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COVER STORY
LIVING FEARLESSLY

Living a fearless life after a spinal cord injury doesn’t mean living with a lack of fear. In fact, it’s the opposite. It’s having fears and choosing to go forward despite them. KENNY SALVINI talks with other wheelers about how doing life post-SCI requires a special kind of fearlessness tailored for the unique challenges we face.

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Issue 303 - December 2018
There are few things I enjoy more than a tasty meal out with friends. On my list of "Top Things that Begin with the Letter F," food and friends lag only behind family. Over 20 years, I’ve learned to live with many of the hassles that come with dining in my bulky power chair: inaccessible restaurants, cramped dining rooms, rude servers, a lack of tables I can roll under — and then there are the gawkers.

Gawkers are the people whose minds are apparently blown by seeing a wheelchair user out in public enjoying their life, and can only respond by staring. Some might think that on the eve of 2019 Homo sapiens would have evolved beyond such behavior, but if you’ve spent any time in public in a wheelchair you probably know too well how far we have to go.

I know gawkers drive some people crazy, but not me. To be honest, I’m fascinated by them. In fact, I’ve developed a rough classification system to help differentiate between types of gawkers. It’s far from complete, but here are some of the predominant classes with details on how common and annoying they are on a scale of 1 to 10, with 10 being Highly Annoying:

**Quick peekers**, Common, 3: Known for their tendency to glance surreptitiously, quick peekers are often found in fancier settings where staring is considered rude.

**Statues**, Very Common, 6: Just the sight of a person with a disability has been shown to trigger facial paralysis and empty stares in many of these individuals.

**Jaw droppers**, Rare, 8: Sometimes confused with their more common relatives, the statues, jaw droppers can be singled out by the dramatic plunge of the mandible.

**Talkers**, Uncommon, 10: Stares lead to an urgent need to make self-conscious conversation, including bad jokes ("How fast does that thing go?"), blessings ("I'll pray for you") and pure awkwardness ("It's great to see you out").

Identifying your own gawkers can be tricky. The hardest part is often separating gawkers from people who may be staring at something other than you or your chair.

For example, on a recent dinner date with friends, the empty, cold looks of the people waiting in line outside the restaurant could easily pass for the frozen grimaces of statues, but experience tells me they are more likely simply focused on getting inside where it’s warm. Similarly, experience tells me that a table full of food is known to produce longing looks from diners waiting for their own meals — expressions that can easily be mistaken for gawking.

With practice, you, too, can identify and classify gawkers. Deciphering the slightest social cues and gestures is a great way to turn what might otherwise be an awkward interaction into a fun evening for you and your friends. Maybe you’ll even discover some new categories! With the exception of the rare aggressive talker, gawkers are harmless.”
Unlike Kenny Salvini’s previous assignments for New Mobility, this month’s cover story didn’t come easily to the Washington-based writer and advocate. “When you first called me, I was terrified of being a fraud or not accurately capturing the idea of living fearlessly,” Salvini says. “The key to finding the narrative was when I started thinking about learned or developed fearlessness, because that matches my own evolution.” Salvini enjoyed the chance the article gave him to have intimate conversations with his friends and to examine himself. “It was a good opportunity to look at my own fears.”

Editor Emeritus Tim Gilmer is no stranger to Habitat for Humanity, the subject of his feature this month. Gilmer founded an affiliate chapter in his rural Oregon town in 2000 and served as an active board member from 2002-2006. “I believe in Habitat for Humanity,” says Gilmer. “It’s a great program.” Gilmer fought to make Habitat homes accessible back when he was involved and proposed writing this story to see how the organization is integrating home accessibility into its mission today.

Before digging into research for this month’s article, the last time Bob Vogel thought about 3D printers was in the mid-’90s, when he was working as a sales rep for medical giant Everest & Jennings. “They had this crazy-expensive, space-age 3D printer, and we were all amazed,” recalls Vogel. “We thought we were living in the world of The Jetsons.” Fast-forward 20 years, and Vogel is blown away to find 3D printers are now affordable and accessible to more people than ever.

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
We Can Relate

Wow! Such an informative article (“Surviving Modern Rehab: A Tale of Two Injuries,” October 2018). I wish I had known about NEW MOBILITY magazine and read this piece before my experience with navigating everything SCI. My husband was in a mountain bike accident last October and has a C7 injury. We could really relate to Edie Perkins’ story. We’ve had to fight for the proper care since the day of the injury. The whole experience has been overwhelming, but it is so helpful to have support groups and to have people like Andrew Skinner of Triumph Foundation share their knowledge and be a fantastic source of support.

Inez Everett
Newmobility.com

Craig is a Savior

Great Article! My SCI rehab was at Craig 34 years ago, at age 22, back in 1984 when I was just a kid (“Surviving Modern Rehab: A Tale of Two Injuries,” October 2018). I’m a T3 paraplegic and Craig rehab made my life after SCI possible again. Luckily, back then I had great insurance and the company I worked for paid for my plane flight out to Craig from New Hampshire. Four months later I was on my way home by myself with a lot of learning curves. But that is part of life. I am still learning today at 57 years young. But always be your own advocate. Good luck!

Alan Duboyce
Newmobility.com

Eco-Friendly Ideas

Terrific article! (“The Environmental Impact of Wheel Life,” September 2018.) Here are a couple more ideas:

• Outside of home and work, I use Cure Twist catheters, and a percentage of each shipment comes as a kit, which drives me crazy, but I’ve been able to come up with a few ideas for using the excess supplies. The small blue pad comes in very handy when collecting the mess generated by peeling/preparing vegetables. The extra collection bags can be blown up, sealed and used to protect items being shipped. I use the gloves when putting olive oil and spice rub on my chicken, and when I make meatballs and cookies. I give the alcohol wipe packets to police departments and pet rescues for quick hand clean-ups.

• At home and at work, I keep a small bottle with just a half inch or so of alcohol in it to store a 6-inch straight catheter. After use, I simply wash the catheter with hot water and soap when I wash my hands and put it back in the bottle and give it a shake. I replace these weekly and have not had a problem with UTIs.

• I have shipped excess supplies to SCI associations in cities hit by hurricanes or other natural disasters. Thanks again for a terrific article!

Kelly McCall
Newmobility.com

Conserve, but Put You First

This was a very interesting article (“The Environmental Impact of Wheel Life,” September 2018). I have had personal struggles with how much my medical supplies add to our ongoing environmental issues. I love how Nils Jorgensen says, “Some people are good at one area of conservation, but you can give yourself a break about another side.” As a friend of Nils, I know he is very diligent when it comes to the environment.

I work in the medical supply industry and have so many customers who need sterile supplies. Medicare changed policy for a reason and that reason is to keep us safe. I give anyone kudos who can reuse their supplies without getting UTIs. To those who can’t, stay positive and don’t feel guilty for keeping your health your number one priority. But make appropriate changes in the areas in your life that you can.

Matthew Tilford
Newmobility.com

Handizap Concern

Do the magnetic fields produced by the “Handizap” interfere with cell phones? (“Driven to Invent,” October 2018.) The correlation between magnetism and electronics can cause some weird results – yes, I used to be an electronic tech.

Mark Barbee
Newmobility.com

Editor’s Note: Josh Smith replies, “Long answer short, they do not. The magnetic field is not nearly strong enough to cause any interference in the circuitry of the phone.”
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At the end of September, the nation’s media outlets produced dozens of stories about the latest news in spinal cord injury research: paralyzed people walking again. The University of Louisville and the Mayo Clinic both published papers outlining advancements in epidural stimulation that have allowed three participants with chronic SCI to take steps under their own power. These studies were the continuation of years of research dating back to 2011, when Reggie Edgerton, Ph.D., designed the first epidural stimulation trial for the Kentucky Spinal Cord Injury Research Center. That trial received significant mainstream media coverage because it was a major breakthrough — one of the first times that SCI research moved from the theoretical to the actual. This wasn’t an SCI treatment story about experiments with rats or monkeys that could possibly be used on humans someday. It featured a man with chronic, motor-complete SCI standing under his own power for the first time since his injury.

There have been dozens of subsequent research publications outlining advancements and new types of functional improvement from epidural stimulation. None of them generated the same level of media coverage that the first report had. The September studies changed all that — national newspapers, glossy magazines and online media outlets all had some manner of story outlining these latest epidural findings. “Paralyzed People are Beginning to Walk with a New Kind of Therapy” from The Washington Post or “This Paralyzed Man Can Walk Again Thanks to an Incredible Device” from Men’s Health were typical of the recent headlines.

If you’re trying to catch mainstream media attention, paralyzed people walking again is about the juiciest clickbait you’re going to find.

The Misplaced Focus on Walking
Susan Harkema, research director at KSCIRC and one of the studies’ authors, has published a steady stream of research focused on everything from locomotor training’s effect on bowel, bladder and sexual function to epidural stimulation’s effect on blood pressure regulation. After that initial 2011 report, she says reporters always asked the same question: When is someone going to walk?

Harkema says this question is rooted in the nondisabled perception of SCI. “The miracle is that you get up and walk again. ... It’s what they think is going to sell, unfortunately.”

Harkema’s point about perception is an important one, especially when looking at mainstream media coverage of disability. This perseveration on walking isn’t just a media problem, it’s a societal problem. The inability to walk is the most visible manifestation of paralysis. This perseverance on walking isn’t just a media problem, it’s a societal problem. The inability to walk is the most visible manifestation of paralysis. It’s why we use wheelchairs, and wheelchairs are not subtle. But for people who have lived with significant, chronic paralysis, walking is often dwarfed by other concerns.

