lie on the couch, what kind of life is that?’ — that’s totally what teenagers say. They showed her playing video games and I thought if this girl was in the pain she says she is in, she’d be in bed screaming,” says Wolinsky. “She wouldn’t be able to make a video, go to a prom. This is more of an emotional decision.”

Jerika told the press that she had more than 30 surgeries. Wolinsky polled her support group of over 100 people with NMD and they said on average they had one or two before they were 14.

Wolinsky’s fellow NMD United board member, TK Small, an attorney from Brooklyn who also has SMA, notes the divide between how many people with SMA viewed Jerika differently than many parents of kids with SMA. “There was one Facebook group called SMA Support Systems. When I started talking about Jerika there, things started heating up very quickly. That particular group is run by parents and I ended up getting kicked out. And there’s another group, the Gwendolyn Strong Foundation, whose motto is ‘never give up.’ If you Google that phrase you’ll find inspiration porn horseshit, but here they were, willing to give up, basically saying we have to support what the mother is doing here. And we were like, ‘your phrase is never give up! But that’s what she’s doing! Don’t you see the inconsistency?’”

But they couldn’t — or wouldn’t.

WE HAD DEATH THREATS

NMD United conferred with Diane Coleman from Not Dead Yet on what they could do, and Coleman was already discussing the situation with Disabled Parents Rights’ child welfare expert Carrie Ann Lucas. Discussions were also happening on DisBeat, as Tari Hartman Squire and Danielle Sheypuk were trying to meet face-to-face with Jerika and her mother.

And remember, “there were several things happening in different areas,” says Lucas, a vent user with NMD and adoptive mom of several children with disabilities. The Me Before You protests were still taking place, and Dear Julianna letters were still coming in. “We were again being bombarded with the notion that we are better off dead than disabled, and the media was saying, ‘Of course! Look how disabled these people are. They might have to be suctioned!’ I have to be suctioned a few times day, but it’s not worth ending my life over. So a lot of that was hitting at once.”

Lucas makes the point that she has supported children who actually were dying to
IT GETS BETTER!!
have their final wishes met, such as the kid dying of cancer who wanted to meet Taylor Swift and got to do it. “Jerika’s situation is different, because this child was not going to die. So the thought was to work behind the scenes to see if there’s something we could do [to stop it] before it got to the point where someone kills their child.”

Lucas drafted a letter on behalf of NDY, NMD United and Disabled Parents Rights that was sent to the Wisconsin Department of Children and Families pointing out that since Jerika’s condition was not fatal, the only way she’d die would be through euthanasia. It ends, “Ms. Bolen is clearly suicidal. This teenager deserves intervention, rather than assistance to end her life. If your department needs assistance locating doctors and specialists who are experts in treating spinal muscular atrophy, referrals are available.”

“We FedExed that letter on Aug. 4. We also made a call to the counties and I faxed it to the child protection hotline,” says Lucas. They don’t know what happened to the letter, but that’s not surprising since the case would be confidential.

“At the beginning of September I received a call from Post-Crescent reporter Jim Collar wanting info about the letter we sent, so I spoke to him about it, and then the letter went everywhere.”

The backlash was prompt and strong. The Post-Crescent published an editorial slamming the advocates for writing the letter. “We actually had death threats. My paralegal was instructed not to answer the phone for any nonlocal numbers that we did not know,” says Lucas. “Everything else went to voicemail because we were getting so many calls: How dare you interfere? Of course this child should be allowed to die. How dare you suggest she not be allowed to die!”

Lucas fears Jerika’s death will embolden other parents to do the same thing. “Ultimately the fact that this girl had the prom and positive media attention may cause other children and teens to pursue this,” she says. “We are on that slippery slope that NDY has been warning about for many years. When you say it’s acceptable to start ending people’s lives, that bright line becomes gray and wider, and now we have a wide beach with no lines at all.”

On one side of that beach is the force of history — from ancient times when crippled babes were left on rocks, to the 20th century when disabled Germans were exterminated in the Holocaust, to just a few years ago when Tim Bowers, 32, fell from a hunting stand and broke his neck at the C3-5 vertebrae. Upon being woken from his medical coma, he was given misinformation — You’ll never hold your son being perhaps the most cruel — until he agreed to be removed from life support. And little Julianna Snow, 5 years old, was asked to “choose” between going to the hospital or heaven.

Disabled people can’t even live happily ever after in the movies, as Me Before You shows.

Jerika never had a chance.

On the other side of the beach, backs against crashing waves, are the people with disabilities who have been able to resist society’s siren song that says to lie down and die. “Disabled people have been fighting for the right to exist since the beginning of history,” says Lucas. “We have to say no, we help people live, we don’t let them die.”

**RESOURCES**

- Disabled Parents Rights, 970/460-6765 or 720/363-1131; info@disabledparentsrights.org, www.disabledparentsrights.org.
- DisBeat, www.adalegacy.com/disbeat/Initiative
- NMD United, www.nmdunited.org
- Not Dead Yet, 708/420-0539; notdeadyet.org
- United Spinal Resource Center, 800/962-9629, unitedspinal.org/ask-us
**SPOTLIGHT: SAN ANTONIO**

**MY TAKE**
As a transplant to San Antonio from Houston, I have found the city’s slower pace to be a welcome change. This city offers the perfect scenarios for a self-admitted people watcher like myself. A major tourist attraction, the city has plentiful opportunities for people — with or without disabilities — to ensure a wonderful experience while here. Known for its sometimes extreme heat during the day, San Antonio also offers cool evenings with even nicer fall days. Every weekend, even as a resident, there is something new to do — such as take a trip to the top of the Tower of Americas, where you can get a 360-degree view of the city or dine at some of the amazing restaurants. If that seems a bit boring for your taste, then I recommend you join the yearly crusade to an event called Fiesta. It is 10 days in April of parades, parties and food.

