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ANYA LOPEZ, lab technician, feels she can now accomplish more activities than ever before.
Spring is almost here and there’s no better time to start planning and planting your dream garden. Whether indoors, outdoors or upside down — flowers, foliage or food-focused — the options are plentiful. PAULA LARSON talks with all types of gardeners about best strategies and tools to guarantee your horticultural success, and TIM GILMER adds his love of gardening into the mix.
Our cover story this month is about accessible gardening and its many benefits. I’d like to tell you about how my wife’s and my gardening experience enriched our lives and prepared us for making a leap we never even considered until it happened — farming organic vegetables for sale to local restaurants and markets.

After several years of enjoyable gardening that started in 1974, we were fortunate to be able to purchase a small farm about 25 miles south of Portland, Oregon. The farm had small pastures for a modest herd of cattle, the kind of operation that appeals to “gentlemen farmers.” But I ain’t no gentleman, and neither is my wife.

Our first year on the farm we rented the pasture to a neighbor who brought over several heifers. The girls took care of themselves, so Sam (my wife) and I planted our usual spring garden with accessible pathways, but upsized it. When fall came, we had a bumper harvest. So the next year we planted an acre of vegetables and placed U-Pick signs on nearby country roads, hoping to make a little spending money. A great plan, but with one major glitch: No one came.

Lesson Number One: Plant only what you can eat, sell or give away.

Lesson Number Two: With no U-Pick customers, the owners become the pickers. Despite getting stuck in the mud in my Stainless Sportster with its 2-inch tires (my Jeep chair), I managed to pick 5 pounds in a couple of hours. Sam picked slightly more, so we bribed the neighbor boys to pitch in and baited friends with promises of wine and grilled steak. By the time we all burned out, we had 30 pounds of pea pods, enough to fill three boxes. Now what?

The nearest Chinese restaurant was 20 miles distant, so Sam and I loaded our boxes, drove there and knocked on the side kitchen door. A chunky Chinese cook opened the door and immediately scrutinized the pea pods.

“Too big,” he said, tossing a few on the ground. “Too small,” he said, picking out the smallest one. Then he picked out the perfect-sized pod and took a bite, making a fresh-crunchy sound. “This good. How much?”

Lesson Number Three: The proof is in the pudding.

Our delivery route grew over the next five years, so we added acreage for beans, tomatoes, eggplant, squash, basil, lettuce, radicchio and more. By year 10 we had about 25 customers, mostly in Portland, a hand-controlled tractor, delivery driver and three seasonal employees. By year 30 we had become known for our fresh produce and were featured on a national TV series, PBS’ Chefs A’ Field.

At our peak we had six acres, deliveries six days a week, and 28 plantings of vegetables, each the size of a large garden.

Lesson Number Four: Do what you enjoy and stick with it.
PAULA LARSON

Paula Larson gardens in Tacoma, Washington — growing veggies, perennials and native plants with her spouse, Julie, and their geriatric kitty, Ursula (aka “Monster”). Paula created her accessible garden by building raised cedar beds while scooting on her bum on her deck; then Julie put them in place and helped fill them with soil. When not digging in the dirt (or freelance writing), Paula works with people who have intellectual disabilities by helping them enjoy recreational activities. She also works for the Tacoma Nature Center, bird watches, rolls 5K races and dabbles in wheelchair basketball and tennis.

KRISTEN SACHS

Kristen Sachs, a caregiver to her husband Jeff, a C4 ventilator-dependent quadriplegic from a diving accident, writes about family, caregiving, and the struggles and triumphs of living with a spinal cord injury on her blog, New Dawn New Day New Life (newdawnforus.blogspot.com). Writing has been Kristen’s best form of therapy to help her deal with the stresses of caregiving. She is an active member of the online spinal cord injury community, and she is also the content manager at AbleThrive. Together, she and Jeff are raising their young daughter, Evie, in Las Vegas, Nevada.

JOSÉ HERNANDEZ

Since becoming a C5 quadriplegic from an injury when he was 15 years old, José Hernandez has had a passion for helping and mentoring individuals with similar disabilities, especially those in nursing homes and rehab centers. Six years ago, while attending United Spinal’s Roll on Capitol Hill in Washington, D.C., he discovered a passion for advocacy. Currently he is able to engage in both peer mentoring and advocacy efforts as a program specialist for United Spinal Association in New York City.

Want to contribute to New Mobility? Please send queries and manuscripts to Ian Ruder: iruder@unitedspinal.org
“Wonderful work being done in New York.”

People of the Year

Wonderful work being done in New York [“People of the Year: Yannick Benjamin and Alex Elegudin,” January 2018]. Bless everyone involved.

Pete Smith
Newmobility.com

NYC Looking Better

I am in a wheelchair due to MS. I moved to Florida and I was afraid of going back to New York City because it’s not friendly for people with wheelchairs. After reading your story, I am ready to go back and hopefully meet you.

Nina Seidner
Newmobility.com

Pneumatic Tools

I have found pneumatic tools easier to work with than their electric counterparts [“Setting Up a DIY Workspace,” Gear Hacks, January 2018]. It takes more initial setup, but provides a bit safer operation and the tools weigh less.

Allen Copeland
Newmobility.com

Cartoon Feedback

Super Funny. I’m the normal guy whose job sucks the life out of me [Please Remain Seated, January 2018]. But, I have a job, so that in itself is a blessing.

Frank Meier
Newmobility.com

Not So Funny

I’ve been a para for over 42 years and I love to laugh at myself. My first reading of this cartoon is still trying to sink in [Please Remain Seated]. I may wake up at 4 a.m. and laugh out loud, but right now I am still looking for the big punch line to hit me.

David Barrett
Newmobility.com

Loving Oneself

I couldn’t agree more! [“The Day Something Changed,” Reframed, January 2018.] I, too, am trying to find ways to care for myself and my body without being in war mode.

Melissa N. Mitchell
Newmobility.com

No Flap Surgery

My husband, Walter, C5-6, 76, in great health and 59 years post-injury, faced this very same type of wound in 2010 and “fired” all medical professionals [“Wound Care ‘Marathon,’” January 2018]. I studied wound care like a crazy person and promised him I would find a way to heal it without the flap surgery that three different doctors/hospitals all insisted he needed ASAP. We ended up choosing Derma Wound from progressivedoctors.com, and I devised a way to inject it into the wound tunnel using a very small oral syringe. It did take a long, slow time to heal and needed treatments twice a day (the big problem with wound care that our current system is not set up to handle), and he spent a lot of time in bed on a mattress overlay, listening to books on tape, but damned if it didn’t heal!

Lois Post
Newmobility.com

Editor’s note: Not all wounds are alike. A wound’s ability to heal can be compromised by complications like diabetes, venous insufficiency, peripheral artery disease and chronic incontinence. Hence, flap surgery should be considered on a case-by-case basis in consultation with a wound care specialist and plastic surgeon.

Get the Best Seating

I found one of the problems [with the current wound care system] is that nearly all of the doctors, nurses and rehab people don’t have that much experience with us and are therefore amateurs [“Wound Care ‘Marathon’”]. It’s a scary reality for those of us in the SCI community. It would be great if we all could fly by private jet to Craig or Shepherd, but for those of us who are ordinary working stiffs, it is just not an option.

Now the good news. Thanks to New Mobility, I read about Aspen Seating in Denver. When I was stable following my last of three flap surgeries, I went there and they designed a seat for me. They did more for me than any surgeon because I have not had a butt pressure sore since 2005. They are masters. So if you’re getting sores from your current seating, I would strongly encourage you to have them evaluate you.

Nick Fowler
Newmobility.com
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CALLAHAN MOVIE TO HIT THEATERS THIS SPRING

Don’t Worry, He Won’t Get Far on Foot, a film based on the memoir of cartoonist and disability icon John Callahan, premiered at the Sundance Film Festival in January and will open in theaters nationwide May 11.

Callahan, who died in 2010, was a major force in American satire. In the late ’90s, his often hilarious, controversial cartoons were syndicated in over 200 U.S. newspapers, an impressive feat considering the number of reader objections they received. Callahan’s New York Times obituary described him as, “a quadriplegic, alcoholic cartoonist whose work in newspapers and magazines made irreverent, impolitic sport of people with disabilities and diseases and those who would pity and condescend to them.”

Perhaps Callahan’s most famous cartoon, from which the memoir and film get their name, shows a posse on horseback coming upon an empty wheelchair in the desert, with one of the posse saying, “Don’t worry, he won’t get far on foot.”

The film was directed by Gus Van Sant, whose work has received both mainstream and indie acclaim, including Good Will Hunting and My Own Private Idaho, among others. Both Van Sant and Callahan lived in Portland, Oregon. Van Sant had been interested in a Callahan movie for decades. Originally Robin Williams had signed on to play Callahan, years before the cartoonist’s death.

In a move certain to cause controversy within the disability community, Callahan, a C5-6 quadriplegic from a car accident, is played by nondisabled actor Joaquin Phoenix. Van Sant, aware of impending activist protests, argued for his choice at the Sundance Indiewire Studio.

NYC’S ACCESSIBLE DISPATCH PROGRAM EXPANDS

The New York Taxi and Limousine Commission announced on Wednesday, Jan. 24, that it would be expanding its Accessible Dispatch Program. The 24/7 service will connect riders with wheelchair accessible taxis via telephone or smartphone app and will be accepting pickups and drop offs in all five of New York City’s boroughs. Previously it had operated only in Manhattan.

Alex Elegudin, one of New Mobility’s 2017 People of the Year and the accessibility program manager for the TLC, says the expansion is huge for New Yorkers with disabilities. “We know that over 80 percent of people with disabilities live in the outer boroughs, so it opens taxis up to a whole new pool of people,” he says. “You could only get picked up in Manhattan before, but it could take you anywhere in the five boroughs. But if you’re home and you miss a ride, or somebody doesn’t come for you, you have no options. There are no other taxi options if you live in Brooklyn, for example, where I live.” He says the program is improving as well as expanding, with better service, a better app, better technology and a new call center.

The expansion marks another step forward in what has been a 20-year-long fight to increase accessibility of the NYC taxi industry. United Spinal Association has been at the forefront of the battle, helping to form the Taxis for All campaign in 1996, along with a coalition of New York disability-rights organizations.

Progress was minimal until 2012, when the campaign won a major legal settlement mandating that at least 50 percent of Yellow Cab fleets consist of wheelchair accessible vehicles by 2020. The settlement also set up a fund, paid for by a 30-cent surcharge on taxi fares in the city, to help defray costs associated with the expansion of accessible taxi service. The Accessible Dispatch Program started in 2012. Along with a steady increase in wheelchair accessible vehicles, it has helped dramatically reduce wait times.

“With dispatch, the waits are down to less than 15 minutes, some of them as low as three minutes in Manhattan. When it first started, it would be an hour, or never,” says James Weisman, president and CEO of United Spinal. “So it’s gotten dramatically better, and if we ever get to 50 percent, it will be even better.”

FROM UNITED SPINAL
Membership in United Spinal Association is free and open to all individuals who are living with SCI/D, their family members, friends, and healthcare providers. Visit unitedspinal.org or call 800/962-9629.

United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.

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- Ongoing Educational Webinars

United Spinal Association is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D) by providing programs and services that maximize independence and enable people to be active in their communities.

“Often comes up with all kinds of lead roles — who are the people playing the lead roles, do they have anything in common with the role itself?” Van Sant said. “I definitely would have used a particular person that was quadriplegic if they were the right actor,” he added, just as composer Danny Elfman chimed in: “A significant part of the story is before the accident, so to do that would have meant completely changing the story, because that’s a major part of the story — before and after the accident.”