Impaired hand function, blood pressure, sexual function, bowel and bladder dysfunction — these are complications of paralysis that, depending on injury level, dominate our lives far more than an inability to walk. Societal narratives about paralysis focus on walking because those narratives come from a nondisabled perspective. And how would anyone nondisabled know about those issues, unless they have personal experience with SCI?
The Evolving Nature of SCI Research

Up until recently, this myopic focus on walking extended into the research community as well. Kimberly Anderson is a scientist and professor at Case Western Reserve University whose work focuses on bridging the gap between the research community and the spinal cord injury community, as well as translating effective research into clinical treatments. She is also a quadriplegic who, upon starting her post-doctoral research in the early 2000s, wondered why so many SCI researchers focused solely on locomotion. “I wasn’t seeing much research on cervical injury models and hand function, very little on bladder and bowel, and almost zero on sexual function,” she says. “I was talking to a researcher and he said, ‘I agree those things are probably important. But until I see data that says they’re important, I’m going to keep doing what I’m doing.’”

The exchange prompted Anderson to collect that data. In 2004, she published a groundbreaking survey, “Targeting recovery: priorities of the spinal cord-injured population.” The results codified what those with SCI already knew — walking is not at the top of our wish list.

The survey found that for quads, the number one functional priority was increased hand and upper-extremity function. For parars, it was sexual function. Overall, walking was fourth, behind sexual function, bowel and bladder function, and trunk control.

In the 14 years since that survey was published, more researchers have started coming around. There are a host of studies now focused on improving secondary complications of SCI — transcutaneous stimulation to improve grip strength in quads, magnetic stimulation to restore bladder control, FES implantation to improve bowel function, epidural stimulation as a means of improving cardiovascular function, next generation diaphragm pacing for high quads, and the list goes on.

Of course, walking and lower-extremity function is still a major component of research, but these days scientists like Harkema are taking a broader aim at functional recovery. “We’re really more focused on the whole system,” she says.

Telling Our Stories in the Age of Clickbait

Of course, data may persuade scientists, but autonomic nervous system function isn’t going to generate a viral click storm. A problem with covering disability in the modern media landscape is that disability is complicated. Telling accurate stories to an audience not familiar with the intricacies of SCI requires explanation and context. Those two commodities are increasingly difficult to find in a media culture that requires writers to deliver stories on a near instantaneous timeline, courting an audience with ever-shortening attention spans.

There is some hope, though. At the end of October, another study was released in the scientific journal Nature. This one came from researchers in Switzerland who also used epidural stimulation, though in a new way, to get a trio of participants with incomplete SCI walking again.

National Geographic covered the study in “New Spinal Cord Therapy Helps Paralyzed Patients Walk Again,” by Emily Mullin. While the headline bends to the public’s focus on walking, the article itself does an excellent job of making the complicated science behind the research understandable to the general public.

Just as importantly, Mullin takes the time to talk to SCI researcher Chet Moritz of the University of Washington to provide perspective on how this specific study relates to the broader research landscape. She also cites Anderson’s 2004 study and gives a quick overview of the other functional priorities of people with spinal cord injuries.

In terms of word count, those additions are a tiny fraction of the total. But in terms of broadening readers’ understanding of a community with which they may have no personal experience — other than admiring a courageous wheelchair user out grocery shopping — they are vitally important.

Nondisabled reporters can tell accurate, informative stories about people living with SCI, but it requires taking the time to delve beyond ingrained narratives. Living with paralysis is about a lot more than an inability to walk. Fortunately, learning about the reality of spinal cord injury isn’t particularly complicated. Just ask us.

Resources
• “Paralyzed People are Beginning to Walk with a New Kind of Therapy,” washingtonpost.com/health/2018/09/24/paralyzed-people-are-beginning-walk-with-new-kind-therapy/?utm_term=.794391fb830b
• “Three People with Spinal Cord Injuries Regain Control of Their Leg Muscles,” nature.com/articles/d41586-018-07251-x
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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.

**CHAPTER LEADERSHIP MEETING GROWS**

United Spinal Association hosted leaders from across the country October 11-13 in Orlando, Florida, for its sixth annual Chapter Leadership Meeting. The event aims to strengthen programs, services and outreach to people living with spinal cord injuries and disorders nationwide.

"This meeting offers chapter representatives, who are truly exceptional leaders, the opportunity to share their success and learn new ways to reach the diverse population we serve within their respective communities," says James Weisman, United Spinal’s president and CEO.

United Spinal chapters are self-dependent regional organizations that serve individuals with SCI/D by promoting health and well-being, inclusion and independence, community integration, accessibility and advocacy. Many of the chapters are led by individuals who have experience adapting to the challenges of living with SCI/D and are dedicated to helping their peers achieve the same.

During the meeting, chapter leaders and United Spinal staff covered a multitude of topics, from enhancing outreach and enriching chapter operations to fundraising and collaboration on future initiatives.

"Although our chapters have different programs and initiatives, we all share United Spinal’s mission to ensure people with SCI/D can regain their independence and quality of life. It’s great to come together face to face with other leaders to contribute ideas and resources," says Jose Hernandez, president of United Spinal’s New York City Chapter.

United Spinal hosted its inaugural chapter leadership meeting in 2012 with 17 chapters serving wheelchair users and others with SCI/D. Since then, the organization has expanded to 54 chapters in 34 states.

"The commitment of our chapters to provide critical resources and support to our members on the local level drives our mission," adds Nick LiBassi, who coordinated the meeting and serves as United Spinal’s vice president of partnership expansion.

Bert Burns, a Paralympian, entrepreneur, and clinician delivered the meet-
ing’s keynote address, discussing the significant role peer support played in his recovery from spinal cord injury.

“Being injured 36 years, I know how important peer involvement is in overcoming SCI/D. United Spinal’s chapter leaders are great role models for the newly injured. It was an honor to be able to tell my story and show how I was helped along the way,” said Burns, who was spinal cord injured at the age of 20 when his vehicle was struck by a drunk driver.

United Spinal also honored two of its chapters for their commitment to making a difference in the lives of individuals affected by SCI/D. Chris Salas and the San Antonio Chapter received the “2018 Creativity Award” for their efforts to find creative ways to connect with chapter members. Debbie Meyers and the North Carolina Chapter received the “2018 Connection to the Community Award” for their ongoing work to improve community engagement.

To find your local chapter, visit unitedspinal.org/join-united-spinal-association.

#WhyWait for the next disaster?
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Jerry Diaz recently met with the woman driving the car he jumped in front of during a 2011 suicide attempt.

**JERRY DIAZ IS FINE**

It’s not always possible to make amends to those we hurt. But metal sculptor Jerry Diaz, 32, a T10-12 para, recently had the opportunity to tell the woman who ran him over that he’s OK, it wasn’t her fault, and it changed his life for the better. And he did so in front of a large sculpture he had recently sold to the city of Kissimmee, Florida.

“On April 12, 2011, I attempted suicide. I ran into traffic and jumped in front of a speeding car. I got hit and pretty much destroyed my body instantly,” Diaz said in an Oct. 24 Facebook post showing a photo of him with the woman who hit him. “It’s been over seven years since that day, and I’ve always wondered about how my selfish action impacted her life. But I had no information on her and I left it at that.”

A few days before that post, she found him and wanted to talk. So he took her to see his sculpture, entitled Dragonfly. “I’m happy that she’s OK and I didn’t ruin her life with my action,” he said.

Diaz rebuilt his life around chairskating, also known as WCMX, and a few years ago took up welding at the Mech-Tech Institute in Orlando, Florida, where he discovered his knack for metal sculpting. “I got bored and asked one of my teachers if I could take scraps and make something,” he says.

He made a skateboard, then a rose, and eventually sold his work at outdoor markets and local galleries. An admirer suggested he submit to the Kissimmee Main Street Experience, and his first large work, Dragonfly, was accepted. Building on that success, he sold a second sculpture to the city, entitled Breaking Free. Diaz is already working on his next big piece, modelled after a dream catcher. “I can’t draw, but I can make stuff look like I want in metal,” he says. “It’s like playing with Legos.”

**ACCESSING THE WILDS OF NORTHERN CALIFORNIA**

It just got a whole lot easier to enjoy the great outdoors in Northern California with the launch of Bay Area Outreach and Recreation Program’s new website, accessnca.org. Here, you’ll find over 100 detailed listings under the headings Explore, Play and Sleep — including info on trails, parks, adapted outdoor adventure programs and various lodging options such as yurts, cabins and hostels.

“People with accessibility needs don’t typically have the luxury to spontaneously go for a hike or take an overnight adventure. They need accessibility information in advance of their trip to make sure that they will not encounter barriers,” says Bonnie Lewkowicz, a C5-6 quad.

Every entry on accessnca.org includes details as specific as trail surface and width. Lewkowicz’s lodging entries include restroom features, door width and bed height.

**EXCY PORTABLE EXERCISE SYSTEM**

Retired Marine and handcyclist Leigh Sumner credits her Excy portable exercise cycle for swiftly getting her back on the road after she took a tumble. “On August 22, while adaptive mountain biking in Colorado, I had an impressive end-over-end downhill crash and fractured my right wrist and hand,” says Sumner, a para. “But I started back on Excy on September 13, riding it every few days as my injury healed and my confidence grew.”