**THINGS TO DO**
San Antonio’s biggest attraction is the Riverwalk. Alongside the river are a number of amazing restaurants as well as historic hotels. Accessible access points can be a bit tricky though. A few blocks from the Riverwalk is the world famous Alamo. A trip to San Antonio is not complete without doing — such as take a trip to the top of the Tower of Americas, where you can get a 360-degree view of the city or dine at some of the amazing restaurants. If that seems a bit boring for your taste, then I recommend you join the yearly crusade to an event called Fiesta. It is 10 days in April of parades, parties and food.

Morgan’s Wonderland was the first amusement park built specifically for people with disabilities and offers an array of fully accessible rides and entertainment options. To top that off, everyone with a disability gets in free.

**GETTING AROUND**
Like most cities, accessible transportation can sometimes pose a challenge. San Antonio has made great strides toward making getting around easier for those with disabilities. The local bus system, VIA, offers wheelchair access for all of its major bus routes. Pro: Inexpensive and everywhere. Con: Can leave you blocks away from your destination.

VIAtrans, the city’s paratransit option, offers door-to-door accommodations as long as you make a reservation. Pro: The cost is only $1.95 per trip. Con: Not always on time and can take an hour to get across town.

Yellow Cab offers a small fleet of wheelchair accessible vehicles. Pro: Efficient way to get around time-wise. Con: Pricey and due to size of fleet, there is not always one available.

Overall, San Antonio offers a few options of transportation to fit everyone’s monetary, as well as actual, ability to use whatever service fits you.

**HEALTHCARE**
San Antonio offers a handful of excellent rehabilitation services for survivors of traumatic injuries. The Reeves Rehabilitation Center at University Hospital offers specialized treatments for a variety of conditions. Being attached to the trauma hospital helps some transition from acute care to acute rehab smoothly.

Warm Springs is the largest rehabilitation center in San Antonio with three inpatient locations throughout the city. I have a special place in my heart for Warm Springs due to my rehab being done there.

Healthsouth RIOSA has the largest gym out of all the rehabilitation centers in town. There is special equipment in that gym that is unique. Select Rehabilitation is the newest of the facilities to get into acute rehab treatment. Located at the newest area of medical establishments, it offers great services. All of these establishments work with Rolling Inspiration’s mentoring program to help newly injured people get inspired despite circumstances. Find out more about Rolling Inspiration on the next page.

**SKINNY ON THE CITY**
Located in south-central Texas alongside the San Antonio River, San Antonio is a large city with a small town feel. When most people hear the name San Antonio, the first things that come to mind are the famous Alamo and Riverwalk. While it’s true those things are synonymous with this city, there is so much more. San Antonio also has two major theme parks and the world’s only ultra-accessible park. With the combination of historic landmarks, theme parks and amazing nightlife, there is something for everyone when visiting San Antonio.

**Morgan’s Wonderland is built to be accessible.**
Having lived through a spinal cord injury, rehabilitation and reintegration into society, San Antonio’s Chris Salas is well aware of how difficult the transition from patient to person can be.

“A lot of people have no resources and no direction,” says Salas, a C5 incomplete quad. “They’re kind of lost.”

Since he was paralyzed in a car accident 19 years ago, Salas has devoted himself to helping others find their way out of this difficult spot after sustaining spinal cord injuries. He started off as a peer mentor, worked as the recruitment director for a regional adaptive athletic program and even set his career goal — becoming a psychologist — around helping others with disabilities.

But his proudest accomplishment is Rolling Inspiration, a San Antonio-based nonprofit he founded that now doubles as United Spinal’s San Antonio chapter. Rolling Inspiration got its start as a simple support group at a local community center in 2010.

“I just wanted to provide a forum for people who needed additional help,” he says. “A lot of the social workers don’t know a lot of the information we do from experience. I see people who get discharged from hospitals and get assigned outpatient physical therapy and occupational therapy, but usually no kind of mental therapy is suggested or prescribed on discharge.”

The first meeting drew only four attendees, but nowadays meetings, held twice a month at a local rehab hospital, average 10-15 wheelchair users and at least that many family and friends. As the group has grown, so too have the organization’s peer mentoring efforts. With three major rehab hospitals in the area there is always demand, and now Rolling Inspiration has a diverse roster of mentors that allow it to adjust to mentees’ needs.

“Whether it’s someone who is newly injured, a brother, a sister, a husband, or a wife, or whether they had a baby pre-injury or post-injury, we have such a wide variety of mentors, that no matter what your situation is we have it covered,” says Salas.

In addition to the support groups and peer mentoring, Rolling Inspiration offers what it calls “community reintegration activities.” These events have ranged from waterskiing and surfing, to visiting a rodeo or amusement park. Salas says the events are about more than just getting out.

“I want to get people to go out and do things … to actually live a productive life and enjoy it despite being in a chair,” he explains. “I don’t want them to just go through the motions. Our goal is to help build that confidence and let people know they can do things they didn’t think they’d be able to do in a chair.”

Salas hopes to expand the number of community reintegration activities Rolling Inspiration offers as the organization grows. He would also like to eventually build or set up an independence center if he can find the money and staffing. But for right now, he is happy with how far the group has come.

“The proudest thing for me is getting the feedback from the people who have known [the group’s attendees] since the beginning of their injury or diagnosis,” he says. “To get that feedback saying how much change they have seen from Rolling Inspiration or the impact the group has had on that person. Just knowing that I’ve played a small part in changing lives and getting people back out is great.”

Philadelphia update
Thanks to a generous donation, the Greater Philadelphia Chapter of United Spinal Association presented member Zully M. Santana Torres with a wheelchair vehicle lift that will enable her to be more independent when traveling to and from school.

Torres, now 27, came to the United States from Puerto Rico when she was 4 years old as part of a program through Shriners Hospital. Born with spina bifida, her spinal cord was stretched, resulting in scoliosis and partial paralysis. In 2015, she graduated from the Community College of Philadelphia with a degree in general liberal arts, and that same year was asked to be part of the Mayor’s Commission on People with Disabilities. She is currently chairperson of the Youth Committee and attends Drexel University. She loves to dance salsa, merengue and bachata.