Those looking for a full biopic treatment or in-depth accounting of Callahan’s life with a disability will be disappointed. The film focuses narrowly on Callahan’s battle with and recovery from alcoholism, both before and after his accident.

Van Sant also argued that Callahan himself wouldn’t have wanted an actor with a disability to play him: “Honestly, if I’d suggested it to John, he would have said, ‘Fuck no.' Because he wanted the most famous person in the world to play him, which was Robin Williams — he couldn’t wait.”

The film is receiving generally positive, if sometimes ableist, reviews. View the trailer at youtu.be/qCzmesxXmkM.

Joaquin Phoenix brings star power to the film, Don’t Worry, He Won’t Get Far on Foot, based on John Callahan’s memoir.

have said, ‘Fuck no.' Because he wanted the most famous person in the world to play him, which was Robin Williams — he couldn’t wait.”

The film is receiving generally positive, if sometimes ableist, reviews. View the trailer at youtu.be/qCzmesxXmkM.

URI-GO WINS MAJOR TECH PRIZE
Uri-Go, wearable technology that alerts you to how full your bladder is, has won New Zealand’s major tech award, the C-Prize. Worn as a belt, this Bluetooth-enabled product’s measuring device is roughly the size of a business card and sits just above your pubic bone inside your underwear. When its time to pee, it notifies you via your smart phone.

Uri-Go was dreamed up by inventor and paraplegic Mike Brown, who partnered with urologist Dr. Frank Kueppers and tech product engineer Brendon Hale to develop the product. Brown says not knowing when he needed to go led to some pretty embarrassing moments, whether it was in a meeting or at his brother’s wedding while giving the best man speech. “I just thought, wouldn’t it be awesome if I knew exactly when I needed to go and how full my bladder was,” he says. As far as how the device actually measures bladder fullness, he jokes, “If I tell you, I’d have to kill you.”

Uri-Go and nine other finalists were given an opportunity to develop their wearable technology products and explore market potential before presenting progress to a panel of judges made up of business leaders, investors and entrepreneurs in hopes of winning a product development and marketing package worth $100,000. The competition allowed Brown’s team to develop a simple prototype, test a number of form factors — basically the device without the technology inside — and prove market demand.

“I interviewed dozens of people with spinal cord injuries who self-cath to really understand their specific needs and what they thought of the concept,” says Brown. “We then gave them an opportunity to wear our form factors and shared their feedback with the judges.” The majority of the feedback was extremely positive, with most people reporting the device was so comfortable they forgot they were wearing it.

The judges were impressed, too, awarding Uri-Go the grand prize — $50,000 cash, a 3-D printer, office space with a one-year lease and a market research trip to the U.S.

“I know this problem intimately, and obviously I want to solve it for myself,” says Brown. “But the real joy comes with knowing there’s potential to solve this problem for millions of others.
I work with many people who have experienced strokes or brain injury, which cause destruction or deterioration of brain cells and can result in muscle weakness, mobility impairments, fatigue, disturbed sleep, inattention, impaired speech and memory, difficulty concentrating, mood swings, dizziness and headaches. For many years, it was believed that a damaged brain could not repair itself or generate new brain cells. But new research demonstrates that the brain can rewire itself and even grow new cells.

Neuroplasticity — the capacity of the brain to change with learning — allows the brain to compensate for lost functions or maximize remaining functions. Changes associated with learning occur mostly at the level of the connections between neurons. New connections can form and the internal structure of the existing synapses can change. People who have sustained a brain injury can support neuroplasticity through nutrition.

The brain requires specific macro and micro-nutrients to function optimally, such as complex carbohydrates, essential fatty acids, B vitamins, vitamin C and protein. Adequate daily intake of these nutrients is essential for anyone with any kind of brain injury.

Increasing the following nutrients in your diet is recommended to help support your brain function and overall nervous system.

**Complex Carbohydrates**: Carbohydrates are the brain’s preferred fuel source. The brain draws nearly all its energy from glucose, which comes from carbohydrates. An inadequate supply of healthy, fiber-rich, complex carbohydrates can negatively affect attention, memory and energy levels. Healthy complex carbohydrates: whole grains (whole grain bread, whole grain pasta and brown rice); legumes (beans and peas); lentils; vegetables (Brussels sprouts, broccoli and cauliflower).

**Essential Fatty Acids/Phospholipids**: The brain is 60 percent fat, and requires healthy fats to function optimally. Specifically, polyunsaturated fatty acids like omega-3 and omega-6 help strengthen brain synapses related to memory. Healthy fats are also a major component in every cell in the body and a key component in the myelin sheath that covers all nerves and promotes proper signaling of messages in the brain. Omega-3 is converted into DHA (docosahexaenoic acid) and helps to enhance neuronal communication and promotes neuronal growth. DHA, found in fish, makes up a large portion of the brain’s gray matter. Neurons are also rich in omega-3 fatty acids. The highly beneficial omega-3 fatty acid cannot be made in the body and must be obtained in the diet. Cold water fish is the best source of omega-3.

Phospholipids, another class of healthy fats that can help support brain function, help make acetylcholine, the brain’s memory neurotransmitter. Excellent sources of omega-3 fatty acids and phospholipids: salmon, sardines, mackerel, eggs and liver.

**Antioxidants**: Antioxidants, found in tea, fruits and vegetables, help regulate oxidative stress, which destroys brain cells and is caused when the body converts glucose to energy and the extra oxygen created from free radicals. Free radicals cause tissue damage and antioxidants neutralize free radicals.

Dark-skinned fruits and vegetables have the highest levels of naturally occurring antioxidant levels. Blueberries and strawberries can protect the brain from oxidative stress and have shown to help improve memory and motor skills.

Consuming nuts also protects the brain. Almonds, walnuts and pecans are great sources of vitamin E, an antioxidant. They also contain healthy fats to support the brain and help promote healthy neural tissue. Antioxidant rich foods: red/green peppers, sweet potatoes, kale, dark berries (blueberries, blackberries and strawberries), guava, papaya, Brazil nuts and green tea.

**B Vitamins**: There are eight B vitamins, all essential to nerve function. Even short-term deficiency of any one of them can result in a shift in thinking and mood. Foods rich in vitamin B: avocados, black beans, lentils, mushrooms, spinach, salmon, beef, eggs and pine nuts.

**Protein**: Proteins break down into amino acids, which are used to make neurotransmitters — the brain chemicals that communicate information throughout the brain and body. Healthy protein sources: fish, beef, chicken, eggs, quinoa, legumes/lentils and nuts/seeds.

*Try this brain boosting meal that contains all of the above nutrients!*
For many years after my injury I would forget I was in a wheelchair, only to be reminded of it by my reflection in a storefront window or my shadow next to that of my sister’s. My heart would tighten and my eyes would hold back the tears. I had this image of what I looked like and how I presented myself to the world. It was disheartening to realize that what people saw was different. I wore oversized clothing to hide my body, though the fashion designer in me screamed I could do better. I avoided dance floors when the music was making everything inside me want to move. I felt I had lost beauty and grace.

Over time, I noticed women in wheelchairs dressing well and I began to make an effort. Eventually I bought a short skirt and was willing to show my atrophied legs. At a wedding, after enough drinks to make me forget my apprehension, I actually danced all night. I didn’t love the way I looked, but it mattered more that I had fun. The experience was liberating.

My shadow was like a ghost that haunted me, humbling me, making me self-conscious of my disability. But over time, moments like buying a mini-skirt, dancing, taking a yoga class or even going to the movies alone became pivotal in letting me love myself. The haunting shadow visits less frequently now, and in its place the darkness that follows me is surrounded by light, reminding me that I am still all of the things I was, but felt I had lost. My quad hands may not cast recognizable shadow puppets, but the way my fingers curl and how my wrist falls makes for a unique image that casts a beautifully abstract companion. One that moves alongside me, not walking, not rolling, just there — reminding me I am still me.

But as a wheelchair user, I need to carry stuff, sometimes lots of stuff. An under-chair bag for daily use and a good backpack for travel and taking my laptop to a coffee shop are things that I need on the regular. Over the years, after going through a lot of different bags, I’ve found a setup that works perfectly for me, and without breaking the bank. My personal preference is for bags made by outdoors companies. I like the style, durability and features of these types of bags. But whatever your personal style, you can follow some simple guidelines to make all sorts of bags function well with a wheelchair.

Chop the Extras

With any bag that you’re going to use on a wheelchair, you need to be merciless with strap chopping. You’re setting the bag up for you, not someone who walks. Things like shoulder, hip, and sternum straps don’t apply. With a backpack, shoulder straps just get in the way. Chop ’em off. The same with hip straps. It’s a constant annoyance to have to fiddle to get straps tucked just the right way so they’re not making the baseball-card-in-the-spokes sound and getting stuck. Both backpacks and under-chair bags are going to be hanging off a metal frame, not your body, so many of the ergonomic comfort benefits of modern bag straps don’t apply, and the form and padding just get in the way.

Under-chair Bag

Basic requirements are that it has multiple pockets and will hang under the seat of my everyday chair without clanking around or having parts that want to feather my spokes. The fashion accessory of the ‘80s, the fanny pack, tends to fit the bill here. Fortunately, fanny packs (“lumbar packs” in today’s marketing terms) have come a long way in the past 30 years. I bought a Mountain Smith Drift lumbar pack made of durable, Cordura nylon for $50 that has two good-sized compartments with internal organization pockets and zipper pulls already attached. Also, a lifetime warranty. Try finding that on a wheelchair bag.

Attaching it to my chair proved even simpler than I expected. While the pack is designed to be worn around the hips, it also comes with a detachable shoulder strap. I removed a small pad from the strap and looped the nylon around the outer bars of my everyday chair so the ends of the strap hang just below the frame. If the length of the strap is funky for your chair style and width, it can be cut and looped and tied separately on the outer bars. The bag has quick release clips to attach and detach, an added bonus if you are a frequent flyer.

Mountain Smith has multiple lumbar bags of different sizes that all could attach the same way. If you’re not into the outdoorsy look, just about any bag with a detachable shoulder strap can connect the same way. If you’re looking for bags online, you want something that’s a minimum of 4 inches narrower than the outer seat width of your chair.

For those who don’t need to regularly break their chair down to pull it into a car, an open top, under-chair bag can be a versatile and practical option. Reader Lou Mortelli, of Massachusetts, offers a cool hack for custom making an open-topped bag.

She bends a length of ½-inch metal tubing (any machine shop should be able to do this quickly and cheaply if you don’t have a pipe bender) to create a simple frame that slides into her wheelchair’s anti-tip bar brackets. She then finds canvas and mesh material from a store like Joann Fabrics or Hobby Lobby and takes it into a leather repair
shop to have them sew up a simple fabric sling that will slide over the tubing and attach via Velcro loop to her back axle. What she ends up with is a stable carrying pouch that’s custom fitted to her chair and can be easily removed for washing.

**Backpack**

If you have enough trunk function to wear a backpack, you can use just about any bag you like. If not, you need something that can easily hang from your backrest and not get in the way of your wheels. I spent long years trying to hang backpacks on my backrest by the shoulder straps and it was always a pain. Then I found a simple solution: miniature carabiners ($3.95 and up at REI).

I found a nice laptop bag made by Mountain Hardware — The Memo — designed not as a backpack but as a shoulder bag. I took off the shoulder strap, clipped the miniature carabiners to the shoulder strap attachment rings and attached loops of nylon webbing to the carabiners. To put the bag on my backrest, I simply grab one of the webbing loops (climbing slings work great, sold for $4.95 each at REI) and use that to slip the carabiner over my backrest post, then repeat on the other side. The nice thing about using carabiners as the attachment to the backrest instead of straps is that the bag sits high and tight. There is very little swing when you’re pushing. None of the thump, thump, thump that comes when pushing up a hill with a heavy bag hung by straps from your backrest.