By mid-October, she was racing again, coming in as the second female handcycler in the Army Ten-Miler and the fourth in the Marine Corps Marathon. “Neither of those are personal records, but I’m very pleased with these results coming off injury,” says Sumner. “I already loved Excy, but I wasn’t sure it would get me race ready. It did!”

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SHOULD I REVEAL MY DISABILITY BEFORE A JOB INTERVIEW?

Q. I’m looking for a job that pays well enough to offset my quadriplegia-associated expenses. Since I’ve heard it is difficult for wheelchair users to get interviews, I don’t tell potential employers about my disability ahead of time. This solution is less than ideal when put into practice.

I kept my wheelchair a secret prior to an interview twice now, and neither time worked out well, as both interviews were in inaccessible locations. There were also some personal questions asked during the interviews that seemed more about my disability than about my qualifications. One potential employer asked how I would get to work on time each day, and another wanted to know how often I needed to visit the bathroom.

Does it make sense to hide my wheelchair from potential employers prior to an interview, and are there any restrictions on what they can ask about my disability during an interview? Perhaps more importantly, what are my protections and recourse if I believe I have been discriminated against?

— Still Seeking

While it’s up to you to decide whether to tell prospective employers if you use a wheelchair, there are a lot of good reasons to do so.

If you require an accommodation in order to be interviewed, it is your responsibility to disclose what you need. Not doing so can be embarrassing for both sides, with the possibility that the sudden introduction of your disability may deflect attention away from your qualifications.

Asking for an accommodation also gives you a chance to show how you can proactively deal with potential obstacles, both disability-related and not. Additionally, the interaction can give you a feel for how the employer will handle disability issues and possible future accommodations or requests. If your request is met with inappropriate questions like the ones you faced, it may be a sign of problems to come.

While your wheelchair may be part of your daily existence, remember it is not you. Presenting your disability as an asset and focusing on ways it has made you a better candidate can be an excellent strategy. If you show that you are comfortable with your disability, that relaxed attitude should cause the interviewers to be more comfortable with you as well.

Your job is to make your prospective employer understand not only that you have the qualifications for the job, but also that you are the one they should hire.

During the interview, employers cannot ask questions about your disability, but they can ask how you would accomplish the essential functions of the job for which you are applying. If you have previous experience in doing that work, including on a volunteer basis, this is an opportunity to bring it up.

If you feel like you have been discriminated against, Title I of the ADA protects you from employment-related discrimination. Qualified individuals with disabilities who are discriminated against at any stage of the employment process may file a complaint with the Equal Employment Opportunity Commission, the designated enforcement agency. Many states have related civil rights laws that prohibit discrimination against people with disabilities; pursuing violations of those laws occurs at the state level. Hopefully your search for the dream job will go well, and you will not need to make use of any of these programs.

Resources


Editor’s Note: This will be the last Everyday Advocacy column. Since its debut in 2011, Michael Collins’ sage advice has helped educate countless readers about the intricacies of disability rights in everyday situations. Visit newmobility.com/?s=everyday+advocacy to access our archive of Everyday Advocacy columns.
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AD WOMAN

Shayla Gaither

Aspiring commercial director, college student, advocate and volunteer Shayla Gaither, 19, has a lot on her plate. The youngest attendee at the 2018 Roll of Capitol Hill and a T8-12 paraplegic since birth, Gaither is determined to change the way people view disability — and she has the tools and enthusiasm to do just that.

A native of Cheltenham, Pennsylvania, Gaither is a sophomore at Albright College. She’s a communications major with a focus in advertising and public relations and a co-major in business administration. “I want to be a commercial advertiser because I feel like commercials these days aren’t as fun and interesting as they could be. A lot of people get bored with them fast, and I think there are ways to make them humorous or positive to society,” she says.

Gaither found her passion early. When she was 15, she studied storytelling and directing during a summer arts program at a local university. She was especially excited about the directing. “Ever since I was 4 years old, I would take my mom and dad’s cell phone — back in the day when we had flip phones — and record videos when I was passing people,” she says. “I would do interviews and all sorts of stuff like that.”

Improving the way advertisers connect with people and tell authentic stories is near the top of Gaither’s list. “I like being behind the camera,” she says. “I’ll always be the kind of person who helps someone get out of their shell. I like seeing someone going from being nervous in front of the camera to being comfortable and confident.”

Tired of seeing carefully crafted cameos of a token disabled person in advertising, Gaither strives to increase, and better represent, people with disabilities. Real, rather than perfect, is how commercial media should be representing disability, she says: “You need to treat disabled people like real people — it makes a cultural impact.”

Gaither’s own experience with disability has been far from perfect. She says elementary and middle school were tough at times, as her classmates weren’t used to being around people with disabilities. Many saw her as different and ostracized her, but she was determined to not let that affect how she went about her life. She credits her positive attitude to her mother — who she says taught her how to analyze and work through different behaviors — and her brothers. She wants to be a good role model for them, and doesn’t want them to see her as different, “but more like, ‘Oh yeah, that’s my sister.’ I want to be a good big sister for them and still interact with them, play with them, go outside. It can be hard — not only am I a woman, but I am also disabled.”

CAN’T LIVE WITHOUT: My motor. I have a Smart Drive, and I couldn’t get around without it.

ON BEING A WORD NERD: Starting in seventh grade, I learned Latin. I fell in love with it. It’s quirky and it relates so much to English.
Gaither believes the difficulties of growing up with a disability have given her an advantage over her peers as she’s transitioned away from home and into the real world. “Having to socialize and understand mature concepts ... you mature at a young age,” she says. “You are constantly problem solving. You have to be positive about situations and you have to learn how to talk to people, in order to get what you need. You have to learn how to be kind because you know you need help. You have to learn how to handle mature situations and not get down.”

Additionally, Gaither craved the freedom that comes with leaving home for the first time. “I was ready for college because my entire life I didn’t have independence. I had to rely on people for eight hours or more. I needed help to just get outside my house because there were stairs,” she says. “So I definitely had an advantage over my friends or other people in college. They were so used to relying on people that they wanted to be nurtured, whereas I was the opposite: I was nurtured too much, and I wanted to be on my own.”

Favorite Travels: When I was 14, I got to go to Rome on a Latin trip. We went to the Vatican, saw the Sistine Chapel, saw the Colosseum. We went to Pompeii. It was so cool.

Why I Joined United Spinal: I went to the Wash ‘n’ Tune organized by my local chapter. I brought all the chairs I’ve had since I was a baby. I was that one person that literally brought six different chairs. I was like, ‘Hey, I can get them all cleaned to maybe donate them to somebody?’ And they said, ‘OK, let’s do this.’ I signed up to become a member.
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For more information on how you can support United Spinal and become a corporate member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
Imagine coming up with a cool idea, being able to design that idea on a computer, hitting print and seeing your idea come to life, ready to use. For three longtime friends, two of whom are quads, the idea was custom disability-related aids for daily living. For a father and son team of engineers, it was novel switch technology that allows people with limited dexterity to use touchscreens. In both cases, thanks to 3D printing, the teams were able to bring their visions to life without breaking the bank. And they can now pass the savings onto consumers.

Welcome to the 3D printing revolution — where hobbyists, inventors and entrepreneurs are creating innovative and affordable disability-related products and other cool stuff.

Wheelchair users often have great ideas on how to make better and less expensive solutions for everyday disability-related problems. But until recently, bringing these ideas to fruition involved costly steps that include creating, modeling and machining prototypes, or having them custom-made by occupational therapists. As a result, many ideas remained at the concept stage, or financially out of reach.

The growing affordability of, and access to, 3D printers is rapidly changing this. The price of 3D printers has plummeted from around $100,000 in the early 2000s to the comparably more affordable $1,500-$5,000 for a machine that produces similar quality prints. Entry-level machines can be purchased for under $200. This has created a movement of people producing innovative and affordable designs for personal use, to support a hobby, for their club or to start a small business.
Makers Making Change

One driving force in the 3D revolution is the web’s myriad offerings of open-source finished designs, as well as user-friendly programs that make it easy to find, create, modify and print almost any shape imaginable. Until recently, aspiring designers had to purchase and learn extremely complex and prohibitively expensive computer-aided design programs. Now, there are a number of quality free options for people wanting to get started with CAD. Both SketchUp and Tinkercad are solid, simple programs built with the amateur hobbyist in mind. Fusion 360 is an extremely powerful program that’s relatively easy to use and free for noncommercial use and startups with less than $100,000 a year in revenue.

If you have an idea for a product but lack design skills, there are websites that focus on matching designers to people with a specific need or idea. Better still, when somebody makes or improves a design, they often share it online.

A prime example of this is Makers Making Change, an online site that connects “makers” — a worldwide movement of hobbyists, people involved in arts and crafts, engineering, science and do-it-yourself projects — to people with disabilities who need ADLs or assistive technologies. It also connects people who have an idea for a specific ADL or project with a maker who can turn the idea into a reality.

The project was started in 2012 by the Neil Squire Society, a Canadian nonprofit whose site says it is “committed to creating an international community of makers who support people with disabilities within their communities by creating accessibility solutions.” The Makers Making Change site has an online library of 3D printable ADLs. It also offers connections to local makers with 3D printers who can either print an existing product or customize a product to fit a person’s needs, all for the price of printing material. For example, an adaptive utensil or pen holder will cost around $3 dollars, compared to $15-20 in many online stores. And when somebody has a cool idea, the site has links to connect them with local makers who volunteer their time to bring that idea to fruition.