Torres says that this wheelchair vehicle lift will be a great help and enable her to attend meetings, appointments, and do things in an easier fashion without struggle.
Standing Up To CMS to get Needed Number of Catheters

Marjorie Williams had grown accustomed to regular calls from her medical equipment provider to check on how many catheters she had left, so when they called this July she didn’t think anything of it. She couldn’t have known that her world was about to be turned upside down. “Thank God I was lying in bed when I answered the phone because I almost passed out,” she says.

Her supplier informed her that the Centers for Medicare and Medicaid Services had forced them to slash the amount of catheters she received monthly from 510 to 200, starting immediately. While 200 catheters may sound like a lot, for Williams, who lives with a paralyzed, neurogenic bladder as a result of lupus and transverse myelitis, it was only enough to cover half a month. That forced her to either face using an indwelling catheter, which dramatically raised the risk of infections because of her already compromised autoimmune system, or to find a source for and the money to pay for catheters on her own.

“I couldn’t believe I basically had nine days to come up with a Plan B,” she recalls. That phone call set off a frantic two months that would force Williams to become an advocate and, with the help of United Spinal and many others, stand up to CMS for the medical equipment she needed.

By the time Williams reached out to United Spinal’s Resource Center in the weeks following the call, she was near her wit’s end. Ten days of phone calls to CMS had only proved more confusing. “I was told so many different answers, ‘No it should be fine.’ It’s covered. ‘It should be covered.’”

Resource Center Director Bill Fertig sensed the urgency of Williams’ situation. “She had tried to fight but it was such an onerous process that she got beat down,” recalls Fertig. He quickly connected her with United Spinal’s policy team to brainstorm solutions.

Senior Policy Associate Jasey Cardenas got in touch with Williams as soon as he got off the phone with Fertig. He urged her to get in touch with her local representative to have them advocate on her behalf. The next day she was in her representative’s in-district office. “If you had told me that an alien had landed in my living room I would have sooner believed that than me discussing my private body function with my congressman down the street, but this is the position I was in thanks to CMS hiring people who have no concept of spinal cord injury,” says Williams.

Working with her congresswoman, Williams learned that the decision to cut her catheter supply had been made by CGS Administrators, a third-party group working for CMS. Williams had tried to explain to them how her neurogenic bladder differed from normal bladders, requiring unpredictable, prolonged bouts of frequent catheterization. She had documentation from eight different specialists, her own primary care physician and her medical advocate but so far, her message had fallen on deaf ears.

“All of her doctors agreed that the chief medical officer for CGS was not making the correct assessment of her bladder,” says Cardenas. “It was completely different but he was ignoring that fact.”

While Williams was working with United Spinal’s policy team to resolve the issue with CMS, she was scouring eBay for catheters that fit her need. Fertig connected her with Resource Center nurse specialist Jane Wiebicky, who provided alternative sources and possible financial resources to aid her. Fertig also sent United Spinal position papers to help Williams understand the policy issues underlying her struggle.

After almost two weeks of agitation, and numerous calls and emails between Williams and United Spinal staff, the CGS chief medical officer finally contacted her. “I tried to educate him about immunosuppression and neurogenic bladder and I realized he still didn’t understand what the neurogenic bladder was,” says Williams.

While her effort didn’t immediately result in a reversal of the decision to cut her catheter supply, it signaled that Williams’ case had the third-party administrator’s attention. Another phone call, this time with Williams’ primary care provider, finally closed the deal. Williams received a letter stating CGS had decided to make a policy provision allowing her 350 catheters per month.

Williams is still angered by the fact that CGS’ decision applies only to her and the possibility that others could face the same struggle she did. But she is thankful that she no longer has to scour eBay for catheters or risk compromising her health further. “I was extremely lucky,” she says. “I was very, very overwhelmed. Thanks to the help of my physicians, and Jasey and Bill and Alex [Bennewith, United Spinal’s vice president, government relations] I kept my head in the game because I was very, very overwhelmed.”

Help is Just a Click Away!

When faced with the challenges of living with a spinal cord injury or disease (SCI/D), the right resources and support can make a world of difference.

United Spinal Association’s Affiliate Service Providers provide the full spectrum of clinical care, products and services, with an emphasis on SCI/D. Search our valuable online directory at http://providers.spinalcord.org/ to discover service providers near you that specialize in optimizing the health, independence and quality of life of people with SCI/D.

Visit our directory at http://providers.spinalcord.org/

If you have any questions, contact our Resource Center staff at http://www.spinalcord.org/ask-us/ or call (800) 962-9629.

Quickly connect with top providers specializing in:
- vehicle & hand controls • therapeutic & bathroom equipment
- urological supplies • scooters • wheelchairs • ramps • assistive devices, and many other disability-related products and services.
Mission

United Spinal Association’s mission is to improve the quality of life of all Americans living with spinal cord injuries and disorders (SCI/D). Membership in United Spinal is open to anyone with an interest in SCI/D. For more information on the benefits of joining, visit www.unitedspinal.org or call 800/404-2898.

ALASKA
Providence Alaska Medical Center
Anchorage, AK 99508; 907/562-2211

ARIZONA
HealthSouth Rehabilitation Hospital Spinal Cord Injury Program, Mesa, AZ; 480/567-0350
Barrow Neurological Institute at Saint Joseph’s Hospital and Medical Center, Phoenix, AZ; 602/406-3000

CALIFORNIA
Dignity Health - Northridge Hospital Medical Center, Center for Rehabilitation, Northridge, CA; 818/885-8500
Rady Children’s Hospital San Diego - Division of Pediatric Rehabilitation Medicine, San Diego, CA; 858/576-1700
Sharp Rehabilitation Center, San Diego, CA; 858/939-6709
Sutter Rehabilitation Institute, Roseville, CA; 916/878-2588