Not every bag happens to have attachment rings for a shoulder strap on the side. But many bags these days have straps and loops along the sides, either for hanging things from, or cinching the bag tight when there’s not much in it. A mini-carabiner/webbing loop setup can clip to just about anything along the side of a bag to provide a functional backrest attachment.

As with under-chair bags, once you develop a system for easy attachment to your chair, which bag you choose is dependent on your personal style and preferences, not on a limited and often woeful selection of “wheelchair bags.”

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**Resources**

- Mountain Smith, mountainsmith.com
- Mountain Hardware, mountainhardware.com
- REI, rei.com

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The main tool you’ll need for this hack is a decent pair of fabric shears. Purchased parts are a climbing sling and a miniature carabiner, both available from REI.
CAN'T LIVE WITHOUT: My Spinergy ZX-1 power add-on is so compact and sturdy that it makes traveling easy. I liked it so much I went to work for the company.

TRAVEL TIP: I’ve had great luck hiring short-term caregivers from agencies in cities I’m visiting. It allows me to travel by myself.

DOG WHISPERER

Daniela Schirmer

Daniela Schirmer had high hopes when she decided to get a Canine Companion for Independence about three years ago, but she never could have imagined the bond she would develop with Zandra (Z-Dog).

Woman’s Best Friend

“I remember my friend Valeria, who is in a chair and has a service dog, kept saying, ‘Oh just wait until you have a dog and you go out on the street — you’re going to feel so confident.’ Those words didn’t really mean anything to me and I just didn’t get it,” says Schirmer.

Then she got Z-Dog and her friend’s advice made sense.

“Before I got her, I had a lot of little anxieties when I went out — people staring at you, feeling more vulnerable because of the chair — I think it was making me feel stressed out. Somehow, she just eliminated that for me. I feel invisible to the eyes when I’m with her. I feel safer. It’s really hard to describe, but she gives me a feeling of comfort.”

In addition to the newfound confidence, Schirmer noticed that strangers didn’t ask as many inappropriate and awkward questions about her disability.

“People started asking me about the dog instead,” she says. “They’ll say, ‘Oh, your dog’s so cute, can I pet it, what’s her name?’”

Schirmer says it took time to build her relationship with Z-Dog, but once the two understood each other she was blown away by her companion’s skills.

“She’s so smart,” says Schirmer. “Even if I’m not actually having her do a task for me, she knows when I’m there with her and I’m engaged with her. She knows when I need her the most. Sometimes when a person is around, it will take her a couple of minutes to pick something up for me because she’s like, no, you don’t really need my help, they can do it. But then when we’re travelling, just she and I, she’s a beast. She is ready. She trots beside me and she’s all proud. It’s obvious she loves her job.”

With the assistance and confidence provided by Z-Dog, Schirmer has gotten back to enjoying social situations and living her life. After a series of unsuccessful Tinder dates, she finally matched with a man she connected with at the end of 2015. The only problem? He lived in Virginia and she lived in California.

“I remember before I was going back to California I was like, all right, well, I guess this is it. I just sort of assumed that it was
going to be over,” she says. “I think a lot of that was based on just having dated noncommittal men in the past. He said, ‘No, I want you to be my girlfriend.’

“I was really surprised by that, and thought that’s a good sign, I’m going to give it a shot. A guy that’s not afraid to date a girl in a wheelchair 2,000 miles away? I’m going to go for it.”

They settled on taking turns making monthly cross-country trips and did so for a year. “Eventually it just got to the point where one of us had to move and it made sense for me,” says Schirmer. “I have a job where I can work remotely and my parents live in Virginia, and it’s home, so I came back.”

The relationship deepened, they got engaged, and bought a house together. They are set to get married this summer.

Schirmer thinks the fact that she and her fiancé both had overcome traumatic situations helped serve a common ground to bring them together. “Something about our characters was drawn together, how we grew because of what we went through. I really feel like that was part of it,” she says. “Ours was definitely a love that grew.”

PERSONAL CAUSE
No Dogs Allowed

Schirmer worries that the proliferation of uncertified and illegitimate service and emotional support animals is creating obstacles for people who rely on trained service animals. “It’s a real problem. There needs to be a governing body that is backed legally to give out some kind of certification.”

“T My fiancé and I drove from Washington, D.C., to New York City for a photoshoot and didn’t get there until 1 o’clock in the morning. We got to the front desk and the guy checking us in would not let me check in because of my dog. I explained that it was a service dog, it’s not a regular dog or a pet, and I’m protected under the law. He wouldn’t have it. I have it printed out on an ID card and he wouldn’t even look it. I was so mad. He turned us away at 1 a.m.

“I asked him, ‘What would you do if I was here alone, like without my fiancé? What would I do right now? There are no accessible taxis at 1 in the morning in Brooklyn.’

“We eventually found a different hotel, but we didn’t get to check in until 3 a.m. It makes me wonder if fake service animals give real service dogs a bad rap.”

THE WEDDING PLANNER: I want my wedding to be really fun for my friends in chairs. I’m working on borrowing some Trackchairs so people just have a blast on them.

WHY I JOINED UNITED SPINAL: Being involved with other people with spinal injuries is important to me. I created a network called DMV (DC Maryland Virginia Wheelchair Alliance). It has about 170 people, and it’s nice knowing it has been helpful for some people.
Imagine you are rolling through an alleyway filled with people singing religious hymns. They walk past you with tears streaming down their faces because they are so moved to be tracing the footsteps of their savior. To your left is the Church of the Holy Sepulchre, built on the site where tradition says Jesus was crucified and buried. Up ahead is the Western Wall, which remained intact after the destruction of the Second Temple and is one of the most revered places in Judaism. And just beyond that, up a long wooden ramp, is the Dome of the Rock, a beautiful gold-topped Islamic shrine where Muslims believe Muhammad began his night journey to heaven.

This uncommon mixture of three major religions and their most notable sites all within half a mile of each other might sound like an alternate fantasy world, but it is very real. And it’s somewhere that you can visit no matter what your abilities are.

This is Israel.

Before I visited Israel for the first time, I was a bit nervous. If you watch the news, you’ve undoubtedly seen plenty of stories about violence and unrest in the Middle East. I remember sitting with my mom in the Atlanta airport as we waited for the first leg of our flight to take off. An hour before the flight we were still contemplating if we should go or not. The danger had been drilled into our minds by the media for years, but we decided to live by the quote, “If you never go, you’ll never know.”

I couldn’t have imagined that Israel would quickly rise to the top of the list of favorite places I have visited, and now have travelled there twice. My safety concerns proved unneeded and my worries that Israel’s ancient history would result in mediocre accessibility were delightfully wrong. With tour companies specifically focused on accessibility and a strong community of startups creating better technology for those with disabilities, Israel is an amazing tourism destination.

**TEL AVIV**

When you fly into Israel, you will surely arrive via the international airport in Tel Aviv, so it makes sense to start your trip in this bustling city. Tel Aviv is one of the more modern and progressive cities in the Middle East, and the city offers a lot for wheelchair users. Some of its absolute must-dos are visiting the beach, shopping in the markets, and rolling in the ancient port of Jaffa.

For some fun in the sun, head to the Hilton. You do not have to be staying at the hotel to use its accessible beach, but accessible rooms are available. The hotel’s main draw is its location and extremely wheelchair-friendly beach, which has multiple manual beach wheelchairs available on a first-come, first-served basis. These chairs can even be rolled into the water if you need a respite from the sun. If you would rather not get in a beach wheelchair, or if it’s taken by someone else, you can still get close to the water thanks to a paved ramp that goes with-

"Tel Aviv is one of the more modern and progressive cities in the Middle East."
After lounging on the beach, head to the markets for some shopping and lunch. Tel Aviv has quite a few different markets to choose from, but two that are totally accessible and worth visiting are Carmel Market and Sarona Market.

Carmel Market is outdoors and always crowded, but if you are looking for a one-of-a-kind experience, this is it. As the largest market in Tel Aviv, you’ll have no problem finding great souvenirs or food, although you may have to run over a few toes to get to any of it. If you can, visit Carmel Market on a Tuesday or Friday. On these days, independent artists sell crafts, art, and jewelry along Nahalat Binyamin Street. The market is busier then, but if you don’t mind a crowd, it’s worth it.

On the other hand, Sarona Market is pretty much the complete opposite of Carmel. It is indoors, much calmer, and not as large, but still offers a lot and is nice to roll around.

GETTING AROUND ISRAEL

From the moment I exited Tel Aviv’s Ben Gurion International Airport, I toured the country with Israel4All. “Israel4All is the only company dedicated to doing tours for people with disabilities here in Israel,” says its owner, Eli Meiri. Before starting the business in 1998 and leading tours, Meiri was a social worker. “I had some people in my family working in the tourism industry, and I love my country very much. I saw the need for accessible tours and decided this will be a good way to combine my desire and my knowledge.”

His passion was readily evident. If a restaurant or attraction wasn’t fully accessible, Meiri would talk with them and suggest ways to improve it.

As the only accessible tour company in the country, Israel4All has a van with a lift and wheelchair tie-downs, and can help you book wheelchair friendly hotels, recommend attractions, and more. It also hosts group tours a couple times per year if you would rather travel with others.

I never had to worry about finding accessible public transportation, which was convenient, but if you’d rather explore the country on your own, you can do it. “We navigated on our own as we almost always do, mostly due to cost,” says Ruud Klaassen, who visited Israel in March 2016 with his wife, Shireen. Shireen has multiple sclerosis and while she can walk unaided for short distances, she depended on a manual wheelchair during their time in Israel. “Tel Aviv was no problem — the train from the airport to the city was accessible with lifts at both stations. All buses we took were also accessible, although we ended up walking all over the place for most of the trip,” says Klaassen.

In Israel’s major cities, public transportation is mostly accessible, but you may want to study the train and bus routes online before going to make sure that you know your way around. In cities like Jerusalem, where the streets are hilly and cobblestone, it can’t hurt to be prepared.

If relying on public transportation or a tour company doesn’t give you the freedom that you prefer, you could also rent a vehicle. Eldan Car Rental has locations all over Israel, and they offer cars with left or right hand controls.

Resources

• Eldan Car Rental, rent.eldan.co.il/en
• Israel4All Tour Company, www.israel4all.com
on my second trip to Israel, I didn’t want to leave without venturing into Palestine for a day. It’s a place that’s all over the news, but I wanted to see what life is really like in the famous town of Bethlehem, and I now highly recommend that any other curious, Israel-bound travelers do the same. A mere 20 minutes by car from Jerusalem’s Old City, it’s convenient to head here for a day or even an afternoon while you’re in Jerusalem. Despite what I had read online, I had no issues crossing the border from Israel into Palestine.

Rolling around timeworn Bethlehem is an experience in itself. While some places can be quite steep (better for motorized wheelchairs) and occasionally the lack of curb cuts might mean that you have to roll along in the road, it is every bit worthwhile. You’ll encounter a number of excellent shops while rolling around the streets, which you might miss if you’re getting around by car.

I visited one souvenir shop that had an extremely steep ramp to get in, but the shop owner came outside and helped me get in. Once I was inside, he said, “You are not obligated to buy anything, but you are obligated to have a drink.” He served me a wonderful mint tea. I asked for a straw, but there wasn’t one available, so he just lifted the tea to my lips and every couple minutes he would ask, “Do you want another drink?” He was one of the nicest people that I have encountered in all of my travels, and of course I bought way too many souvenirs in his shop.