“3D printers have created a movement of hobbyists who are getting into making things,” says Harry Lew, manager at the Neil Squire Society. “It is sort of parallel to the ’50s when you had the emergence of power hand tools that became available and people were making their own furniture. The 3D movement covers all ages, including retired engineers who have ideas, like to model and create, and now can do a 3D print for next to nothing.”

Lew says occupational therapists refer disabled people with limited funds to Makers Making Change so they can obtain inexpensive, custom ADLs directly from the maker. “These connections provide cool solutions to maximize independence,” says Lew, adding that the connections also help makers and disabled people have a broader understanding of each other.

A Boon for Business

Just as 3D printing is used by groups like Makers Making Change to empower individuals, the technology also helps many small businesses get off the ground. “As a small startup, time and money are in short supply and 3D printing saves a lot of each because we can prototype and refine our ideas right at the shop, rather than having to spend thousands of dollars and a lot of time to have each prototype made at a machine shop,” says Stefan Henry, 29, co-founder and CEO of Level The Curve, a small, Manhattan-based company that makes ADLs.

The company was co-founded in April 2017 by three close friends — Henry, Eli Ramos, and Khan Sakeeb — two of whom, Henry and Eli, are quads. “A few years back, Eli and Kahn and I said, ‘Let’s start a company that makes stuff to help people with disabilities get through life more easily,’” says Henry.

They design their products using two complex and expensive CAD programs, SolidWorks and Rhino, and print them on a FormBot 3D printer, whichretails for around $900. Their first product is the Eating Tool, a device that looks a little bit like two-holed brass knuckles that holds a utensil. It’s intended to make it easier for people with limited finger function to get food from the plate to their mouth and retail online for $20. “Orders are coming in,” says Henry. “It’s slow, but building momentum, and we have more products in the beta test stage.”
PTW Design & Development has also benefitted from the ease and affordability of 3D printing. The assistive technology and ergonomic design company was launched three years ago in Berkeley, California, by the father-and-son team of Philip and Richard Weiss. Philip, 32, is an electrical engineering/computer science graduate who has limited dexterity because of Duchenne muscular dystrophy, and his dad, Richard, is a scientist. They used 3D printing to make prototypes of their first two products, the AireLink and AireTouch, which enable switch activation and interfacing with a smartphone or computer touchscreen for people with limited dexterity and sell for around $50. “We got as close as possible to the final design before committing to the cost of having molds cut,” explains Philip. “This was much faster and less expensive than sending drawings to a machine shop or making expensive injection molds.”

The company also has prototypes for a hand brace for keyboard operation. “It is good we were able to save money with 3D prototyping because we thought when we had a prototype, we were 50 percent of the way to market. It is more like 1 percent of the way,” says Philip.

Still, Philip and Richard are enthusiastic and currently beta-testing the AireLink and AireTouch. They are looking for beta testers in case any readers with limited dexterity are interested in testing a light touch switch or need to access their smartphone with a switch (see resources).

Create From Home

3D printing has also empowered inventors with disabilities looking to create ADLs for personal use or for friends. “Making things for myself and others gives me a feeling of accomplishment and allows me to overcome obstacles, which makes my life easier and helps me feel less trapped,” says Tim Beidler, 50, from Beaverton, Oregon. He is the treasurer of NW Inventors’ Network, a club and resource network for inventors.

Beidler has been making items for over 18 years, from parts that make his van easier to drive, to a tennis ball launcher for his service dog. He designs each item from scratch using

“Making things for myself and others gives me a feeling of accomplishment and allows me to overcome obstacles, which makes my life easier and helps me feel less trapped.”

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The ‘Sup

Another hobbyist, Jacob Field, 18, from The Dalles, Oregon, designed The ‘Sup — a low-cost sip n’ puff joystick controller that enables a user to move, click and scroll a cursor on-screen. It can be printed and assembled for about $50, compared to the $1,000 to $1,500 that similar retail devices sell for. “I designed and made the project for a friend who is a quadriplegic and interested in figuring out how to play video games,” says Field. “I got the idea from a YouTube video of a commercially available sip n’ puff controller that was really expensive.”

Wright’s favorite 3D printing site is Thingiverse because it has plans for disability aids.

complex CAD programs. “Before 3D printing, I had to send files out to local and sometimes national machine and sheet metal shops to have parts made,” he says. “It was both costly and time-consuming.”

Five years ago, the NWIN purchased a high-quality Replicator 2X printer, the current version of which retails for $2,499. It resides at Beidler’s house. “Now I can print items right here in my office, which is faster and much less expensive,” he says. “Of the 11 different items I’ve designed and built for my daily use, seven were 3D printed.”

Beidler’s 3D prints include an articulated arm for his cell phone that fits on his power chair; a dog treat dispenser for Harvey, his yellow lab service dog; a custom box enclosure for holding USB sockets; and custom side guards to keep his feet from spasming off his footrests. “The side guards would have cost well over $100 from a wheelchair company, and all they cost me was the price of printing material, which is around $6.

If a person has an idea for a design, Beidler has the skills to take it from conception to 3D printing. Among the clients Beidler has designed and printed items for is a local accessible van shop and some of their customers. Items he has designed for them include joysticks for mirror and window controls, and key fobs with bigger housings and easy-to-push buttons. “As a full-time tinkerer and aspiring inventor, I understand many of the trials and tribulations involved in bringing ideas to life, and I know all too well what it’s like to need help,” he says. “I enjoy using design skills and 3D printing capabilities to help others develop their ideas.”

Beidler generally charges $35 per hour to design for others, but adds, “I work on a sliding scale down to zero, depending on a person’s resources.”

Kary Wright, 55, of Bashaw, Alberta, was turned on to 3D printers last summer when he saw a guy flying a drone similar to his, but with extra-long landing gear that kept the propellers from breaking when setting down in tall grass. Wright, a C5-6 quad who writes Outdoor Tracks for New Mobility, found out the pilot had 3D printed the unique landing gear. The pilot gave Wright the set and told him he’d just print another that night. Most importantly, he told Wright he could order a printer online for 200 bucks. “That night I went online and ordered a Monoprice printer for $280 Canadian,” says Wright. “I was hooked.”

Wright quickly discovered many online sites where people share free 3D designs and easy-to-use programs. “My favorite site is Thingiverse because it has categories like disability aids, and people share what they design,” he says. “Another free program I like is Tinkercad because it’s a user-friendly program for the person who doesn’t know CAD. It’s easy to use and lets a layperson like myself modify shapes by clicking and dragging, or if I know the dimensions for my project, I can type them in.”

The list of cool ADLs and disability-related items Wright has made already is impressive: a holster-type cell phone holder that zip-ties to the armrest of his chair, joystick extensions that enable him to fly his drone with limited hand dexterity, a mount to hold his
cell phone while he’s flying the drone, USB plug adaptors and, most useful of all, a leg bag drain that he can independently operate. “A big pain for me as a quad was having to ask somebody to drain my leg bag for me,” he says. “I looked at commercially available automatic ones, but they are going for around 400 bucks. I made one on the 3D printer for a few bucks in filament, a spring and some zip ties.”

In addition to the fun and satisfaction of turning an idea into what he needs, Wright explains that 3D printing is extremely economical. Most of his ADLs were made for just the cost of printing filament, which is only a few dollars. He says it usually takes him three or four prints to adjust and tweak a design so it’s just right. “I’m happy with the inexpensive 3D printer. The only downsides are it is slow — the average length of time it takes to print something like my cell phone holder is about six hours — and it can’t print shapes that require thin or complex areas,” says Wright.

More expensive printers are faster and can print more complex objects. They also have multiple print heads, are easier to clean and have bigger print beds — the printing size limit of Wright’s is 4.5 inches by 4.5 inches.

Check out the resources below to learn more about the 3D printing revolution. In addition to creating cool and affordable solutions that maximize independence, as Wright says, “3D printing is an inexpensive way to design exactly what you need.”

Resources
- Fusion 360, autodesk.com/products/fusion-360/
- Level The Curve, levelthecurve.com
- LipSync, makersmakingchange.com/project/lipsync
- Makers Making Change, makersmakingchange.com
- PTW Design & Development, ptwdd.com
- NW Inventors’ Network, nwinventorsnetwork.com
- The ‘Sup, instructables.com/id/The-Sup-a-Mouse-for-Quadriplegics-Low-Cost-and-Ope
- Thingiverse, thingiverse.com
- Tinkercad, tinkercad.com
- What is 3D Printing and How Does It Work? youtube.com/watch?v=Vx0Z6LplaMU

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Level the Curve uses a 3D printer to more affordably create prototypes.
Always up for an adventure, Josh Hancock fosters an attitude of taking life as it comes.
‘Doing Life’
Pushing Beyond Fear

BY KENNY SALVINI

When I tattooed the phrase "do life" on my right wrist to mark the eighth anniversary of the skiing accident that left me with C3-4 quadriplegia, it was equal parts memorial and mission statement. It was a tribute to my first wife, Kristen, who I’d lost to an accidental overdose a few months earlier. She’d used the mantra with me incessantly when we first met, soon after my accident. At the time, I didn’t want to hear what the cute rehab nurse in my hospital room was trying to tell me, but her words took on a whole new meaning when she wandered back into my life six years later and helped show me that I was far more capable than I gave myself credit for.

Flash forward to today, and the old me wouldn’t recognize the new. A glance at my social media feeds portrays me as the guy who, 10 years after it happened, went back up the mountain where I was injured to exorcise some demons. I’m also the guy who travels the country advocating on behalf of the SCI community, even though the airlines have destroyed my wheelchair and left me abandoned on multiple occasions. What isn’t shown is the long, winding path I took that first decade — especially the first six years, when I barely left my hospital bed, let alone my bedroom or house.