COLORADO
Craig Hospital, Englewood, CO; 303/789-8800

CONNECTICUT
Gaylord Specialty Healthcare, Wallingford, CT; 203/284-2800
Hospital for Special Care, New Britain, CT, 860/827-2761
Mount Sinai Rehabilitation Hospital Hartford, CT; 860/714-3500

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

FLORIDA
Brooks Rehabilitation Hospital, Jacksonville, FL; 904/345-7600
Pinecrest Rehabilitation Hospital, Delray Beach, FL; 561/498-4440

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

HAWAII
Rehabilitation Hospital of the Pacific, Honolulu, HI; 808/531-3511

ILLINOIS
Marianjoy Rehabilitation Hospital, Wheaton, IL; 800/462-2366

ILLINOIS
Memorial Medical Center, Springfield, IL; 217/788-3302
Rehabilitation Institute of Chicago - Midwest Regional Spinal Cord Injury Care System, Chicago, IL; 800/354-7342
Schwab Rehabilitation Hospital, Chicago, IL; 773/522-2010

INDIANA
Parkview Rehabilitation Hospital, Fort Wayne, IN; 260/373-4000
Rehabilitation Hospital of Indiana, Indianapolis, IN; 317/329-2000

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

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

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

MASSACHUSETTS
Spaulding Rehabilitation Hospital, Charlestown, MA; 617/573-2770
Weldon Rehabilitation Center at Mercy Medical Center Weldon Rehabilitation Center, Springfield, MA; 413/748-6840

MARYLAND
Adventist Rehabilitation Hospital of Maryland, Rockville, MD; 240/864-6132
International Center for Spinal Cord Injury at Kennedy Krieger Institute, Baltimore, MD; 888/554-2080
University of Maryland Rehabilitation and Orthopaedic Institute, Baltimore, MD; 410/448-2500

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

MISSOURI
The Rehabilitation Institute of Kansas City, Kansas City, MO; 816/751-7812

MISSISSIPPI
Methodist Rehabilitation Center, Jackson, MS; 601/981-2611
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<td>Carolinas Rehabilitation, Charlotte, NC</td>
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<td>QLI - Spinal Cord Injury Program, Omaha, NE</td>
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<td>NEW JERSEY</td>
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<td>Mount Sinai Medical Center, New York, NY</td>
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<td>The Burke Rehabilitation Hospital - Spinal Cord Injury Program, White Plains, NY</td>
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<td>PENNSYLVANIA</td>
<td>Allied Services Integrated Health System Spinal Cord Injury Program</td>
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<td>Healthsouth Rehabilitation Hospital of Altoona, Altoona, PA</td>
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<td>800/873-4220</td>
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<td>Moss Rehabilitation Hospital, Elkins Park, PA</td>
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<td>Spinal Cord Program at The Children's Institute, Pittsburgh, PA</td>
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<td>UPMC Rehabilitation Institute at Mercy, Pittsburgh, PA</td>
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<td>HealthSouth Rehabilitation Hospital of Charleston, Charleston, SC</td>
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<td>Vanderbilt Stallworth Rehabilitation Hospital, Nashville, TN</td>
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<td>VCU Spinal Cord Injury Rehabilitation, Richmond, VA</td>
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<td>WISCONSIN</td>
<td>The Spinal Cord Injury Center at Froedtert and The Medical College of Wisconsin, Milwaukee, WI</td>
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**Organizational Members**

- **Center of Recovery & Exercise (CORE)**
  - Longwood, FL; 321/378-3050

- **Florida Spinal Cord Injury Resource Center**
  - Tampa, FL; 813/844-4711

- **Life Beyond Barriers Rehabilitation Group**
  - Rockford, MI; 616/866-6859

- **Miami Physical Therapy Assoc., Inc.**
  - Miami, FL; 305.444.0074

- **Neuro Fit 360**
  - Pembroke Pines, FL; 954/252-8020

- **NeuroWorx**
  - South Jordan, UT; 801/390-0760

- **Neuroxcel**
  - North Palm Beach, FL; 866/391-6247

- **Project Walk - Atlanta**
  - Alpharetta, GA; 770/227-4239

- **Project Walk - Boston**
  - Stratham, NH; 603/583-5119

- **Project Walk - Houston**
  - Missouri City, TX; 281/410-8348

- **Project Walk - Kansas City**
  - Overland Park, KS; 913/451-1500

- **Project Walk - Mt. Laurel**
  - Mt. Laurel, NJ; 484/800-1563

- **Project Walk - Orlando**
  - Sanford, FL; 407/571-9974

- **Project Walk - Spinal Cord Injury Recovery Center**
  - Carlsbad, CA; 760/391-9789

- **Project Walk - Walnut Creek**
  - Fremont, CA; 510/623-1924

- **Push to Walk**
  - Riverdale, NJ; 862/200-5848

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**Interested in becoming a hospital or organizational member? Please contact Nick LiBassi at 718-803-3782, ext. 7410 or nlibassi@unitedspinal.org**
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We are not going to be a tragic love story.” That was what Sydney said to me the first night in the hospital. Her phrase became our goal for my recovery, our mantra, our war cry. It was the mindset that determined everything we did for the next 270 days. It motivated us to seek new ways to communicate with medical staff and to find good doctors.

Our journey to my becoming a successful partner in my medical care began with a 104-degree fever. After a few days in the hospital, I was diagnosed with osteomyelitis, a bone infection in my T12 vertebra. A colony of dormant strep bacteria woke up and were consuming my spine. On the 13th day, Sydney took me home. I went from being in the hospital and septic to being home on IV antibiotics to combat the bugs.

It was a losing battle. Into our 10th week of IV treatment, the X-rays showed no signs of improvement. Our infectious disease doctor said, “The antibiotics could stop working altogether. Your spine could collapse. You must pick a spine surgeon.”

We had our pick of four world-class orthopedic surgeons working at the best teaching hospitals in the area. Well, three actually. The fourth “wouldn’t operate on [me] with a 10-foot pole.” All the hardware already in me — Harrington rods and a plate from T2 to T10 — promised the surgery would be long, complex, and bloody. The remaining three surgeons each favored procedures very different from one another. And that was our hold up.