After rolling around a bit, find your way to Bethlehem’s most popular attraction, the famous Church of the Nativity. While there is no accessible alternative to the stairs leading to the church’s grotto, where tradition says is the exact spot of Jesus’ birth, it is inspiring enough to be in one of the world’s oldest Christian churches. The Church of the Nativity has been around since the 500s A.D. and aside from visiting the altar, one of my favorite parts of the church was the life-sized nativity set in the courtyard.

I was only in Bethlehem for about four hours, but if you have more time, you could visit other notable attractions such as the Milk Grotto, where it’s said Mary nursed Jesus after he was born, or you might just enjoy a simple afternoon of people-watching in Manger Square.

Thanks to renovations within the past decade, more and more attractions in Bethlehem are becoming wheelchair friendly. While they may not all be 100 percent accessible yet, there is plenty for wheelchair users to experience.

The ports of Tel Aviv are another attraction that any traveler should seek out. I loved my first experience so much that I actually came back the next day — I simply couldn’t get enough of rolling along the spacious, seaside promenade and popping into various stores along the water.

The historically significant Port of Jaffa is another highlight of Tel Aviv. While it can be a bumpy ride on cobblestone roads, we followed the signs pointing toward the best view of coastal Tel Aviv and it didn’t disappoint. I had one of the most incredible dining experiences of my life at the Nalaga’at, a cultural center in Jaffa that aims to open a dialogue between deaf and blind culture and the general public. At the Blackout restaurant, guests are served by blind waiters and eat in complete darkness so that they can experience life from a different perspective and eat with their other senses heightened. It’s a remarkable adventure that I’d recommend to everyone.
of Judaism, where you will encounter an incredible emotional scene. Visitors will be praying, crying and cheering, many basking in the fact that they’ve finally fulfilled their vow to journey to this holiest of sites.

In my experience, rolling up to the wall wasn’t bad, but if you don’t have an organized accessible tour, it can be challenging to find parking nearby. There are separate entrances for men and women, and men must put on a free kippah (traditional Jewish headwear) to enter. I particularly enjoyed this, as the kippah had the words “Western Wall Heritage Foundation” inscribed on it and made an excellent souvenir.

If you’d like to meander about the Old City and bask in its unique ambiance, there are accessible routes to roll from one site of significance to another. Longmire says she was surprised by the accessibility in the old city. “Of course, there were places I couldn’t enter, but vendors would come out to help me and there were ramps into some of the more historic older sites as well,” she says.

Thankful that our local guide from Israel4All knew such accessible routes [see sidebar, “Getting Around Israel”], I took the opportunity to roll along from the Western Wall to the Church of the Holy Sepulchre. This is a must-see site for many Christians, as it contains the Stone of the Anointing, where it’s said that Jesus was laid in preparation for his burial. Once you get there, the church is pretty accessible, though one of the entrance ramps would be steep for manual wheelchair users, and you may have to request that a portable ramp be laid down to get you up one small step in the entryway.

If you’re exploring the Old City on your own, look for the “Accessible Trail” signs. Finding such a path and rolling through the Old City is a great chance to look beyond the tourist attractions and interact with local residents and shopkeepers.

Of the four quarters, I think the Muslim Quarter was the smoothest to roll through and had some of the kindest people. At one point, as I was rolling by a shop, the shopkeeper came outside and gave me a free souvenir magnet. At another point in the Muslim Quarter, a man came up to me, hugged me, and put a Palestinian scarf known as a keffiyeh on my head.

While the Old City is the heart of Jerusalem’s tourism, there are plenty of other accessible places to see. In fact, I’d recommend that any trip to Jerusalem begins with a visit to one or both of its famous viewpoints. The Haas Promenade and Mount Scopus both offer breathtaking views of this holy city, and they allow you to get a bird’s eye panorama of the places you’ll see close up later on.

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Not far from the bustle of the Old City lies the Tower of David citadel, and it’s here that I spent my favorite night in Jerusalem. A 45-minute sound and light show, projected on the walls of the citadel, tells the fascinating history of Jerusalem. Whether you’re particularly interested in history or not, the Israel Museum is a great place to see relics unlike anything else in the world. It’d be easy to get lost among the museum’s world-renowned art and archaeology for days — but if you have less time, seek out the famous Dead Sea Scrolls, the ancient biblical manuscripts discovered in the Qumran caves in the late 1940s. Trading historical wonder for historical sorrow, Yad Vashem is a sobering, yet essential place to see in Jerusalem. Israel’s touching memorial to the holocaust, the country’s second-most visited tourist destination, is as somber as it is educational.

Last but not least, Jerusalem’s markets are just as vibrant as those in Tel Aviv. Head to the open-air Mamilla Mall for a more modern and glamorous shopping experience, or if you’re looking for something more akin to the authentic Middle Eastern markets, wander around the classic Machane Yehuda Market, where it’s easy to work up an appetite with all the scrumptious offerings. Machane Yehuda is not quite as accessible as Mamilla or the markets in Tel Aviv, but it is possible to see most of it in a wheelchair.

THE NORTHERN CITIES

Though not frequented as much as Tel Aviv and Jerusalem, the cities of Northern Israel are every bit as charismatic. Stunning locales like Haifa, Tiberias and the Galilee region rounded out my first Israel trip better than I had even imagined, and are a great option if you have time to tour a bit more of the country.

Most people who head north do so to see the picturesque Sea of Galilee. It’s obvious why. The Sea of Galilee, where the Gospels say Jesus walked on water, is a large freshwater lake with a regal and mystical aura. While there, I stayed in the town of Tiberias, named for a Roman emperor, and took day trips to nearby attractions like the quaint fishing village of Capernaum, where Jesus began his public ministry. I was surprised at the wheelchair-friendliness of the place and how easily I could roll around some of its still-standing ancient ruins.

If you’re in Capernaum, another astounding sight to see is the Ancient Galilee Boat. When researchers discovered it in the Sea of Galilee in 1986, they were astonished to find out that it dates back to the first century, or the time of Jesus himself. The boat and the associated museum are incredible to behold.

Whether you’re Christian, or just have an appreciation for great historical figures, you’ll be fascinated with how prevalent Jesus was in this region’s history. At the Mount of Beatitudes, some of the words from his famous Sermon on the Mount are on display. It’s inspiring to witness, regardless of personal piety.

Finally, make time for the famed Church of the Multiplication. No, this doesn’t have anything to do with math. Rather, its name refers to the miracle that is said to have taken place here, when Jesus fed thousands of people with two fish and five loaves of bread. The church is a beautiful and calming place that wheelchair users can get around in with no problem.

The other gem of Northern Israel is Haifa, Israel’s third largest city and an impressively beautiful UNESCO World Heritage Site. Near the sparkling Mediterranean Sea and just two hours from Tel Aviv by car, it’s a convenient stop on any Israel itinerary.

Part of the reason I loved my hotel...
there was because it was a short stroll away from the world-famous Baha’i Gardens. Also known as the Hanging Gardens, this UNESCO World Heritage Site houses the headquarters of the Bahá’í faith and is where Siyyid Ali Muhammad, the spiritual predecessor to the Bahá’í religion’s prophet, Bahá’u’lláh, is buried. While the gardens themselves are unfortunately not accessible, a wheelchair-friendly path leads from the Dan Carmel hotel to the Louis Promenade, an accessible area that gives you an incredible birds-eye view of the gardens that lie below, terraced on the slopes of Mount Carmel. Although I was slightly disappointed to not be able to roll around in the actual gardens, it was still worth visiting to see them from above.

After admiring the Hanging Gardens, head down the mountain to the Haifa German Colony, which gives you another perspective of the gardens from the foot of the mountain looking up. It’s worth it just for the view, but you’ll probably want to explore this area anyway, as it has some of the best and most bustling shops and restaurants in all of Haifa. Some shops are not wheelchair accessible, but if you are visiting in the warmer months, many eateries have accessible outdoor dining.

CAPTIVATED

As my Israel trip came to a close, I found myself thinking about those hours in the Atlanta airport when my mom and I contemplated the potential risks of our trip. The thought of not going had even crossed my mind, but as I was waiting in Tel Aviv to head back home, I thought about how wrong I had been. Israel captured me from the moment my wheels hit ground, and I don’t think anywhere can ever top the Holy Land for me.

I couldn’t believe that I had the opportunity to visit so many sacred and historic sites, as well as cities that had been around for centuries, without running into any major accessibility issues. The experience of exploring a holy city for so many major religions will expose you to a culture unlike any other place in the world, and it will captivate you.
You might have a preconceived notion of what a garden is, but here’s the thing you need to know: A garden can be almost anything. Gardening is simply arranging your corner of the natural world in a way that you enjoy. Flowers, native plants, vegetables, water features, even rocks, if Zen is your thing, can all be “gardened” both indoors and outdoors.

The requirements for you to start a garden are surprisingly few. You don’t need a huge yard or a ton of money. You don’t even need to go outside. You just need to want to give it a try and be open to accepting a little assistance here and there.

We talked to wheelchair gardeners from across the country who are passionate about planting and watching their harvest grow. Following are their tips for you, future gardeners. We hope they inspire you to join us in the garden.

**WHY WE GARDEN**

For many gardeners, the greatest joy is just being in their garden, watching it grow and taking in the smells and colors. The appeal is the ability to quietly relax and enjoy nature. Getting more fresh fruits and veggies is a perk for most, for sure. And for some, such as Riley Poor, a C5-6 quad living in Portland, Oregon, one appeal is the exercise he gets.

“Every time I garden it’s a full-on workout because I just tend to go until I can’t anymore!” laughs Poor, who tends veggies and other plants using a manual chair with power assist wheels. “It’s the best. I love getting home from work, rolling out there and checking the progress of everything, doing the watering, cutting stuff back and just tending to it and watching it as it grows up.”

“Identifying and vanquishing your barriers to gardening sometimes requires a little creative thinking, but you’ll figure it out.”

While Poor enjoys a great physical workout, Sarah Rose gardens for a different purpose. “I find it to be a meditative activity that relaxes me and makes me feel that life is all good and how it should be,” says Rose, who has a type of muscular dystrophy called Charcot-
Marie-Tooth. She gardens using a manual chair — and sometimes her tractor — at her home in Durango, Colorado. “I love how I feel after working in the garden for a few hours, and I enjoy just hanging out in the garden watching the bees, butterflies, and hummingbirds.”

For Vini Portzline, a C1-2 quad from Harrisburg, Pennsylvania, it’s a way of plugging into the very essence of nature. “It creates all kinds of connections,” says Portzline, who has gardened from her power chair for nearly 20 years. She grows flowers, vegetables and even fairy gardens at her home. “It gives me a sense of purpose, a sense of connection to something bigger than me, the planet, and even to other people.”

One of the big perks for gardeners who raise fruits, vegetables and herbs is immediate access to ripe, fresh produce. “I love to roll outside and pick a vine-ripened tomato — that is the only way to eat a tomato,” says Lisa Lanier, who has osteogenesis imperfecta. She gardens in Mocksville, North Carolina, using her power chair. “We eat tomato sandwiches, and they’re not good unless you pick the tomatoes directly off the vine.”

The food is the point for Craig Kennedy, a T12 complete para, as well. Kennedy, who lives in Steamboat Springs, Colorado, gardens indoors and outdoors in his manual chair. “Now that I’m in the health and wellness industry I know the importance of nutrition,” says Kennedy, a health and business coach for the Juice Plus Company. “The stuff that we get at the

Riley Poor gardens for the workout as much as the fresh produce.
store sometimes isn’t nutrient-dense. I feel like the food from my gardens tastes better because I grew it.”