My injury was easily the most disorienting thing I’ve ever experienced. It was as if a curtain had been raised, showing an entirely new spectrum of danger that I never knew was there. Hell, during that time, I didn’t even look in the mirror or allow people to take photos of me because I was terrified of facing the reality of my new life. Kristen helped to change that by lighting a fire inside me. It’s a torch I’ve been carrying ever since she passed.

What I discovered during that slow evolution from depressed shut-in to experienced traveler and advocate is that doing life post-SCI requires a learned fearlessness. It’s only by exposing ourselves to our fears, whether they are perceived or legitimate threats, that we find ways to move beyond them and unlock our full potential. It is our willingness to push past our limitations that helps us find rich and meaningful lives.

I spoke with four people from our SCI community about how they embrace doing life. Whether they learned to go with the flow, reclaim vocations, strengthen family bonds or resist overprotective parents, each one says that cultivating fearlessness improved their post-injury life.

SAYING YES TO CHALLENGES

Environmental consultant Josh Hancock has always tried to foster an attitude of taking life as it comes. His positive outlook was put to the test four years ago when he injured his spinal cord at T12 while ice climbing near Source Lake in the Washington Cascades.

Soon after his injury, Hancock, living in Seattle at the time, planned a trip to the Western United States that turned into a two-year-long odyssey. To help quell his initial fears about traveling independently post-injury, he mastered important basics like transferring into his manual chair from the ground and getting in and out of his minivan. But he was unprepared for the emotions that washed over him when he finally set out.

“I felt this wave of both fear and excitement,” says Hancock. “I felt so exposed — it was like climbing. I was in the world again. I was thinking, what if my car breaks down, or if I get a flat tire, what would I do? And I didn’t have any of those answers.”

Allowing this mixture of emotions to fuel him, he packed his van for a month-long trip starting with the No Barriers Summit in Park City, Utah, where he got his first taste of adaptive sports.

“It was a large gathering of really interesting people,” he says. “This woman said, ’Josh, have you ever wanted to go down the Grand Canyon?’ And I was like, ’Fuck yes! I mean … yes, I want to be on that trip, put my name down.’ She
said it was a year and a half away, and I said ‘I don’t care, put my name down.’”

Hancock says making a habit out of saying yes to life’s challenges develops mental pathways in the same way that repetitive exercises strengthen muscle memory. Just as bad experiences distort your perception of the world toward the negative, good ones build confidence, and that confidence is compounded with every success.

Once the summit finished, he made his way up to Jackson Hole, Wyoming, for two and a half weeks. While there, he was forced to confront his disability head-on. “I was alternating between new friends introducing me to fun things like whitewater kayaking, and being in my van for two or three days, lying there naked and pissing all over myself from bladder spasms, just feeling like … what is all this?”

Hancock credits what he calls mental jujitsu for his ability to deal with these ups and downs. “I try to remember that consciousness is a gift. I’m in chronic pain all day, every day,” he says. “There is a saying that even the opportunity to feel pain is a privilege.”

As 2015 drew to a close, he made his way back up to Seattle. The lease on his apartment was coming to an end, and he could feel the itch — it was time to make a change. “I didn’t really know where I wanted to live, but Seattle was not working for me in many, many ways,” says Hancock, who is originally from Fairpoint, New York.

That’s when he decided to buy a Sprinter van, outfit it as a camper and make it his new home.

Hancock spent most of 2016 zigzagging across the western states, chasing cool opportunities that seemed to come one after another. He traveled through Oregon, Wyoming, Colorado and California. He learned to monoski, spent some time learning about adaptive surfing in Southern California, embarked on a 10-day trip on the Salmon River in Idaho, and topped it all off with mountain biking in Colorado. The fun came to an abrupt halt in December when an accident suddenly left him homeless and vanless at the same time. “I felt so helpless and depressed, just crushed,” he says. “That was gnarly.”

Hancock eventually found a suitable place to live that was not quite ready for him to move into, leaving him a few weeks to kill. Instead of wallowing in his misfortune, he had a realization. “If I’m paying for rental cars and hotels and all that,” he remembers thinking, “why not travel?” He sent out a message to friends to see who might be free for an impromptu trip and four days later wound up in Columbia, South America, on yet another adventure. “We had a magical time,” he says.

GETTING BY WITH A LITTLE HELP FROM FRIENDS
A 1,600-pound hay bale fell off the front-end loader of Ken Vetter’s tractor and nearly crushed him in June 2017. The third-generation farmer from the rural outskirts of Montesanto, Washington, found himself in the hospital, a C6-7 quad. He was at the bottom of
a steep learning curve with the clock ticking toward discharge. “The way insurance is, hospitals don’t have time to teach you everything you need to know,” he says. “You have to relearn your whole life in a month.”

In total, he and his wife, Janet, were given 45 days to work on his physical recovery while trying to find answers to the infinite number of questions they had about the future. What would happen to the family farm? Who would manage it if he could not? In a tiny town of barely 4,000 people, what kind of resources could they expect to come home to? Thirteen days after being admitted, they got an unlikely answer to the last question in the form of a new friend.

Jeff Miller recalls hearing a radio broadcast about Vetter’s injury while driving back from the auto repair shop he owns in the nearby town of Aberdeen. Days later, he sustained a T11 injury of his own when he fell off a ladder while trimming trees at his home, a mere 13 miles from Vetter’s farm. When Vetter first heard the news that a neighbor had suffered a similar injury, he wondered aloud to his wife if this was all part of a larger design.

Vetter and Miller connected in rehab and quickly bonded over their shared sharp-witted sense of humor and love for working outdoors. They were nearly inseparable from that point on. It became normal to see Vetter towing Miller up the hills near the hospital to help conserve his friend’s energy. When it came time for discharge, the Vetters moved Miller into their home while he awaited the remodel of his own.

Once he moved back home, with the help of Vetter’s farm hand, Miller modified his side-by-side UTV with crude hand controls, and hatched plans to get his friend back in the saddle as well. “It’s been important to me to be able to get him doing things that might make him a little more independent,” says Miller.

Janet jokingly refers to Miller as her second husband and the duo as “a couple of knuckleheads who are always finding ways to cause trouble.” Take the time the guys told her they had a plan to get Vetter into some of his old equipment. “I thought they were just going to get him in the gator,” says Janet, referring to a small all-terrain vehicle.

What she didn’t know was that the guys rigged up a pseudo-Hoyer lift inside the barn and attached a steel plate to the bucket of the very same loader Vetter was driving when he got hurt. “A therapist would never condone sitting on this giant piece of steel and being shoved into an excavator,” quips Miller. “I got about three hours of work out of him before he tuckered out.”

“It’s not as scary as he makes it sound,” Vetter retorts before Miller fires back, “Oh no, it most definitely is.”

Less than 18 months after their respective injuries, you wouldn’t even notice Vetter and Miller were paralyzed if you came rolling up to the construction site of the Vetter’s new accessible home. You’d see the pair manning heavy machinery, one doing the grade work for the front yard and the other backfilling the new drain field installation.

It’s testament to the bond that is created through peer connections, and the power that bond imbues. “They would have been best buddies no matter what,” Janet says of the weird twist of fate that brought them together, given how many mutual acquaintances they have. “It’s hard to imagine how they weren’t already friends.”

**FUELED BY FAMILY**

For family man Brad Hensley, who wound up a T1 para after a routine cervical fusion to relieve three herniated discs went awry three years ago, it seems like not doing life is not an option. His wife, Cara, and their blended family of five children needed him. What exactly that looked like, he wasn’t sure. A lead for a plumbing contractor for 20 years in residential and new construction, he’d always been a hands-on kind of father, and he couldn’t help but wonder how his injury would affect the family dynamic.
He’s quick to credit Cara for being his rock since day one. The two were married just 14 months prior to his injury, and she did much of the grieving in the first five weeks, during which he was in a medically induced coma in the ICU. By the time he woke up, she was already on the run, and it took him a while to catch up. “She said, ‘You don’t have the luxury to be down and out, or woe is me,’” he recalls. ‘You have five kids who look up to you for inspiration and guidance.’”

Shouldering the burden of being a parent while simultaneously trying to make sense of his new life was a challenge early on. He made time for his emotions at night and during the day when no one was around. “There was a switch that went on when the kids were up in the morning,” he says. “I needed to focus on them.”

Hensley talked with several parents with SCI who all said the same thing: It’s not important how they show up for their children’s activities, but that they show up. It’s invaluable advice he takes to heart, making his best effort to be present at every game or recital. “As much as possible, I try to be there, even if I can’t be sitting on the sideline,” he says.

At some point, Hensley started to notice he was no longer just showing up for the family — he could feel himself adjusting to his new normal. “It was time to get rolling — there was so much more life to live,” he says.

Hensley started to recruit his kids to help with home projects, and then to help neighbors on small remodels. When a friend who uses a wheelchair was having issues lining up a drain for a sink, Hensley sent videos of his oldest son, Spencer, walking through the steps. “He’s been my right hand when I need something done,” says Hensley.

Still, when Hensley’s youngest daughter, Alyssa, asked him to go to a father-daughter dance, he was nervous. “I was scared for her because I didn’t want her to be singled out for not really dancing, just being with a guy in a wheelchair,” he says. But he got dressed up anyway, and the two of them quickly realized that it didn’t matter what other people thought. “She’d stand on my feet, sit on my lap or stand next to me. It turned out great.”