We couldn’t get any of them to give us all the information we needed to make our decision. We asked why their diagnoses and surgical approaches were so different. But none could take us from start to finish in how they decided on their specific actions in a clear manner. Instead of an explanation, each merely maintained a “this is how it’s done” stance. We were even told, “Ask 10 surgeons, get 20 answers.” Twice. We left these appointments frustrated and confused.

Our infectious disease doc advised, “I’d go with the surgeon who seems most confident.” They were all confident. We needed something else to go by. Confidence alone does not demonstrate competence. Words — clear, honest words — demonstrate competence.
I resigned myself to the first surgeon we consulted. He had treated me before. My spasticity and infectious disease doctors recommended him. I wanted to get the surgery over with despite my unease.

Sydney freaked out. “Dr. Number One? You’re picking the doctor who said, ‘…If I can find a general surgeon to assist me?’ That’s the guy you’re picking to make this NOT a tragic love story? No way!” She trusted her unease and refused to settle.

She realized the usual ways of picking a surgeon were not working. Next, she did something unusual. She asked for help from a different kind of doctor altogether. Sydney called her colleague Dr. P, a psychiatrist, who said, “You need to consult a surgeon who doesn’t have a vested interest; no financial incentive or potential reputation boosts. Many of my patients have gone to Dr. L. after other surgeons have botched things up.”

Sydney hung up the phone. “Of course,” yelled Syd. “We need someone who fixes other people’s mistakes!”

Right Doctor, Right Procedure
We arrived at Dr. L’s office at 10 a.m. He had agreed to meet with us as a consultation to help us pick out the right procedure, and therefore the right surgeon, to settle on.

Dr. L. came into the exam room, sat on a stool, rolled closer and chatted with me eye-to-eye. “Sorry I’m late. My patient-family meeting ran long. We started an orthopedic surgery and recovery unit next door. Patients do so much better when their families stay with them.”

The first five minutes can tell you a lot about a doctor. Sometimes it’s the opposite of what you’ve heard in the past. He seemed to be focused on rapport, respect, relationships.

“Let’s take a look at what you brought,” he said. We handed him a stack the size of two phone books. Pausing only to ask questions, he read the hospital and outpatient summaries. He took the same care with our handwritten daily symptom logs, which we had started with our infectious disease doctor, and had maintained over the last few months.

Sydney jumped in to ensure he saw me as a person with goals. We were still newlyweds, under two years, and this was not going to be a tragic love story. Beyond my injury, he showed a real curiosity in how Sydney and I lived.

He put up the current X-rays. “Tell me about your original injury, the other infections and surgeries.” I rattled off my complete history. I was careful to use terms from the medical field in my description (more on this later). Back in the hospital we found that the staff treated us differently, better, when we used their language. Dr. L. responded favorably, too.

He looked at the infection site, and then pointed to the arch in my upper back. Kyphosis had begun to hunch me forward. He ran his hands down my spine and felt the rods pressing against my skin. “Has anyone ever X-rayed you sitting up?” No one had since my original injury 10 years earlier. “Well let’s take some now.”

Just minutes later, his X-ray tech was bringing him new films of me sitting up. “Hey, Dr. K! Have you got a minute?” Twenty minutes pass with him in the hallway with Dr. K and then Dr. L. comes back in, “We’ve got a plan.” He puts the X-rays up and begins drawing on them with a pencil. He explains not only what the infection has done to the T12 vertebra, but how my old fusion is affecting me. “We have to restore balance.”

He talked us through how he would fix my back. There was a logical connection between the problem, the data, and his approach. It made sense. We watched his hands as he mimicked removing my rods; although he had thick muscular hands, the motion was delicate and expressive. “Nothing good happens in the OR after 10 hours. We’ll do the surgery in two procedures spaced three days apart.”

As a scoliosis doctor, he had an innovative approach to recovery — no stabilizing back brace. “I just don’t want you to twist, you’ll break the rods, but I want you weight bearing, it builds bone.” He explained that I’d be sitting up three days after surgery and home in two weeks.

By now, we had picked our procedure, and our surgeon. We asked Dr. L. if he would take on my surgery. He said yes. “You’re a young, active guy, I want you to go out there and live your life to the fullest.”

It was 1:30 in the afternoon when we left Dr. L’s office. It was the first time I felt calm after leaving the ortho-spine surgeon’s office. On the drive home Sydney and I debriefed, as we did after every appointment.

We talked about what was important to us about Dr. L. and his treatment plan. We never had to press him for answers; he addressed our questions directly. He respected our input, the information we brought verbally and in our personal records, in addition to the clinical documentation. Unlike the other surgeons who wanted to fuse my spine ever more, focusing only on the T12 damage, he wanted to maintain a supple spine and preserve my freedom of movement by addressing the entire spine. He was collaborative and prudent (“My partner, Dr. K will babysit the cord while I work on the spine”). All of these traits and philosophies were absent in the other surgeons we met with.

Partners in Healing: Owning Responsibility
Having a good surgeon played a key role in becoming a successful partner in my care, but it didn’t end there. Sydney and I employed our own expertise as well. I had a decade of living with a spinal cord injury and all the knowledge I had acquired along the way. And Sydney was a learning style specialist and brain researcher who makes a habit of studying how people think, problem-solve, and interact with one another. Using our talents in the rehab setting post-surgery contributed to our successful outcome.

The two surgeries had been a success, and after three days in the ICU I was transferred to the rehab wing of the hospital. Sydney was staying in my room, and would for the next three weeks as I recovered. She was a fierce protector, warm companion, and driving force in partnering with me to manage my care in coordination with Dr. L. and the hospital staff.

Sydney started with taking control of the white board in the room. She moved the “Call. Don’t Fall” sign off to the side, and created spaces for vitals, to-do lists, and questions. There were things for me to do, like using my incentive spirometer hourly. Internal appointments with X-ray, PT, OT and admin staff went on the board. She put checkboxes next to the questions. She knew an unchecked box would drive people to do whatever it
took to check it off. We got a lot of questions answered quickly because of that insight. Everyone checked and updated the board, nurses and doctors alike, as part of their regular routine.