Christina Mills gardens using her manual chair and attaches a Firefly power assist to help with the hills and gravel of her yard in Benicia, California. Mills, who has osteogenesis imperfecta, makes her love of gardening vegetables and fruits a family affair. “My kids absolutely love it,” she says. “I find it really rewarding to show my kids how our food actually grows, how they can grow their own food and we can eat what we grow. It doesn’t require you to spend a lot of money necessarily and it’s great quality time with your spouse and your kids.”

BREAKING DOWN BARRIERS

Since a lot of gardening takes place in the ground, wheelchair height is an obstacle for almost all adaptive gardeners. Limited reach is also a consideration for many, but both issues can be worked around. “I couldn’t get down to the ground,” says Portzline. “And then I thought of lifting the ground to me!” She gardens in tall pots and elevated table beds that she rolls under, making bending and reaching easier.

There is a huge variety of roll-up-to and roll-under beds available that allow a comfortable and accessible garden environment. One idea is to buy inexpensive wheeled planter caddies from a hardware store that large pots or containers can be placed on, making moving and arranging them on decks or patios much easier.

If you are able, another way to solve the access issue is to get out of the chair, sit on the ground and garden literally by the seat of your pants. If you can safely use this method (think skin protection), it will save the expense of building beds or buying containers, but it is clearly not for everyone.

Terrain can be a barrier to gardening as well. Mills moved into a house with raised beds already set up and ready to go, but the only access to them was stairs. “I had this amazing garden setup given to me that was not accessible because I literally could not get to it,” she says. The solution? Her family designed and put in a paver walkway down to her garden.

Some of our other gardeners have also conquered terrain issues. Poor laid crushed granite, which is cheaper than pavers or concrete, next to his beds so he can roll up to them. Kennedy has an indoor garden, using two vertical hydroponic systems with artificial lights to grow veggies in his house all year around. Portzline gardens on her deck, using a variety of standing pots and hanging containers, which eliminates outdoor terrain issues altogether.

Getting water to an outdoor garden can also be an issue. While there are a number of watering hose attachments that are fairly easy to use, hoses can be remarkably heavy and difficult to manage when full of water. Lightweight hoses are available, but they are still heavy when full. One solution is to put your garden close to your water source as possible. Our gardeners also suggested options such as using a portable pump sprayer, installing drip irrigation or soaker hoses, and even clipping the hose to the back of your chair to drag it around the garden.

A LITTLE HELP FROM YOUR FRIENDS

Whether it’s garden beds or large containers, preparing them and/or filling them with soil can be difficult to impossible for many wheelers. It often helps to have, well, help. Don’t be afraid to ask for assistance getting your garden set up. After all, gardening is, by nature, a community activity. Gardeners love to talk about gardens and to help each other. Working with other people to realize your garden dreams can be a lot of fun.

Poor, who has been gardening for a little over a year, got help putting his garden together from his family. His partner, Andrea, and his dad built a variety of garden beds that fill his back yard. Some are raised wooden table beds that he can roll his legs under, and some are chair height wooden or metal structures that he can roll up to in order to plant, water and harvest. These beds were all created to meet Poor’s specific needs, and when it comes to caring for the plants, Poor’s mom is his go-to for advice. Together he
Gardening has an amazing array of health benefits, from stress reduction to increased strength. It has so many proven benefits that it has been used in rehab programs for many years. In fact, there is an entire branch of rehab called “horticultural therapy.” “Horticultural therapy uses interaction with nature, particularly growing and cultivating plants,” says Barb Kreski, director of horticultural therapy for the Buehler Enabling Garden at the Chicago Botanic Garden. The Buehler Garden is a demonstration garden that teaches accessible gardening techniques for people with all types of disabilities. The staff at the garden routinely fields questions from all over the world about adaptive gardening tools, techniques and resources. “There is pretty solid evidence now that spending time engaged with nature is stress reducing. Stress makes everything worse, so if you can take that down a few notches you're contributing significantly to other therapies working better.”

This is great news because chronic stress can contribute to a mind-boggling number of health issues that we'd all like to avoid. And being “engaged” in nature can be whatever you need it to be. In addition to stress reduction, gardening has other physical benefits. “Gardening for all sorts of people is considered a moderate-level physical activity,” adds Kreski. “It’s a very good type of activity to do half an hour a few times a week. If you’re a gardener, that’s pretty easy to accomplish.”

And there are so many ways to garden that don’t even require getting down on ground level. “Containers are the fastest, easiest, cheapest way to bring something up to a workable height,” says Kreski. “I like to encourage people to do things with plants that change over time, plants that bloom or have something happening with them — something stimulating in one dimension or another. For an introduction, that’s ever so much more fun than watching grass grow!”

GARDENING: IT’S GOOD and GOOD FOR YOU

Gardening is about lots of things for Riley and Andrea, from exercise to the joy of watching seeds grow.

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HOW DOES Your GARDEN GROW?

Your garden can be grand, amazing and fill up your whole yard, or simply be a seed planted in an old coffee cup on a windowsill. It’s up to you to decide what kind of garden you want, what resources you have and how much money you want to spend.

“Figure out what garden type might work for your ability and also your region,” says Lanier. “You always have to check what’s best for your climate.” The planting season where she lives in North Carolina begins weeks earlier than the planting season in states that are further north.

Some plants grow better than others indoors, some grow better in outside containers — you’ll be a happier gardener if you pick plants that will thrive in your type of garden. Also consider how much time and energy you realistically have to play in a garden, and how much help you can count on. Some plants require more work than others, so do some research and select plants that match the effort you can put in.

“Try something easy. Don’t try to do too much the first time — see what works in your back yard. You really have to be OK with some trial and error,” says Mills. “There are a lot of factors when it comes to gardening — it’s just not about reading the book … there’s got to be some creativity to it.”

INDOORS

Maybe digging in the dirt outdoors isn’t realistic for you, but don’t let that stop you from gardening. You can do something as simple as a cheap and easy indoor herb garden with some small pots by a sunny window.

If you want to step up your indoor game, you can grow fruits, flowers and veggies in a hydroponic garden like Kennedy has. You can build a do-it-yourself version or buy a ready-made kit, which come in sizes from tabletop to full towers.

OUTDOORS

We’ve touched on many of the outdoor options already. Raised beds and containers are popular options for wheelers, but don’t discount the idea of straw bale gardens (hint: it’s exactly what it sounds like!). These gardens are made by planting directly into bales of straw. Bales are a great height for wheelchair gardeners and are a relatively cheap short-term garden option. Both Rose and Poor used straw bales to grow vegetables last year and both reported unequivocal success!

When planning an outdoor garden don’t forget to consider whether you can easily and safely access your growing area. If you can’t, either make some changes to make it accessible or change your plans to garden in an area that you can get to.

UPSIDE DOWN

You can grow tomatoes and some other fruiting plants in hanging, upside down pots that you either buy or make. These have a dual purpose of getting the pots up out of the way and growing the crop lower where it is easier to harvest from a wheelchair.
TOOLS OF THE TRADE

The tools you need will depend on the type of garden you design and your own physical abilities. Container gardeners will use different tools than hydroponic gardeners, just as outdoor and indoor gardening will benefit from unique approaches. You may be able to use off-the-shelf tools or modify them to suit your abilities and preferences. You know your abilities — couple that with some trial and error, and you will figure out the tools you need.

In general, you need a shovel or trowel to move dirt, a hoe or cultivator to remove weeds and “work” the dirt, and clippers to harvest and prune your plants. If you have good upper body strength and trunk control you may be able to use tools you can buy at any hardware store. But because a gardener that uses a wheelchair is closer to the surface than one who stands, you may find that standard tools are awkward to use. They are also pretty heavy and can cause a fair amount of strain. Consider tools with short handles, kid-sized tools or cut tool handles down to the size you like.

To help provide more control, you can also buy add-on handles and cuffs that attach to long handles. These reduce the strength and endurance required to use standard tools. They are easily found online by searching for adaptive gardening, ergonomic tools or tools for people with arthritis. More and more, you can also find such tools in your local stores.

“I use off-the-shelf tools for now,” says Rose. “The only ‘adaptive’ thing I use is a plastic toboggan type sled with a rope handle that I rake debris onto. Then I drag it with my scooter and tip it sideways into the compost pile.”

To extend your reach, the grabber you use in the living room also works great in your garden. You may also find garden-specific tools to meet your needs. “As somebody who is 3 feet 10 inches tall, it’s not easy for me to reach very high in my trees,” says Mills. She found a telescoping pruner on wildflower-seed.com that she uses all the time. “I love that thing! It’s lightweight and doesn’t take a lot of strength to close.”

If hand strength is an issue for you, gripping aids may come in handy. These are widely available and you may already own some. You can also invest in tools specifically designed for use by people with reduced upper body function. Poor uses Active Hands gripping aids, Quad Tools brand reacher-grabbers and garden shears. “These tools are pretty crucial for me,” he says. “They are expensive, but I think of it as
somebody took the time to work out the problems for me. I definitely splurged, but I don’t regret it.”

Many states have accessible technology programs that will loan you garden tools to try. Borrowing them will help you decide which ones work best for you. That way your money will be well spent when you buy your own. When it’s time to buy, some of these same accessible technology programs have low interest loans so that you can stock your shed without breaking your budget. Grants may be available to you or your gardening group as well.

GET PLANTING!
We have just touched the surface of adaptive gardening, but a few internet searches will open a world of information in minutes. And you may have local adaptive gardening resources in your area you don’t even know about. Check to see if your Center for Independent Living or even a local nursery has an adaptive demonstration garden near you. Senior centers may also have good information on adaptive garden resources. Colleges and extension services sometimes offer adaptive gardening classes as well, so a little research should turn up the help you need.

“Also, there is nothing wrong with starting a garden inspiration board on Pinterest,” notes Rose.

Poor advises simply taking the plunge. “My advice is probably to just get some seeds in the dirt,” he says. “To get started you just need some soil, some seeds, something to put them in and a patch of indoor sun. And then it just becomes your project all of a sudden. They become your babies in a way, because you’re invested in seeing this seed grow. It’s such a cool process to watch.”

Once you get the basics down, your best teacher will be experience. Because gardening is as much art as it is science. “It’s trial and error,” says Portzline with a smile. “Every gardener will tell you that you always learn from what happened this season. The journey never ends!”

RESOURCES
Tools:
• Active Hands Gripping Aids, www.activehands.com
• Quad Tools reacher-grabbers, quadtools.com
• Telescoping Pruner, wildflower-seed.com

Ideas from Pinterest:
• Best 25-plus Vertical Hydroponics Ideas on Pinterest, pinterest.com/explore/vertical-hydroponics
• Over 823 Best Raised Garden Beds, Elevated Table Gardens, Containers on Pinterest, pinterest.com/accessgarden/raised-garden-beds-elevated-table-gardens-containe

Organizations:
• American Community Gardening Association, Communitygarden.org/find-a-garden/
• Bueller Enabling Garden, Chicagobotanic.org/gardens/enabling
• Center for Independent Living directory, Ilru.org/projects/cil-net/cil-center-and-association-directory
The world of seeds and soil calls to me at the dawn of each spring when daffodils bloom. It is an annual ritual of rebirth, not only for Mother Earth in all her glory, but for me as well. I was born in early March, and every year for the past 44 years, beginning in the ninth year of my SCI at age 29, I have started seeds in fresh potting soil or native earth.