By the time the family took its first substantial road trip last summer, they were all used to going the extra mile. Before they ever hit the road, troubles with their adaptive van threatened to derail their plans completely. Cara would not be denied. “I wasn’t going to let this one little hiccup spoil our trip,” she says.

Using a borrowed Hoyer lift, Cara and their eldest daughter, Emily, managed to maneuver Brad into the passenger seat of an unadapted rental. Then they loaded the lift and chair into a small travel trailer they towed behind them and resumed their vacation.

Successful on-the-fly ingenuity, coupled with trust built over prior experiences, deepened the family’s well of perseverance the next time plans inevitably went sideways. Facing wheelchair battery issues and a handful of inaccessible hotel rooms on the trip, they all worked as a team to improvise, adapt and overcome. “Everything that happened, we all just kind of rolled with it,” says Hensley.

Brook McCall lives where she chooses — and how she chooses.
FACING THE FEARS OF OTHERS

It’s not just our own fears we have to deal with in the aftermath of a new injury or diagnosis, but the fears of everyone in our support network, says Brook McCall. McCall fell from a balcony while attending University of California Santa Barbara in 2002 and ended up a C4 quad. She vividly recalls the anxious looks on the faces of family and friends when she first woke up after spinal fusion surgery.

Like pieces attached to a shaken mobile, when a person experiences such a dramatic change, everyone attached to them spins uncontrollably. They may experience a natural tendency to try to control what they think they can in an attempt to regain their own bearings, but that overreaction can prevent the natural motions of the injured person’s life from taking place. “Many people were dismissive about my desire to try to finish college,” says McCall. “I don’t believe they meant harm, because these were people who loved me. But at the same time, it hurt me that this was the story they pictured for me.”

Add in medical professionals conveying a grim prognosis, and McCall found herself facing a bleak and empty future. “I didn’t see it like that, but it’s how things are presented when you are newly injured,” she says. “All I had to go on was that I’m a good person, and I would never take advantage of those situations. So I had to have faith in humanity,” she says. “I had to ask for a lot of help.”

She posted flyers everywhere and after a lot of searching, wound up hiring a former resident advisor as her first caregiver. That helped open the doors to other students working for her. As her care team began to solidify and her ability to self-direct her care alleviated her family’s fears, the need for their supplemental support became less frequent. “It was definitely more of a show than tell — basically proving to them, the school and myself, by just doing it and making it work,” she says.

After a year and a half of relentless effort, sometimes taking up to five or six classes per quarter, McCall completed her undergraduate degree in biological anthropology. She then earned a master’s degree in public health from the University of North Carolina at Chapel Hill, parlaying her personal journey into a platform for change. Given how hard the rehab system was for her, she fears it is even worse for someone with no resources or support system. “My injury and hospital experience enlightened me to a world I was unaware of and realities that spurred me to be involved in change for the better,” she says.

Now settled in Portland, Oregon, and working as the grassroots advocacy manager for United Spinal Association, McCall is helping knock down barriers for others all over the country and encouraging them to do life.

FEARLESS VS. FEAR LESS: MY OWN CONCLUSIONS

Being fearless is not lacking fear. In fact, it’s the opposite. It’s having fears and choosing to go forward despite them. It’s a blend of persistence and courage that can be developed over time. There are mental, emotional and spiritual muscles that can be strengthened through repetition. They can, when
flexed at the right time, catapult your life to the next level — whether it’s moving out on your own, taking a road trip or reconnecting with your true passions in life.

It’s easy to get caught up in the day-to-day grind and negative self-talk that convinces you you’re going to be an utter failure on the next endeavor, all the while forgetting how far you’ve come. Living fearlessly takes a lot of many things: asking for help from family and strangers, being open to learning with and from others, getting to know your reactions to life’s challenges, and developing new habits.

At some point, you flip from fearing what might go wrong to fearing you’ll miss out on the growth that lies just beyond. By continually pushing against your boundaries, you learn to see the world, and yourself, from a perspective you may have never considered.

This happened for me this past spring while my future wife, Claire, and I planned our wedding. Claire, a diehard Dancing with the Stars fan, sweetly, but unequivocally, demanded that we dance at our wedding.

At first, I shot it down, for fear of the inevitable embarrassment. But then I realized I didn’t want to start this chapter of our lives with the narrative that there were certain things I wouldn’t do because of my insecurities surrounding my life in a wheelchair. All it took was a single lesson with an adaptive dance coach to help me see ways Claire and I could have fun with it. So we had that first dance, and it turned out to be the most memorable part of the entire wedding. It really brought the house down.

So the next time life presents an opportunity to stretch one of your comfort zones, I hope you’ll take the chance to be fearless and surprise yourself.
This is the tale of my doomed quest to solve the salad bar conundrum. New Mobility reader Don Gallagher provided the impetus for this quest when he emailed his concern that wheelchair users can’t access the world’s delicious salad bars and buffets. “I keep looking for solutions wherever I wander,” he wrote from his home in Lititz, Pennsylvania. “Salad bars present some unique design dilemmas ... getting a wheelchair close enough to see and reach things, longer tongs aren’t much of an answer, and then there’s the issue of sneeze guards.”

He wondered about the accessibility of rotating Lazy-Susan displays or terraces in a pyramid that rise and fall upon command, delivering cheese cake or meat loaf to the intrepid diner.

Strangely, this excited no one on staff but me. I figured it was because these folks didn’t realize how crucial salad bars, buffets, smorgasbords and all things long and laden with lard-infused food are to Central Pennsylvanians, to which they responded, “Well, yeah.” To which I said something like, “Aha! But the Amish! Even if we cannot solve this conundrum, writing a travel story focusing on Lancaster County, which is not only home to the largest smorgasbord in America but also to the erroneously-named Pennsylvania Dutch, could be a lot of fun.” I say erroneously-named because they’re not Dutch, they’re German. They ought to be called Pennsylvania Deutsch, but that’s never caught on.

This is the resulting story of how I valiantly sought to find a solution to the salad bar conundrum, but was led astray by the beauty and quirkiness of Amishland.
First Stop — Lititz

Named America’s Coolest Small Town in 2013, Lititz definitely won’t be winning any awards for accessibility. It’s cute and packed with over 70 businesses, but maybe one in five is accessible.

“I can’t think of any,” says the Lititz Visitor’s Center employee when I stop into the converted railroad station to ask about accessible businesses. I suggest Wilbur Chocolate, naming the store where I picked up a bag of locally-famous Wilbur Buds — bite-sized pieces of chocolate — and parked my pick-up for the day.

“Well, yes, there’s that. Oh! The Moravian church and the Historical Society are accessible,” she says.

Like the Mennonites and Amish, Moravians settled here in the 17th century, escaping religious persecution. “I saw Olio, too, coming in,” I add, referencing an accessible store that sells olive oil and accoutrements. “Yes! There you go,” she says. “Oil and chocolate.”

Fortunately, a few eateries are also accessible. The Bulls Head Public House offers a gastropub-quality menu and has no-step entrances and spacious bathrooms. Seating choices include low and high tables, and stuffed armchairs. It’s all beautifully coordinated in a highly-polished wood and leather sort of way.

The other accessible dining option I find is Café Chocolate, an open, cheerful space with various chocolate-infused entrees and other offbeat offerings, such as West African peanut chowder. Follow the path on the left around the back to the ramp. The door is unlocked today, and I am told it’s kept unlocked during business hours.

For a snack, locals gush about watching the pretzels being made at Julius Sturgis Pretzel Bakery. It’s accessible, as are Purple Robin Reserve art gallery/gift shop, Cherry Acres Old Barn Wood Furniture & Home Decor and the Matthew 25 Thrift Shop.

After my visit, I wonder why Gallagher focuses on salad bars when so many of the shops in his town are lacking access.

If you do go, grab a bag of Wilbur Buds.

Trains! Trains! Trains!

The Strasburg Rail Road was first chartered in 1832, and there’s nothing quite like a ride through the countryside on an old-fashioned steam locomotive. I’ve taken friends and family from out of town. My favorite trip was during the Christmas season when a brass band and choir, dressed up in 19th century duds, joined the ride. It felt like being serenaded on the Polar Express.

Many cars are accessible via a mobile lift that can handle 400 pounds, and all the shops in the complex but one have an accessible entrance. I cannot recommend the food. It’s best to hold out for one of the county’s storied smorgasbords.

Cross the street to visit the Rail Road Museum of Pennsylvania. This sprawling complex holds some of the oldest iron horses manufactured in our nation as well as one of every type of train ever built — at least that’s how it seems to my amateur eyes.
A thriving tourist industry has grown up around the Amish, as people come from all over the world to see how the “plain folk” live.

The $10 entrance fee allows you to freely wander around admiring the brute strength of these massive machines. Also, the bathroom is nicer than the one at the Strasburg Rail Road.

**Meandering Through Amish Country**

Back in my truck, I pull into the Old Mill House Shoppes, whose original building dates back to 1767. Now gift shops and a furniture store, the conversion is a good example of the repurposing common throughout Amish Country. The result is often-accessible ground floors, probably because the buildings used to be barns or mills of some sort.

Visiting this historic brick-and-stone cluster of gift shops is a lovely sojourn, next to a picturesque brook that actually babbles. Also, there's an accessible bathroom in case of a needed pit stop.