X-rays were another effective communication tool. Dr. L. used X-rays in the office to diagnose and explain my condition to us. In the hospital, he brought the X-rays into my room to give us status updates on the new fusion. Sydney began posting them in my window.

Simply putting the X-rays in the window enhanced my care and well-being. It was easy to show nurses why I shouldn’t be twisted or moved in certain ways. Every time Dr. L. came in, he went to the window where he pointed out the significant changes and how my spine was healing.

For me, it was therapeutic to have them on the window. They were not only visual markers of progress, but they became a conversation piece for our visitors. I could talk knowledgeably about the procedure and the hardware inside me. This gave them a new appreciation for the magnitude of what I’d just been through. This ability gave me a sense of ownership of the surgery and my recovery process.

Talking was an important part of the success as well. It was especially important that we learned how to have conversations that included key medical terms. There were many benefits to speaking to medical professionals in their language. Our opinions, observations, and questions were considered carefully. In the hospital room or at a doctor’s office, using medical terms made our interactions more productive; we didn’t waste time reviewing fundamentals, we just moved to the next level of understanding. They treated us more as colleagues than clients.

In our conversations, we only focused on understanding key terms for descriptions, causes, conditions and real-world implications. I picked up a lot of medical terms over the past decade of living with SCI, but didn’t always understand them as well as I thought I had. Sydney automatically remembered everything except the exact word. To bridge the gap, Sydney began bringing a copy of Frank H. Netter's *Atlas of Human Anatomy* to our meetings. Filled with illustrations labeled with the terms, Sydney asked the doctors to use the book when explaining diagnoses and procedures. This brought together symptoms, X-rays, terms, concepts, and real-world implications when we talked about me. The Netter book helped us learn the vocabulary and we also used it as a stand-in when we couldn’t remember the words or their meanings. It allowed us to ask things we would have skipped because we didn’t know how to phrase the question properly. In effect, it allowed us to become experts using simple words and gestures.

One final area where we developed our own expertise was logging. Keeping detailed logs which included date, time, and details of the item being tracked (temperature, heart rate, medicine taken, elimination volume, etc.) were essential to our success during the infection. Our infectious disease doctor was able to make crucial decisions about my antibiotics and treatment because we provided detailed information during our visits. If we had not practiced this discipline, my doctors would have gotten partial recollections rather than catalogs of diagnostic data.

In the end, this was not a tragic love story. I didn’t die of an infection. Sydney didn’t let me pick a surgeon who did not have the best approach; we picked one who wanted me to “live life to the fullest.” And the two of us worked together to use what we already knew about medicine and brains to develop new areas of expertise while we were going through a major health crisis. Everything we said and did demonstrated to our medical team that we had the capacity to be partners in my healing and we would settle for nothing less.

It worked. We got care that was higher quality and more inclusive. The tools we had are available to everyone. How we used them is what made the difference. We hope that what we learned will help you become a successful partner in your care.
When it comes to full-time wheelchair use, the one aspect we all have in common is pressure management. There’s a misguided notion that some of us are at risk of pressure sores (decubitus ulcers), while others of us are not. The fact is, full-time wheelers are all at risk for pressure sores. Approximately 75 percent of our body weight is concentrated on our buttocks when seated — a region that isn’t physiologically designed to sustain static weight for extended periods. As a result, we all have to routinely adjust positioning to reduce concentrated pressure in order to lower our risks of pressure sores.

For low-risk individuals — and a lot of factors contribute, from natural movement to hydration to moisture control to age — pressure management is an intuitive process. However, for those at higher risk, most commonly due to a lower sensation level, declining skin elasticity and difficulty performing weight shifts — pressure management is a far more vital, complex subject. Therefore the question becomes, what are among the most innovative, effective seating solutions that ensure better pressure management for advanced needs?

**When the Cushion Shifts Pressure for You**

Alternating air cushions are not new, consisting of air cells that inflate and deflate using an electric pump. However, Ease Seating Solutions has refined the technology to create a durable, practical system in its G5 model. The G5 moves away from an all-air cushion by providing a foam surround for both postural and transfer stability. From there, it features alternating air cells in the area of highest weight concentration, as in the rear of the cushion, encompassing the ischial tuberosities (buttocks) and coccyx (tailbone).

The air cells are arranged in two bladder patterns that, from left to right, look like ABABABA. There are three, three-minute cycles that alternate. The first cycle inflates only the Bs, appearing as B-B-B-. The second cycle inflates all cells, appearing as ABABABA. The third cycle inflates only the As, appearing as A-A-A-A. In this nine-minute total cycle, pressure is redistributed throughout the buttocks, dramatically alternating pressure on any specific area. The G5 runs for a minimum of 50 hours per battery charge, and has a low-pressure sensor, so all-day use is possible for effective pressure management.

**It Teaches You to Tilt**

Another effective means of pressure management is tilt seating on complex rehab power chairs. By tilting the whole seat to 45-degrees or greater, pressure is dramatically reduced on the buttocks. Ideally, one should tilt every 15 minutes for two minutes. However, there’s a lot of room for error, especially for newly-injured individuals. Tilting far enough back at the right times for the right amount of time can be tricky. Permobil’s Virtual Seating Coach removes the guesswork by connecting your smartphone to its 3G seating for pressure management monitoring.

VSC covers the three areas most common to user error in a tilting regimen, all through an easy-to-decipher app screen. Firstly, through settable intervals, it alerts you when to tilt. Secondly, it shows you how far to tilt via a sliding icon that tracks the seat angle, directing you to the optimal angle zone. And, lastly, VSC displays a countdown timer to ensure proper duration. Further, all is logged, so your clinician can monitor your tilt regimen and make adjustments. For long-time power chair users, VSC isn’t needed. However, it’s proving a beneficial tool for newly-injured users at high risk for pressure sores.