Seeds are nothing short of miraculous. Each tiny capsule of energy, so unimposing in dormancy, holds a wonderful surprise of unique size, shape, smell and color. But the allure of the garden awakens in late winter when the seed catalogs arrive in the mail. I spend days browsing the catalogs looking for interesting vegetable varieties to grow and eat.

Striped German tomatoes have unsurpassed flavor and beauty with their red cores and yellow-orange marbling. Romano beans are often overlooked in favor of green beans, but the flavor of romanos is nutty, unique. Baby corn varieties, if you have the space (they need as much as regular corn) are sweeter than the sweetest corn. And romanesco broccoli grows in a spiraling geometric pattern that comes right out of fantasyland.

It’s not just about the colors, shapes and flavors. The textures and aromas of a diverse garden are actually therapeutic. For a while, my wife and I delivered bags of fresh basil to local customers. Driving on a summer day in a car filled with fresh basil is bracing, invigorating, intoxicating. But the real joy is in the midst of the garden, with the smell of rich earth, fresh air, the textures and colors of multi-layered plants waving in a gentle breeze, and earthworms, ladybugs and birdsong. And of course, bordering the food plants, flowers. So many different colors and patterns, many of them attracting beneficial insects.

When my wife and I first got together in 1974, we decided to move from California to Oregon, to make a new beginning in a new land with a new dream. My inspiration came from one of the most famous gardeners ever — Henry David Thoreau — who wrote about his time living in a small cabin on Walden Pond: “I learned this, at least, by my experiment: that if one advances confidently in the direction of his dreams, and endeavors to live the life which he has imagined, he will meet with a success unexpected in common hours.”

Pursuing our dream, we rented our first apartment in the country upon arriving in Oregon’s Rogue Valley in the spring of 1974. The first thing I did was select a garden site, plop myself down in the dirt, and start digging with a short-handled shovel, scooting along as I dragged my wheelchair cushion beneath me. We grew our first garden there, and each afternoon until dusk we took drives, looking for a small acreage to buy. We had no money to speak of, only our shared dream, imagination, and hope.

We rented seven different apartments or small homes in six years, working odd jobs and teaching, always driving and searching for our dream acreage. Wherever our quest took us, every spring we planted seeds, because every garden is not only an anchor in the present, it also represents a new beginning, a promise of renewing life.

In 1980, we bought a small farm south of Portland in the Willamette Valley. Our first year on the farm we grew a large garden. The next year we expanded to a one-acre U-Pick business. Two years after that we plowed new ground and expanded our U-Pick to a small-scale organic farm, specializing in lettuce varieties, tomatoes, basil and a variety of fresh vegetables, delivering them to Portland restaurants and organic markets.

From then until now, nearly 38 years, most years we made a modest profit, and some years we made nothing. But it was never about the money. It was about cultivating our dream.

Where there is a garden, there is sustainability for the soul.
VetsFirst is a program of United Spinal Association that assists veterans and their eligible family members in obtaining the benefits they are entitled to, deserve and need.

Our Mission
VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

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

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

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

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

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

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

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

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

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

www.vetsfirst.org
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Register online today. It’s free!
The first nine years of my life, I moved like a charged particle: buzzing with energy, always in motion. Then the pain came. Within six months, the wildfire of juvenile rheumatoid arthritis had spread to nearly every joint in my body. The pain was horrendous. Its unceasing severity meant that within five years many of my joints were catastrophically, permanently damaged.

By ninth grade, my school day was exhausting. Most of my energy was spent dragging myself from point A to point B on crutches. The effort I put into short bursts of locomotion ground me down to a nub.

The simplest, most sensible solution would have been for me to use a wheelchair for mobility. But at that point in my life, it was unimaginable. Wheelchairs were only acceptable for the profoundly disabled and the elderly. If you drooled, wore diapers and spent your day making potholders, enjoy your seat on wheels. But if you were capable of anything more, you better get your ass up and move.

That same year, my ankles became so painful I had no choice but to have both of them surgically fused. My rehab was a long, painful slog to regain the ability to walk. It left me no choice but to return to school in a wheelchair. My dad took me to school my first day back. The school administration suggested we come in through the loading dock, then pass through the boiler room. I was cargo to be unloaded, like a case of industrial-strength rat poison.

Most of my classmates had no idea I was returning to school at all, and I’d told only a couple of close friends that I’d be using a wheelchair until I regained the ability to walk. I could see the shocked looks of students and teachers as my dad and I entered the corridor.

I’d attracted plenty of stares and snickers before the surgeries, with my leg brace and crutches. But in the chair, I had reached a whole new nadir of gimpdom. Funny how sticking your ass in a 25-pound metal, vinyl and rubber contraption can bring about a new world order.

By the start of sophomore year, I was no longer using the chair. But six years of severe arthritis had transformed my gait from one of long, speedy strides to the side-to-side, slow waddle of a penguin. Three minutes was barely enough time for me to change classes. To accommodate me, all of my teachers agreed to let me leave class a few minutes early. But that solved only one of two problems. The first was my slowness in getting from here to there. The second problem was how to get from a seated to a standing position. My pain and limited mobility made getting up from chairs or desks really tough. I often had to rock back and forth to get enough momentum to stand. I strained hard, holding my breath in the process. For a few seconds, my brain was deprived of oxygen to the point where everything around me got fuzzy and faint, making me feel like a spray paint huffer.

The rest of my high school years included multiple surgeries, rehabs, temporary parent-approved wheelchair use and striving to get back on my feet. It was an ongoing cycle of pain, shame and struggle to become mobile enough to go to college.

Placing my butt in that chair I bought into my parents’ belief that using a wheelchair equated with tragedy and failure. It was all I knew. And when they moved me into my college dorm room during freshman week, I was a teary-eyed, nervous wreck. I was uncertain how much walking I would have to do each day. What if the walking was simply too much? What if I had a flare or sudden pain that kept me off my feet? What if I missed too many classes and flunked out? My anxiety ratcheted up so much that I was vomiting each morning and crying every day. Finally, my parents woke up to the reality of my situation.

After freshman year winter break, I returned to school with a very basic Everest & Jennings sling-seat power wheelchair. My parents made it clear that I must walk whenever possible. They felt certain that if I used a chair even part of the time, I would grow lazy and stop walking altogether.

I had to admit that the chair’s very presence eased my mind. I was comfortable using it in my dorm. I lived in my university’s gimp ghetto:
the only floor of the only dorm accessible to girls with disabilities. I was among friends.

Still, I had to mentally sort out for myself exactly what relationship I would have with the chair. But the rules I developed for when and where to use the wheelchair were not crafted strictly by common sense. I was fighting a very personal inner battle about how I saw myself and how I wanted others to see me. There was something about planting my butt in that chair that seemed to lower my status as a potential friend and more importantly, girlfriend. The bottom line was this: wheelchairs were boner kryptonite.

If I had a major spinal cord injury, I'd have to use a chair for mobility — there'd be no room for debate. But I inhabited a realm betwixt those who walked all the time and those who never did. There was no "how-to" guide for someone like me, or at least I'd never seen a book titled Sometimes Your Ass Walks, Other Times it Rolls: A Guide to the Wheelchair Netherworld.

It was all pretty ridiculous, since even when I was up and walking, I would never be mistaken for a nondisabled person. Standing or seated, I was still a gimp. But to a lot of people, a wheelchair is a prison, a sign of tragedy, a symbol of defeat. The chair is a mechanism of freedom and empowerment that can make the difference between getting an education or not, holding a job or sitting at home, exploring hillside towns in Spain or never traveling beyond one's front stoop.

IT ISN'T ALWAYS ALL-OR-NOTHING
Part of me still bought in to the idea that to use a wheelchair was a sign of failure. Perhaps I simply wasn't trying hard enough, wasn't soldiering through the pain like I should. I'm ashamed to admit it, but on days I did take the chair to class, I hid it. I would arrive early, find an adjacent empty classroom, park it there, then walk over to my class. That way, I could stride into my classroom as if nothing was wrong. (Or, as if nothing was wrong with me.)

Outside of class, I struggled to meet guys who could look past the chair and see me. I had lots of male buddies, but rarely did things progress beyond friendship. Then I met my husband. We fell hard for each other. Before I got too far in, I secretly gave him a test to pass. The first time we went out together, I held his hand, making it clear to passers-by that the chick in the chair was dating the guy who walked. He gladly took my hand, even kissed me, and never flinched. He passed with flying colors, and we got married two years later.

Now that I'm over 50 and have had more than two dozen orthopedic surgeries, I use my chair from dusk 'til dawn. The only time I'm out of it is to walk short distances, several times a day. If I don't, I get achy, stiff and fatigued. This means that my co-workers sometimes see me up on my feet.

People are especially puzzled by someone who mostly uses a wheelchair yet sometimes walks. They think it should be an all-or-nothing thing. When you're not in the chair, you're bound to get smiles and comments like: "How nice, you're getting better!" My typical response is to smile and nod, while thinking: "Screw you, asshole! There ain't no 'getting better' for me. New, healthy joints don't just magically appear like leprechaun gold."

But I refrain from such comments. I'm comfortable now with who I am: a virtually full-time wheeler. When I can't get into a restaurant or book an Uber ride, I don't find fault with myself. I place the blame squarely where it belongs — on a society that continues to devalue disabled folks by designing only for the temporarily non-disabled.

Temporarily, did you ask? Yes, because karma is a bitch.
It all started with a simple suggestion ...
We should all get together sometime in Vegas.
I live in Vegas and had met Monica and Andrea in an
online support group for wives and girlfriends of quad-
riplegics. Their husbands, Glen and Chad, are both high-
level quads like my husband, Jeff. They also both have one
daughter, and all three of our girls are only eight months
apart in age.

The similarities are clear. So it’s not surprising that the
three of us — me, Monica, and Andrea — all struck up a
friendship. Our girls started writing letters to one another.
They even had video chats so they could talk face to face.
And I would chat with my new friends over Facebook
messenger.

That’s when the idea of meeting in
person first came up.

Here’s the actual conversation:
Monica: I seriously was telling
Glen last night that we need to plan a
group trip to Vegas. Kristen, I know you
said you guys are not thrilled to fly, and we’ve
never been to Vegas! Who’s in?

Andrea: We have been to Vegas. I’d go again if I
didn’t have to endure walking the strip.

Kristen: We would LOVE to have you come visit us!
And so the planning began.

Before long, flight reservations were made and hotel
rooms were booked. And the excitement levels began to rise.

Both visiting families — one from Pennsylvania, one
from Minnesota — flew out to Vegas several days ahead
of when we all planned to gather at our home. Monica,
Glen, and Elaina headed to Yosemite while Andrea, Chad,
and Mari explored the Grand Canyon. When they headed
back to Vegas, we realized we would all be available the
evening before we planned to get together, so we decided
to have dinner together at the hotel they were staying at,
which was just a few miles from our home.

MEETING IN REAL LIFE

Jeff, Evie, and I waited near the cafe at the hotel. We were
all smiles and jitters. We waited for our new friends to
come down from their hotel rooms and meet us in person
for the first time.

“What way will they come from?” Evie kept asking.

“I’m not sure, Sweetie,” I answered. “Just be on the
lookout for two power chairs.”

And soon enough, through the throngs of people, we
could just make out those chairs — with two men sitting
in them — coming toward us. Their wives walked on ei-
ther side of them, and a few steps ahead were two little girls
holding hands. They were making their way toward us.

Evie was like a race horse and my hands on her shoul-
ders were the gates holding her back. She was trembling
with excitement.

Finally, when the girls were close enough, I let go, and
Evie flew to them. The moms followed suit with hugs all
around, and the dads all did their quad nods to one another.