While driving between tourist sites, I stop at one of the ubiquitous roadside farm stands and see an Amish boy practicing archery. He puts the compound bow down to wait on me, and I buy some homemade root beer — an Amish specialty — but since their credit card machine is down that’s pretty much all I can afford. Yes, Amish shop keepers often use credit card machines.

**Kitschy Kitchen Kettle Village**

My next-to-last stop in rural Lancaster is the Kitchen Kettle Village located in Intercourse, not far from Blue Ball. Yes, these are real place names. So are Virginville, Bird-in-Hand and Paradise. Taken all together, these monikers are a never-ending source of amusement for tourists, as they seem incongruous with the 19th century religiosity of the local culture.

I like to tell myself the only reason I come to the village is because when my sister is in town she insists on buying the Perfect Pickle Chips that are only sold here. But I end up staying much longer than I plan and enjoy every minute of it. Whether I’m watching the one-man-band singing old-timey tunes, or taking pictures of amusing T-shirts for friends (Intercourse, hee hee hee), or visiting a pricey gallery that features local artists, the smell of buttered popcorn and potpourri wafts through the air.

This is what makes Kitchen Kettle Village so much fun — on the surface it’s kitschy, but many of the 40 shops sell quality local-made items that are hard to find anywhere else. Most shops are intuitively accessible, although some of the stores are packed pretty tightly, which could make picking out souvenirs difficult.

There is an inn at Kitchen Kettle Village, but it only has two accessible rooms. The ground-level room’s doors are wide, its mattress low and the bathtub’s built-in wooden shower bench usable if the handheld shower is placed within reach. But I can’t see an accessible path to the front desk. Staff says they’ll bring the key out, and if it’s after 8 p.m., a caretaker will make it there in 15 minutes or less. It is a central location with restaurants and amenities right here, but it’s also easy to find a close-by hotel chain that’s newer and more dependable.
The Corner Coffee Shop is the only accessible store across the street from the village, and like so many others, it also sells local handmade furniture and home décor. Stopping by for a chai latte, I notice a young Old Order Mennonite woman checking Facebook on her smartphone. You can tell Mennonites apart from Amish because their head-scarves are smaller and their dresses often have floral patterns. Mennonite men often wear flannel shirts and baseball caps, whereas Amish men wear black pants and beautifully-dyed deep purple or blue shirts.

These conservative Christians are often fiercely protective of the right of all women to wear headscarves, regardless of their religion. Thanks to the Mennonites especially, Lancaster County is home to more refugees than anywhere else in the nation, an unbroken 300-year-old tradition.

**The Largest Buffet in America (And Maybe the World!)**

Shady Maple is the largest smorgasbord in Lancaster County. The customer service clerk says it is also the biggest in America, and maybe the world — she’s not sure.

The facility is divided into two floors connected by an elevator. The 110,000-square-foot restaurant with its constellation of dining rooms is on top, and the 44,000-square-foot gift store — with its small café offering fragrant, mouth-watering chicken corn soup — is on the bottom. The actual smorgasbord is 200 feet long and laden with local favorites such as potato filling, pork and sauerkraut, thick and hearty chicken pot pie with noodles on top instead of crust, and American favorites like prime rib. And because this is Pennsylvania, you may also find kielbasa and pierogi.

Alas, I am so taken by the sight of so much delicious food that I forget to grill the proprietors on how to make the salad bar more accessible. However, it is all easily visible and reachable by most paras, and there are plenty of servers to help if needed.

Across from this building is the equally iconic Shady Maple Farm Market. It’s larger than the smorgasbord and features immense amounts of cheeses, meats and produce. That may not sound special, but you’ll see cuts or brands that are hard to find elsewhere and, if you haven’t rubbed shoulders with enough Amish people yet, you’re bound to here.

The produce in Lancaster County is delectable, and most farms are family-owned. But Central Pennsylvania is also a snack-food powerhouse, and with all those locally-produced potato chips, chocolate bars and soda, it can be hard to choose the cauliflower.

**All Things Good and Wholesome … and Tasty**

I wrap up my visit in the City of Lancaster, where I lived for a few years in the ’00s. I miss its balance of urban and urbane, a city where you’re as likely to hear Spanish or German as you are English. It’s where I tasted my first Puerto Rican-style empanada, and I’ve never been the same since.

First stop is Central Market, located on Market Street near Queen and King. Founded in 1730, it’s the oldest continuously-run farmer’s market in the United States. Entrances number one and two are accessible, but most of the others are not. It gets packed close to lunch-time, so get there as early as you can. Besides, you don’t want what others have picked over.

When I lived in Lancaster, I’d tell the guy running Shenk’s Chicken my recipe and he’d know just the bird to sell me. I think he really did know that chicken. Dairy from Maplehofe’s is the creamiest, produce from Groff’s is always quality, The Herb Shop won’t let you down (sorry, cooking herbs only), and the Grain Shop hooked me up with protein-packed Anasazi beans.

Parking is a beast, but if you come early, you can get a spot in the adjacent lot. Prince Street garage has significant access issues, so I cannot recommend it.

There are streets and streets of restaurants, galleries and stores hugging the Market. The shops in Market Alley are almost all accessible on the King Street side, and most of the shops on King in this district are accessible. Many on Orange are as well, but the accessibility of Prince Street’s famed art gallery row, frustratingly, is lousy.

**An Unexpected Solution**

At New Mobility we strive to present you with interesting, accessible-enough destinations worldwide, and yet here was such an area worthy of being explored in my own back yard — probably there’s one in yours as well.

Every region has people that make it special, history that shaped us all, and food outsiders may enjoy sampling. For Lancaster, it’s the Amish culture and the tourist industry that’s grown up around it.

For you, perhaps it’s that quaint neighborhood you’ve heard so much about yet never visited, or a specialty chocolatier one county over. For me, the biggest surprise was how much I enjoyed Lancaster’s blatant tourist traps, like Kitchen Kettle Village.

With apologies to Gallagher, the salad bar conundrum remains unsolved. But I think I solved a different one: Sometimes if we stop searching elsewhere for a definitive travel experience, it sneaks up and taps us on the shoulder.
It’s early April in Washington, and my husband and I are traveling over Snoqualmie Pass on our way from Tacoma to Leavenworth. We’re straining to see through the sudden flurries when the snow abruptly disappears. The road clears as we drop in elevation and I know we’ve arrived at our destination when I see the ubiquitous Bavarian storefronts against the backdrop of snow-capped mountains. Even the local gas station is designed to look Bavarian.

When it could no longer be sustained as a logging town, Leavenworth was reforged into a tourist destination, the result of foresight and planning by its civic leaders. Now, half a century later, year-round festivals and celebrations ensure entertainment to suit everyone’s taste. Oktoberfest, Maifest, the Christmas Lighting Festival and the International Accordion Celebration are all accessible, and events at the Festhalle and Leavenworth Summer Theater are also wheelchair-friendly.

I stop by the Danish Bakery for apple strudel and coffee, then head down Front Street to the Nutcracker Museum. “We have an elevator, and we do all we can to make the museum accessible for all,” manager Debbie Watkins tells me. This delightfully distinct place displays over 6,000 nutcrackers made of a variety of materials — carved wood, silver, ivory, ceramic. They’re shaped like toy soldiers, Disney characters, rabbits, pirates, pilgrims and more. An artfully-painted Santa seated at a sewing machine caught my eye. Some nutcrackers are tiny and some are as tall as a man.

For fresh air, I take advantage of the 1.5-mile packed dirt trail at Waterfront Park on the Wenatchee River, easily accessible in my power chair. Right now, it’s a peaceful roll in the shade, but in the wrong weather it can get muddy. The main square is a great place to sit in the sunshine. It is also one of three areas with clean, accessible public restrooms. Across the street is Kris Kringle, a festive Christmas shop that smells like cinnamon sticks. As I wheel by a myriad of ornaments and decorations, Bing Crosby sings “White Christmas,” filling me with nostalgia. The Obertal Mall is another wheelchair-friendly shopping option.

I meet up with family at Yodelin Broth Company for lunch. We go through a back alley to enter. The food is tasty, and the view of the North Cascade Mountains is fantastic from the deck where we sit. I ask the receptionist at Icicle Village Resort about other accessible eating/shopping choices, and she tells me the first floors of most shops and restaurants in town are accessible. Icicle Village Resort, Muchen Haus, Good Mood Food and Kristall’s Restaurant also offer accessible dining. For overnight stays, Icicle Village Resort has both accessible rooms and condos. Bavarian Lodge, Enzian Inn and Posthotel provide accessible rooms.

For me, the five-hour ride is worth it to see this lovely Bavarian town. It feels like I’m in an entirely different country, right here at home.
Owning your own home is a cherished dream in the United States, but in the last decade, rising real estate prices have priced far too many potential homeowners out of the market and driven the cost of rentals sky high as well. But since 1976, one nonprofit — Habitat for Humanity — has stood consistently strong for safe, affordable homes built for people in need. Today Habitat, an ecumenical Christian nonprofit that is open to all, is the nation’s largest homebuilder. It may also be the best option for wheelchair users to own an affordable, accessible home.

The secret to Habitat’s success is simple. Approved homebuyers make a down payment with “sweat equity” — 300-500 hours of work, with help from family and friends, instead of cash. The work can be done on their own home, someone else’s, or by assisting Habitat Humanity in another way. Homeowners also reap the benefits of donations and construction help from volunteers, as well as financing by Habitat with zero percent interest. All of this adds up to unbeatable prices, the lowest possible monthly payments, and feelings of long-lasting gratefulness and connectedness with family, friends and community.