**Time to Move!**

Just coming to market is the Pressure Assistant. Independent of any wheelchair or cushion brand or style, the Pressure Assistant is a reminder tool for weight shifts. It features a pressure sensor that fits under your cushion, then connects to a small user interface box.
The system calibrates according to your weight, then alerts you if you haven’t shifted your weight within 30 minutes. At the 30-minute mark, it sets off an alarm and then times you for a two-minute weight shift duration, upon which it then resets for 30 minutes. The Pressure Assistant, although all-encompassed, can also connect to a smartphone to monitor progress. Also, an optional Wi-Fi module can transmit data in a rehab facility setting. What separates the Pressure Assistant from other systems is that it’s more intuitive than rigid — that is, it only reminds you when you truly need it.

Reducing the Pressure
The old saying, “out of sight, out of mind,” can catch up with us when it comes to pressure management and weight shifts. These technologies can, well, save our butts when life understandably distracts us. Yet, there’s also merit that through such technologies, we can worry less about our rears and focus more on our lives.

Resources
• Ease Seating Solutions; easecushion.com, 866/376-1878
• The Pressure Assistant; www.pressureassistant.com
• Virtual Seating Coach; vsc-us.permobil.com, 800/736-0925

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Q. I am 55 and in my 20th year as a T9 complete para. Over the past five years the skin on my feet has become quite fragile. I recently developed a pressure sore on my left heel from a minor bump on my foot rest during a transfer while I was barefoot. Although I managed to get in to see a wound care specialist within a week of the injury — when it was no bigger than the size of a pencil eraser — it took over a month of care and weekly visits to the specialist to heal it. It seems all of a sudden — through nightly mirror checks — both heels would be red from pressure. I've had to move to a full size larger shoe than usual to keep the pressure off my heels. Is this common in people with spinal cord injuries? Is there anything I can do about it?

— Mark

M ark, the people I roll with have the same issues. At some point post-injury, the skin on our feet becomes more fragile, especially heels, around toes, and ankle bones.

To answer your questions I turned to Kathleen Dunn, clinical nurse specialist and rehab case manager. Dunn says that people with SCI have the same high risk for skin breakdown in their feet as people with diabetes — for similar reasons. Both groups have lack of sensation that can lead to scrapes and pressure sores. A slow healing wound on a foot or toe can quickly lead to infections such as cellulitis or osteomyelitis (infection of the bone). Edema (swelling) makes skin even more vulnerable. The good news is there are many steps that can and should be done to help keep feet healthy.

A good place to start is to avoid going barefoot, even around the house. Darryl Murphy, 58, in his 40th year as a T11 para, says, "In the first 20 years after my injury I lost toes from getting minor stubs and scrapes. I would go barefoot in my chair and stub a toe (or a few) and they would be very slow in healing. At the time I was a smoker, so it made healing even slower. Eventually an infection would set in, it would get into the bone, and then my only options were months of IV antibiotics to try and knock out the infection and hope it didn’t spread to the foot, or have the toe(s) amputated. I opted for amputation at an outpatient surgical center. I finally learned my lesson and now put on shoes before I get in my chair. And I quit smoking."

Candace Cable, 62, in her 41st year as a T10 para, concurs. "I pay close attention to my feet because if I get any scrapes or wounds on them, it takes a long time to heal," she says. "I always wear shoes. Even if I’m just getting up at night to use the bathroom, I’ll slip on a pair of shoes. Plus it prevents my feet from sliding when I’m doing transfers."

Another area where it is all too easy to scrape a foot is during swimming and watersports. This can be avoided by wearing canvas tennis shoes, or better yet, by wearing neoprene wetsuit boots or thin “water socks” (around $20 at dive shops or places like Amazon.com).

“Be careful when selecting footwear. I have seen too-tight shoes cause autonomic dysreflexia,” says Dunn. “New shoes should only be worn for two hours, then removed to check for pressure areas.” Then wear them four hours, then six, etc., to make sure there aren’t any red areas. Pay close attention to heels, outside edges of feet, bony areas over the toes, and with high-tops or boots, the malleolus (bony prominence on each side of the ankle).

For people who have problems with edema, be extra sure shoes aren’t too tight, says Dunn. Diabetic shoes are often the best option, but with any shoe it is recommended to increase both size and width if feet are developing edema at the end of the day, especially because edematous skin is more vulnerable to pressure. When buying new shoes, keep the box and receipt until you’re sure they’re the ones for you.

Other foot-related pressure areas to check are the outside of foot-plate posts, and where feet rest while driving — if you transfer to the driver’s seat.

Lying in bed is another potential foot-pressure area, especially for heels and the malleolus, says Dunn. She suggests wearing pressure-relieving boots to protect these areas (found on Amazon.com for around $40 a pair). Cable suggests another option. “I stack two pillows under my calves and hang my feet over the end of the pillows. This also reduces any edema I’ve developed over a long day.”

“Feet should be inspected and
cleaned daily, a bedtime foot-skin-check is a must, and an additional morning check is also important,” says Dunn. If skin becomes dry or flakey, Dunn recommends using a good moisturizer that is high in urea that helps soften dry, rough, and scaly skin, such as U-Lactin, which can be found at most drug stores, or a petrolatum cream like Aquaphor. Dunn is not in favor of exfoliation (rubbing off flaky skin) because on areas that have no sensation, it can be done too harshly and cause more problems than it helps.

“Be sure to pay attention to your toes and the area in between,” says Dunn. After bathing it is important to carefully dry between toes. For problems with chronic moisture between toes or if toes are rubbing together, a thin piece of lamb’s wool threaded around the toes will prevent rubbing and allow more air into the area. Athlete’s foot should be treated with appropriate antifungal agents like Tinactin or Lotrimin. Another way to help keep toes dry and athlete’s foot at bay is to wear foam “toe separators” to bed (can be purchased at most major drug stores).