And there, in the crowded casino of a Las Vegas hotel,
the bonds of a unique friendship were forged. There must
have been a million eyes on us that evening. Three
quadriplegics in power wheelchairs
pulled up to a long table on the cafe pa-
tio. Three wives helping their husbands
to varying degrees with their dinner
and drinks. Three little girls sipping root
beer and chocolate milk, giggling their way
through their meals.

It was a perfect way to kickstart our friendship.
The next day, in the early afternoon, we all met up again — this time in our home where we could relax and hang out away from prying eyes and loud background noise.

The girls immediately stuck to one another like glue, and seemed to move around the house as a unit. They occupied themselves with such things as tea parties, karaoke, splashing in the spa, painting toenails, and sneaking snacks. Suffice to say they were in heaven.

The couples spent their time getting to know one another. We compared wheelchairs and gadgets that have become part of our everyday lives. The guys swapped injury stories with nods of understanding. And thanks to Glen, we got to hear some harrowing post-injury stories — as if the spinal cord injuries weren’t bad enough!

Monica and Andrea shared what it was like to fall in love with their husbands, as both women met their husbands many years after they were injured. I shared what it was like to go through the trauma of the injury with Jeff and the way our life abruptly changed.

The topics ranged from funny to solemn and from shocking to serious.

As we talked, I watched how these women moved around their husbands — how they helped them with things like taking a sip of a drink or putting food in their mouths, or helping them put on a sweater. They did it all without missing a beat in the conversation, and I realized this is what I must look like when I’m helping Jeff. It was my first time seeing the dance from the outside — seeing how husband and wife move together as a synchronized unit.

It’s something I’m glad I got to see from a new perspective.

We gushed about the lights of our lives — our daughters. We talked about parenting issues that every parent can relate to. And we talked about parenting issues that only quad parents can relate to.

We took time to snap some photos of this incredible experience. Monica even brought shirts for us moms and our girls that say: Here’s to strong women
May we know them
May we be them
May we raise them

Finally, when the girls were close enough, I let go, and Evie flew to them. The moms followed suit with hugs all around, and the dads all did their quad nods to one another.

Meeting other kids whose dads also have quadriplegia helped the girls form a bond that they expect will last a long, long time.
It was both relaxing and energetic at the same time. Our conversations just flowed. Nothing was forced.

We were immersed in an environment where no one stood out. We all just blended in. And believe me, blending in as a quadriplegic family is something none of us were used to — but all of us welcomed.

Later in the evening, we were treated to a visit by yet another quad couple — Claire and Kenny (yes, THAT Kenny from broken wheelchair fame!) Claire is also part of our online support group, and knew about our plans to get together. She and Kenny happened to be in Vegas for a conference at the very same time as the other families! Their arrival was the icing on the cake.

Our house was so full! Full of hugs and laughter. Full of questions and answers. Full of sharing and learning. Full of understanding.

Full of so much understanding, in fact, that when Jeff’s body was overly tired from all the talking, our friends gladly moved the conversation into our bedroom after I got Jeff transferred back to bed. If there’s any group of people who know that sometimes you just need to get out of your chair and into bed, it’s certainly this group.

A little while later, we hugged and said our goodbyes to Claire and Kenny. Then Monica, Glen, Andrea, and Chad headed back to their hotel while the girls embarked on their long-awaited sleepover.

I went to bed that night with my head spinning (which may or may not have had something to do with red wine), wondering how in the world I was going to capture all of this in an article.

How do you write about an experience like this? A gathering of people who understand your life — not just people who sympathize with you, but people who truly get you. For the first time, we were able to sit down and see glimpses — sometimes whole reflections — of ourselves and our lives in our new friends. How do you summarize what that’s like and what that means to your family?

THEY KNOW WHAT IT’S LIKE

The next morning, the girls were up early, eager to spend more time together. They were in the spa by 9:30, unfazed by the windy chill.

Afterward, they opened friendship necklaces and gathered close to see how the three pieces fit together.

Before we knew it, it was time to say goodbye. Parents arrived, bags were packed, and hugs were given all around. Sincere words of how we really want to get together again were spoken.

We said our farewells with sad smiles and happy hearts.

Later that afternoon, as Evie was nursing a slumber party hangover, she and I were resting on the bed.

“Did you have fun with your friends?” I asked.

“SO MUCH FUN.”

“Did you guys talk about how all of your dads are paralyzed?”

“No.”

That’s when I realized my question was rather silly. Why would they talk about it? For the first time, they were in an environment where they didn’t have to field questions like “What’s wrong with your dad?” and “Why is he in a wheelchair?” They didn’t have to explain what the word paralyzed means.

They could simply be themselves.

“Do you think you will be friends with them for a long time?”

“A loooong time. Longer than any of my other friends.”

“Really? Why is that?”

“Because their dads are like Daddy. And they know what it’s like.”

And with those five words, I got my answer to how I was going to sum up this entire experience — my answer to why it’s important for families like ours to meet and connect and forge bonds.

They know what it’s like.

Yes, they sure do.

Glen, Jeff and Chad exchange “quad nods” as their wives and daughters meet and embrace off-camera.
THE POWER of CONNECTING

BY KENNY SALVINI

W hen my fiancée, Claire, and I arrived at Kristen and Jeff’s house last October, our meeting was a testament to the power of social media to connect people with similar situations. Though we had never met any of the attendees in person, we weren't rolling into a group of strangers, but an extended family separated only by distance and length of Facebook friendship.

“That’s what’s so unique about the situation,” says Glen. “Here you show up, I’ve never met you in my life, but there is that immediate familiarity. Here’s a guy that knows exactly what you’ve gone through; there’s an immediate camaraderie.”

Connecting like this is something people take for granted these days. It hasn’t always been this easy to find each other. When Glen and Chad were injured in 1996 and 1998, respectively, the internet was barely even a thing. I became a C3-4 quad in early 2004, and that was only the dawn of the social media era. Save for a handful of labyrinthine message boards with impersonal screen names and endless rabbit holes, the only way to find one another was the old-fashioned way, at outpatient rehab or randomly on the street.

Chad visited a local transitional care center soon after he was discharged, but was unable to establish any meaningful connections. “It just wasn’t the right fit for me at the time,” he says. “So I decided to dive back into school and work.” Glen had the random dumb luck of moving to a neighborhood that had two other quads within one small loop. “I was super fortunate to have that camaraderie early on. But before that, I had nothing. I would go out and about in my wheelchair and I was the only one.” I wasn’t so lucky. My first six years of post-injury life were spent as a virtual shut-in, battling a string of pressure sores that helped trigger a toxic level of depression. Getting out in the world wasn’t an option. I would hear about others in the community through my home health nurses, but that’s as far as it got. Not that I was all that eager to meet anyone else in a wheelchair anyway. For quite a while in my early recovery, I was more focused on the differences between me and others instead of any common threads we might have.

That all changed in 2010 after a random encounter with another quad introduced me to a seat cushion that would get me healed and back out in the world once and for all. That one connection saved my life and set me on a mission; I went from the guy who didn’t want to meet anyone in a chair, to the guy that needed to meet each and every one I could find. At first it was mainly about self-preservation, but the more people I met, the more those common threads began to shine through. I didn’t have to explain every dirty detail of my life to these people because they understood it in ways nondisabled friends and family never could.

Flash forward to today. A quick Facebook search for “spinal cord injury” brings up dozens of support groups of all kinds. Often grouped by diagnosis, location, or relationship, there are pockets of thriving support all over the globe. In fact, it was only a couple days after Claire and I got engaged that Andrea Hansen reached out and graciously welcomed her to the “What We Share in Common” wives group. It quickly became an invaluable resource for the both of us. Even only four years into his injury, Jeff can see that his family needs just as much support as he does. “For Kristen, it was a great way to express her feelings, which was nice.”

Within minutes of our arrival, we were eyeballing each other’s chairs, comparing and contrasting our respective assistive technologies, chair hardware. “It was the little things,” says Chad, referring to minor quad life-hacks or recommendations for which types of clothing keep you warm. By the evening’s end, we’d all learned something new.

For me, the timing could not have been more perfect. Here I am on the verge of some major life changes — getting married, hopefully starting a family — and I’ve got three guys at my level who are living that life and living it well. Chad and Glenn shared tips and tricks for adapting wedding dances, and Jeff shared how much having a child adds to the richness of his post-injury life.

Both Chad and Glen, who have very little arm function, left the gathering with their perspectives changed after seeing how independent and active both Jeff and I are without any arm function at all. Jeff points to the wealth of knowledge and wisdom his three visitors had in more than 50 years of collective paralysis experience. “It’s always good to have peers you can count on, folks you can reach out to and see if they’ve gone through it before.”

Connections on social media are great and can be invaluable resources, but there is nothing quite like the ability to get knee-to-knee with someone who knows what you’re going through. “ Granted, there’s something to be learned from anyone,” says Glen. “But there is crucial information, motivation and growth in meeting other quads.”

FROM LEFT TO RIGHT ARE CHAD AND ANDREA; GLEN AND MONICA; JEFF AND KRISTEN; AND KENNY AND CLAIRE.
I’m 28, in my fourth year as a C5–6 quad and have had a suprapubic catheter since rehab. It works well, so I thought it enabled me to dodge taking anticholinergic drugs like Ditropan that control bladder spasms. At a recent SCI support meeting, I heard that long term use of an indwelling catheter causes permanent bladder shrinkage and that bladder spasms makes this worse. The discussion also brought up two equipment options, a “dual-balloon” Foley called the Duette, and a catheter valve called the BioFlo that can help reduce bladder shrinkage. What can you tell me about these two products?

— Nancy

According to Paralyzed Veterans of America’s Bladder Management Guidelines for Adults with Spinal Cord Injury, long term bladder management with indwelling catheters — urethral or suprapubic — tends to cause decreased bladder compliance (elasticity and size), which is irreversible and can cause other problems, including formation of stones, reflux and an increase in UTIs. The guidelines say that regular use of medication to manage bladder spasms, as well as bladder irritation, which leads to inflammation, can help mitigate the bladder shrinkage associated with long term indwelling catheter use.

“Even though an indwelling catheter is ‘free-flowing,’ it is still important to manage bladder spasticity,” says Kennelly. Fortunately, there are a variety of newer medications to quiet the bladder that don’t have the detrimental side effects of older anticholinergics, like Ditropan (oxybutynin). “I discuss managing bladder spasticity with my patients that have indwelling catheters. A lot of them have found that Botox therapy is beneficial to them.” In addition to helping mitigate bladder shrinkage and fibrosis, Botox quiets the bladder and helps eliminate leakage at the urethral or suprapubic opening.

GUIDELINES AND OPTIONS FOR INDWELLING CATHETER USERS

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Make sure to leave some slack in your extension tubing and properly secure it with straps to avoid any tension. Pulling on a Foley catheter will cause the balloon to scrape against the bladder wall and can trigger bladder spasms and cause inflammation. Also, if a Foley is chronically tight, it can cause pressure necrosis — skin breakdown. And be mindful that extension tubing doesn’t get tugged or pulled during transfers. This is especially important for people with higher level injuries relying on attendant help for transfers to secure their extension tubing and collection bag before, during and after the transfer, explains Kennelly.

Another source of inflammation is the catheter itself. “This is where a new type of Foley catheter called the Duette seems to help preserve the bladder,” says Kennelly. The Duette, made by Poiesis Medical and introduced in 2014, has a dual-balloon design (the second balloon inflates over the catheter tip, and along with the primary balloon creates a small, protected area around the bladder opening, which helps avoid inflammation.)

By allowing fluid to build in the bladder, the system prevents the Foley balloon and tip of the catheter from rubbing against the wall of the bladder, which helps avoid inflammation.”
lumens — catheter drain holes). "With an indwelling system, the collection bag sits lower than the catheter, creating negative pressure and suction in the bladder. In a standard Foley, the suction can pull the fragile lining of the bladder into the lumens, which causes polypoid cystitis — elongations of the bladder — which are areas of inflammation."

The Duette’s dual-balloon design reduces inflammation by preventing the bladder wall from contacting the lumens and protects the bladder wall from contact with the catheter tip. An 11-month-long study (see resources) concluded that using the Duette Foley catheter reduces trauma to the bladder wall and reduces UTIs, compared to traditional Foley catheters. Duette Foley catheters are covered under Medicare. Online retail prices range from $12.70 to $16.99 per catheter.

Another product that can reduce inflammation is the BioFlo AutoValve (see resources), explains Kennelly. The AutoValve fits into the drain end of a Foley tube and has a magnetic closure valve that lets 20 cm of pressure (approximately 20 ml of urine) build up in the bladder; then the magnets separate and allow the bladder to empty. "By allowing fluid to build in the bladder, the system prevents the Foley balloon and tip of the catheter from rubbing against the wall of the bladder, which helps avoid inflammation," says Kennelly. Another benefit of the BioFlo AutoValve is its Quick Disconnect, which includes a spring-loaded closure that snaps shut when changing collection bags, making it a closed system that keeps out bacteria. Studies show this reduces UTIs. BioFlo General Manager Eric Freer says BioFlo systems are reimbursable under Medicare. Suggested retail for the AutoValve is $198. Freer adds that BioFlo has a hardship program for people on limited budgets (contact the company for info).

Another option from BioFlo is the ActiValve, a small manually-operated flip-to-open drain valve that can be operated with limited hand function and connects to the AutoValve. This gives the user the option to "cycle" — go without a leg bag and let the bladder fill, then drain it on a schedule, similar to an intermittent cathing schedule. Kennelly says there haven’t been any long-term studies on bladder cycling, but it is reasonable to project that it will preserve bladder capacity since it mimics the bladder’s expanding and contracting with intermittent cathing. He cautions that bladder cycling should only be done under the guidance of a urologist, and only after a full urodynamic study to test for volume, control of bladder spasms — from Botox or other medication — and some type of “body clue” that lets a person know it’s time to drain (not autonomic dysreflexia). If a person doesn’t have a body clue to tell if their bladder is getting full, they would need to have a naturally large bladder capacity and the commitment to empty every three hours. They must also have the ability to release the drain lever and be highly motivated to do so on a regular basis. Suggested retail for the ActiValve is $25.

A word of warning: Kennelly says that bladder cycling should never be done without a thorough evaluation and discussion with your urologist. Never clamp or plug a Foley for more than 20 minutes without this discussion. Doing so can cause severe problems, including autonomic dysreflexia and permanent kidney damage.

"I customize volume recommendations and times between drainage for every person based on their urodynamic study," he says.

Resources
- BioFlo, bioflo.us
- Duette Foley Catheter, poiesismedical.com/products/duette/
- Duette study, Journal of Urology, jurology.com/article/S0022-5347(16)01063-6/pdf
- Para/Medic: Bioflo, A New Option for Indwelling Catheter Users, newmobility.com/2015/03/bioflo-indwelling-catheter/
- Para/Medic: Options to Manage Bladder Spasms, newmobility.com/2015/05/manage-bladder-spasms/
- PVA Bladder Management Guidelines, pva.org/media/pdf/CPGBladderManageme_1AC7B4.pdf

Editor: In response to readers’ concerns, New Mobility’s policy is to disclose author-product relationships when appropriate. Accordingly, NM senior correspondent Bob Vogel works twice annually at an Abilities Expo booth in California promoting Peristeen, a bowel management product made by Coloplast, which also makes urological and ostomy products.
“Go over the top of the river,” says Swede, “that’s where they are!”

“Sounds good,” I reply, pointing the camera down.

“There it is … the honey-hole!” he teases, as usual. Below us is a dark deep hole in the river bottom at the tail-end of a gravel island. We stop and hover over it, looking down. “That’s where we fish!”

“Now let’s follow the river to the west!”

I turn west and fly down the river at about 100 feet above the water. We can see the clear water, the fast-flowing shallows, and the dark, deep holes. There are several places that look great for fishing. The meandering river snakes its way lazily all the way from the horizon toward us, cutting a deep wide valley through the countryside. The shores are tree-lined, providing the perfect cover for wildlife.

“Are there any cables across the valley?” I ask. Flying into a cable or power-line stretched across the river would be devastating.

“No, you’re OK, there’s none there,” replies Penny, Swede’s wife.

Richie “Swede” Johnson is a friend from waaay back. Years ago, he owned the local butcher shop, and being in a small town, everybody knew everybody. A group of us used to ride horses into the mountains, staying out for a week or two at a time. We experienced some of the most beautiful and remote mountain lakes just teeming with trout eager to take a fly. We are both lovers of the outdoors and love to be in nature. After I became a quadriplegic, I was no longer able to go on the horseback riding trips, but I wanted to learn how to smoke fish and make deer jerky and sausage. Swede — butcher, smoker, and sausage maker extraordinaire — was my go-to guy. He taught me how to brine the fish, cure meat, make jerky, what temperature and how much smoke to use, and how long to smoke them. He’s a wealth of knowledge in this area and even taught his expertise in college.

About this time, Swede and Penny built their dream home. Their place borders a river that is full of trout, walleye, goldeye, and I don’t even know what else. Outdoor living for them is paradise. From their home they see deer, moose, elk and more. The fishing in the river within walking distance from the house is incredible. Needless to say, they spent countless hours at the river.

As life would have it, Swede developed multiple sclerosis, which ended their river excursions together. He hasn’t been out there for a while. I guess we will never know why life is like this, but Swede has always been so positive and remains this way, which he credits to great family and friends to share life with.

First-Person View for Two

So here we are, a couple of guys in power wheelchairs, zooming over the river near Swede’s house checking out his favorite fishing holes with a drone and first-person-view goggles.
I had seen an article where people who were not able to get out very much were taken for a virtual ride with these goggles on. The goggles hook up to the drone and allow you to see in real time as if you are inside the drone. These can be linked to additional tablets, or cell phones, etc., so more than one person can view the fun. When I received my own goggles, I was amazed that I could once again explore inaccessible areas. And I got to thinking about my friend Swede, now a power chair user who could no longer go fishing on the river that is so close, yet so far. I got the idea to bring the drone and have him wear the goggles, and I would fly it using my cell phone as my screen. It is so amazing that two guys in power wheelchairs can be exploring, laughing, and zooming up and down a river with a drone. Swede is acting as tour guide and pointing out where the good fishing is while I do the flying.

**Unexpected Gifts**

Like most people with disabilities, it takes a lot of help for us to get to do the things that we want to do. I am so very grateful for those that help me achieve my dreams, and always hope that they get something out of it, too. Sometimes I feel guilty about the effort others put in for me, and then I remember a conversation with one of the pilots out of our flight club. He reminded me how much people enjoy seeing the smile on my face when I get to fly. He let me know how good he felt about himself after helping me to get into the sailplane and experience flight, and that he thought he should be thanking me for the gift. I had never looked at it this way, and was speechless.

So here I am, sharing my drone experience with a friend, and he is able to show me the old fishing holes and sights on the river that I’ve heard so much about. I think this is such a positive use for a technology that’s sometimes controversial. Swede’s smiles and excitement on seeing the inaccessible river for the first time in years made me feel so good about sharing my good fortune of being able to “fly” from my chair. It made my day. I know now what the pilot from the flight club meant.

Thank you for the gift, Swede!

---

**Frequently Asked Questions**

**What kind of drone are you flying?**

We are flying the Mavic Pro using a cell phone as a screen and it is also paired to DJI Goggles.

**Who is doing the flying?**

I was doing the flying and Swede was guiding me as to where he wanted to go.

**How far can you go?**

The drones nowadays can fly for nearly a half an hour and the range is about 5 miles. You need to check the rules in your area, but around here you’re supposed to have a spotter that can see it at all times.

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Kessler Institute for Rehabilitation, West Orange, NJ; 973/252-6367

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Sunnyview Rehabilitation Hospital, Schenectady, NY; 518/382-4560
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Summa Rehabilitation Hospital, Akron, OH; 330/572-7300

OKLAHOMA
Integris Jim Thorpe Rehabilitation Network, Oklahoma City, OK; 405/951-2277

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Legacy Rehabilitation Institute of Oregon, Portland, OR; 503/413-7151

PENNSYLVANIA
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Healthsouth Rehabilitation Hospital of Altoona, Altoona, PA; 800/873-4220; 814/944-3353
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Spinal Cord Program at The Children’s Institute, Pittsburgh, PA; 412/420-2400
UPMC Rehabilitation Institute at Mercy, Pittsburgh, PA; 800/533-8762

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Houston Methodist Hospital, Houston, TX; 713/394-6000
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UVA - HealthSouth Rehabilitation Hospital, Charlottesville, VA; 434/924-0211
VCU Spinal Cord Injury Rehabilitation, Richmond, VA; 804/828-0861

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Rare Patient Voice, www.rarepatientvoice.com
Trusted Mobility, www.trustedmobilityrepair.com

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

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.

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TOYOTA’S START YOUR IMPOSSIBLE CAMPAIGN

Saying it wants to, “Make movement better for everyone, whether you’re 1 or 100 years old,” Toyota, the Worldwide Mobility Partner of the Olympic and Paralympic Games, has released commercials featuring people with disabilities as part of its Start Your Impossible campaign. “Mobility Anthem” depicts compelling futuristic images of flying personal cars, sleek robots and people using iBots. “Magic” shows an adorable young wheelchair user who discovers he has magic powers while watching hockey. “Good Odds” may be the most powerful video — it follows Canadian Paralympian Lauren Woolstencroft, born without legs below her knees and without a left arm below her elbow, as she learns to walk, then ski, then compete. Watch as her odds of winning a gold medal go from 1 in 997,500,000 to 1 in 1. It’s an epic journey.

View all of the videos at: mobilityforall.com/global/en

PLEASE REMAIN SEATED

LOOK AT YOU- SO BRAVE! LET ME KNOW IF YOU NEED ANY SPECIAL HELP, OK DAN?

THANKS JANET, BUT PLEASE TREAT ME LIKE EVERYONE ELSE. I’M JUST PART OF THE TEAM, SELLING PLUMBING SUPPLIES.

I TOTALLY GET IT. DO YOU HAVE THOSE TOILET SPREAD-SHEETS?

*SIGH* SO INSPIRING.
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.

**Membership is free**, and we intend to keep it that way. However, if you have means to help with our mission, please consider a donation of any amount by visiting: www.unitedspinal.org/ways-to-give

You can also call us at 800/404-2898, ext. 7203.

- $10 pays for a 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 Association 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.
Your world isn’t one dimensional. Your seat elevator shouldn’t be either. ActiveReach™ technology is the ultimate advantage in accessing your environment. By combining up to 14” of seat elevation and up to 45° of forward tilt, Permobil’s ActiveReach™ technology enables you to reach beyond obstructions, into high cabinets, and can even assist in transfers. Truly putting your world within reach by enabling the following:

- Improving functional reach
- Maximizing the use of available upper extremity strength
- Increasing interaction & enhancing engagement in activities

YOUR WORLD WITHIN REACH.

AVAILABLE ON THE F3, F5, M3, M5