Last but not least: toenail care. Dunn explains that people with SCI are at very high risk for developing ingrown toenails, something that should be seen by a podiatrist because they can become infected and can cause autonomic dysreflexia. One of the many causes of ingrown toenails is improper clipping. “Clipping toenails is a high-risk activity and needs to be done properly,” says Dunn. “A visit with a podiatrist to learn proper nail care, or even having nail clipping done by the podiatrist, can be money well spent. Many insurances will cover this with a justification of insensate feet.” Medicare will pay for trimming, cutting, clipping or debriding of toenails by a podiatrist, osteopath, or doctor of medicine with certain “systemic” conditions, including neurological ones, that may require specialized foot care by a professional.

“For people with SCI who already cut their nails, various ways are possible. Some cut the nail straight across and some do a rounded cut. Do what works,” says Dr. Daniel McFarlane, a podiatrist affiliated with Craig Hospital. “Straight cut toenails should be a little longer; round cut should be shorter.” Take care to leave enough nail to avoid nicking the skin. WebMD.com’s advice for diabetic feet is to cut toenails after bathing when they are soft. Trim them straight across, then carefully smooth them with a file, and be careful to avoid cutting the corners of your toes.

As a routine part of “daily SCI systems management,” foot care only amounts to a few minutes a day — time well spent to avoid serious complications that could result in hospital stays.

**Resources**

I’ll tell you another good thing about being a lifelong cripple. I don’t waste time longing for a return to the good old days.

If I became crippled later in life, maybe it would be a different story. Maybe I would yearn to go back to that wonderful, carefree time when I could run like the wind, feel the cool green grass under my bare feet, not have to worry about my leg bag springing a leak in the middle of a hot date, etc.

But for lifelong cripples like me, there are no good old days. Looking backward for hope and strength just makes me break out in hives, both physically and psychologically. Forget about going back to any point in time before around 1965. Maybe life began 200,000 years ago for the rest of Homo sapiens. But for Homo sapiens cripples, life began around 1965, at least in the U.S. I mean, cripples like me didn’t even have motorized wheelchairs before then, except for those inventive cripples who fashioned makeshift motorized wheelchairs out of two lawnmowers and an ironing board or something like that. How the hell did anybody who was crippled like me survive before there were motorized wheelchairs?

How about 1970 or so? No thanks. Any public school from kindergarten to college could turn any crippled kid away back then, no questions asked. And they did, too.

1980? Yeah right. Have fun finding a public transit bus or train that was wheelchair accessible back then. And have fun finding any newly constructed housing that was even remotely accessible, because there was no Fair Housing Amendments Act requiring basic access. Oh, and if you needed somebody to wipe your butt every day without going broke paying someone to do that for you, have fun finding that, too. Most programs like the one I use where the state pays the wages of the people I hire to assist me in the home and community didn’t exist back then. I guess back then cripples like me also had to come up with makeshift butt wiping solutions, like calling the fire department.

How about 1990? You mean before the ADA? And let’s not forget about Social Security or Medicare or Medicaid. Who wants to go back to before those programs were around? Don’t raise your hands all at once now.

I don’t even want to go back to six months ago. It was about six months ago that CVS drugstores announced that some of the clinics in their stores will have scales that are wheelchair accessible. So now cripples like me can do yet another thing that uncrippled people routinely do every day.

So yeah, I’ve never had any nostalgia for the good old days, even though that was back in that glorious era that will soon be known as BT: Before Trump. Now, if he and his fascist buds get their way, look out, cripples!

Now it’s true that Trump didn’t specifically scorn cripples in the same way he did just about everybody else. He didn’t say cripples are rapists and murderers or that we’re ugly and eat like pigs or we all ought to be herded up and sent back to wherever we came from. All he did was give us his generic spazzed-out-cripple impression, which was so lame that even Jerry Lewis could do better.

But we are on Trump’s hit list. Have no doubt about that. Here’s how you know if you are among those populations Trump would like to see bound and gagged and thrown into a bottomless well. Ask yourself this simple question: “Is there anybody like me on Leave it to Beaver?” There are no gay people in Beaverville. No trans people for sure. No black or Latino people or anybody not white, except maybe in cameo roles as servants or shoeshine boys or proprietors of the Chinese laundry. And there are absolutely no cripples like me in Beaverville, not even in a cameo role as a lowly street beggar. And Trump is determined to restore the blissful purity of Beaverville, even if he has to send in armed troops to make sure everybody keeps smiling.

There’s no place for cripples like me in that world. So I imagine pretty soon I’ll find myself pining for the BT good old days. And it’ll probably be while I’m calling the fire department.
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TRUE ACTIVISTS DON’T JUST DRIVE BY

Here’s an unpopular opinion: Anderson Cooper’s recent coverage of “drive-by lawsuits” on 60 Minutes wasn’t nearly as egregious as many disabled people seem to believe. Such lawsuits, named for the speed and lack of warning with which they are initiated, are filed against business owners whose locations do not fully comply with the accessibility standards set forth by the Americans with Disabilities Act. Cooper’s angle was, unfortunately, strongly slanted against the importance of adhering to the laws set forth by the ADA. But even from my vantage point as a wheelchair user and activist who fights fiercely for accessibility, I’m not fully on board with the disability community directing the majority of their anger toward Cooper. Though his reporting on these lawsuits missed the mark in multiple ways, it shouldn’t go unnoticed that Cooper exposed a major issue: There are lawyers out there undermining the hard work of activists, and the ADA itself, by recruiting disabled people to sue for even the most minor ADA violations as a money-making scheme.

— Emily Ladau, editor-in-chief, Rooted in Rights, www.rootedinrights.org/true-activists-dont-just-drive-by/
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Clinicians typically recommend a repositioning regimen for clients who utilize power wheelchairs with power seat functions. It’s clinically understood that using the seat functions on your wheelchair allows you to stay in a chair longer, be more active, get more things done, and potentially prevent secondary issues that could occur. But what happens when the client goes home? The problem many clinicians and clients face today is maintaining a consistent repositioning regimen for improved health and well being over time.

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