A History of Building Accessible Homes
Early awareness of the need for accessible homes came about largely as the result of Atlanta, Georgia, advocate Eleanor Smith’s groundbreaking initiative, Concrete Change, which advocated for each new home built by Habitat for Humanity to incorporate its “visitability” guidelines. These guidelines call for basic wheelchair access — a no-step entrance, wide doorways and a clear path to the bathroom.

A major breakthrough came when Smith’s group secured pledges from Habitat’s Atlanta
affiliate in 1989 and the city of Atlanta in 1992

tential applicants, the Habitat office chose


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Melvin Hardrick, a 35-year-old T5-6 para

who had been injured in 1991. His need was

obvious. Following rehab, Hardrick was

discharged to his existing home, where he,
his wife and four children lived in a high-
crime neighborhood in a cramped apartment

with an inaccessible bathroom — a

nearly impossible situation for Hardrick, a

manual wheelchair user.

Rogers and Fierman took Habitat’s basic

accessible floor plan, which included wide
doorways and more space in the bathroom,

and modified it specifically for Hardrick by

adding a sloped, graded no-step entrance, a

wraparound porch, expanded interior space

with an open floor plan, wider hallways,

accordion-style doors in the bedroom, a

roll-under sink in the bathroom with more

space, height-appropriate switches and

outlets, and more. To make it all happen,

Shepherd’s staff took on the fundraising re-

sponsibility and contributed $25,000 for the

build, which in the mid-1990s, combined

with other donated materials and volunteer

labor, funded nearly the entire project.

In 2002, Minnesota’s Twin Cities Hab-

itat affiliate teamed up with the Courage

Kenny Rehab Institute to take the con-

cept of accessibility a step further. They

built an accessible home complete with

assistive tech devices throughout for Lisa

Baron and Scott Dehn, both of whom had

cerebral palsy — proof that the national

nonprofit’s awareness and willingness to

work with individual homeowners with

disabilities was evolving.

The Twin Cities affiliate is one of the

largest in the nation, building upwards of

50 homes per year since 1985. “Each year,

we build one or two accessible homes,” says

Kaitlyn Dormer, communications director

for the affiliate. “In these cases, homebuyers

are matched to a property before construc-

tion begins so we can tailor the home design
to their needs. Our architect meets with the

homebuyers and an occupational therapist
to identify design elements to be added to

to the house to adequately provide indepen-
dence, safety and health needs.”

A Contemporary Duplex

While these pioneering Habitat homes ben-
fitted from being located in urban areas with

well-known rehabilitation and independent

living programs, the widespread growth of

the nonprofit has brought the concept of “a

hand up, not a handout” to small towns in

rural areas as well. Habitat’s model works

because it depends on the generosity of ev-

eyday people wherever they reside. Whole

communities driven by local churches usu-

ally start the ball rolling, but volunteers and

homebuyers come from every ethnicity and

belief system. Good will is infectious.
parents purchased an older home and rented it to her. “I had a helper and a roommate and lived there for seven years, but couldn’t afford repairs and maintenance on the old house. It was too expensive,” says Jaspering. “My parents were losing money and I couldn’t pay the mortgage.”

Both Cantonwine and Jaspering looked into Section 8 housing, but there was a two-year waiting list, and the rent was still too high. So together they went to the local Habitat for Humanity affiliate, not knowing what to expect. “They ran our numbers, including valuing a lot of work from our families, and a lot of contributions,” says Cantonwine. “My family knew Jaspering’s, we knew of each other and everything kind of fell into place. The executive director, Sandi Risdal, seemed very excited about the idea of our going in together to build a duplex. We were the first ones in our area to do it.”

Risdal willingly modified the usual sweat equity requirements because neither Cantonwine nor Jaspering could do construction work. “But our families did work on the build, which counted toward our sweat equity requirements,” says Cantonwine. The time from application to the actual build was about a year or so, and they moved into their duplex in late 2014.

### Unbeatable Economics of Habitat Homes

Habitat homeowners are not given a home — they must buy it. To make certain that homeowners are able to make payments consistently, Habitat requires that each applicant be able to make mortgage payments that are no more than 30 percent of their monthly income. Both Cantonwine and Jaspering had steady, part-time jobs. Cantonwine is a dispatcher who works 25 hours a week for a paratransit company, while Jaspering works for Wheatsfield Cooperative, a community-owned grocery store, doing computer work with pricing and sales.

In addition, both families had the kind of combined work experience that is especially valuable in the Habitat model. “My dad’s an electrician, and we knew a lot of people in construction, so they were able to donate labor, and others made in-kind contributions,” says Jaspering. Cantonwine’s family and other volunteers also made significant labor and in-kind contributions.

The total construction cost of Cantonwine’s duplex unit was about $155,000, counting the value of labor and contributions such as appliances, roofing, concrete and whatever went into the house, including furniture. But Cantonwine’s mortgage loan, purchased from Habitat, was only about $110,000, with a second, forgiveable mortgage over and above that amount.

“Forgiveable” means each year a portion of the second mortgage is forgiven. In Cantonwine’s case, this comes to about $45,000. As long as payments on the first mortgage are made, the second mortgage will incrementally “disappear” — and the homeowner will have paid zero dollars out of pocket on the second when the term expires. For Cantonwine, this resulted in a monthly first mortgage payment of slightly more than $600, including taxes and insurance. After four years of payments, his principal balance has already dropped nearly $20,000, to a current total owed of $91,000, and the unit’s value is now well over $155,000. Home equity builds super-fast compared to conventional loans, mainly due to volunteer labor, in-kind contributions and the zero interest factor. “Every dollar paid goes to ownership of the home,” says Cantonwine.

Jaspering’s loan was similar. Her total cost was $160,000, slightly higher than Cantonwine’s due to upgrades on flooring and a fully accessible kitchen. Her payments are $620 per month. By contrast, rent for a two-bedroom apartment in the Ames areas is at least $700. And there is no comparison when it comes to size, quality and lifestyle enhancement.

Now I have my own space,” says Jaspering. “I feel like more of a normal 40-year-old. I do my own laundry, do what I want when I want. I can have my life as an independent woman. Friends can come over, or I can meet people and go out. I like the location. I can roll to work if the weather is good. If I wanted to, I could take a bus. I’m near groceries, entertainment, a hospital. An ideal location.”

In all, hundreds of people pitched in to make the duplex happen in a way that was affordable, accessible, and appropriate to both Cantonwine’s and Jaspering’s needs. They each have a concrete parking space for a van. Cantonwine was able to have a basement built for his live-in attendant, and Jaspering got the kitchen she wanted.

“I cannot say enough about the Habitat for Humanity program,” says Cantonwine. “Globally and locally. I’m very thankful. For people to come together, whole communities, and do something so worthwhile. It’s amazing stuff.”
A Path to Independence
Tess Kessinger, 48, another C5 quad, has been a Habitat homeowner since 2017. After being injured in 2006, she rehabbed at Frazier Rehabilitation Institute in Louisville, Kentucky. She was one of the first subjects to do treadmill work as part of Susan Harkema’s epidural stimulation research. “It really helped me — muscle tone, weight, increased lung capacity,” she says. “The group I was in went on to be like a second family. Most of my meaningful relationships have come out of my meeting people at Frazier. They finally hired me in 2013 because I refused to go away.”

At first, following her injury, she had to live with her parents on their farm in Palmyra, Indiana, located just north of Louisville, in a modified living room with bathroom. “I was managing OK but didn’t want to live with my parents or in a nursing home. I always had the will to be independent but not the way.”

Then in 2015, someone told her mother that Habitat was open to building homes for disabled people. She applied to the nearest Habitat chapter in New Albany, Indiana, and was accepted.

“For my sweat equity I contacted restaurants and helped set up food for catered fundraising events, and food, snacks and soft drinks for the builders,” says Kessinger. “The University of Louisville and Frazier staff put groups together to help volunteers on my build. I had eight or 10 build dates with different volunteer groups. My dad did over 300 hours of sweat equity. He’s a licensed electrician, but he and two or three others were the core group swinging hammers and doing whatever had to be done.”

The state vocational rehabilitation department also helped with certain necessities. “I love my shower, my favorite room, all tile,” she says. “Voc Rehab suggested a certain fan. It sucks all the moisture out of the bathroom.” And then there’s a feature straight out of her farm background — sliding barn doors. “I have barn doors on all of the rooms. Track doors. They are super light. Even the dog knows how to use them. She will use her nose to open the door and come into the bathroom.”

The open floor plan is inviting, especially for a power chair user. “When you come in the front door, you can see the door on the other side of the house. No walls to get in the way of having multiple visitors over. To accommodate my van lift, they gave me an oversized lot with a large carport,” she says.

Kessinger’s mortgage payments for all this are just $497 a month. They are so low because they’re spread out over a 40-year mortgage at zero percent interest. “I would never be able to rent even a small apartment for $500.”

All in all, Kessinger is approaching her dream of complete independence. Now all she needs is for the state of Indiana to provide adequate attendant care. “I thought it would be easier — there are 47 state licensed homecare agencies, but only seven with skilled nursing and only one could take me, and they require me to have full-time care, which I don’t need and they can’t fill,” she says. “It would cost the state less if I had part-time attendants, but when I talk to the Medicaid people, they just say we feel for you.”

For now, to get by, her mom stays with her two nights per week, and on weekends she goes home to the family farm. But the upside prevails: “I feel like I’m more part of a community now,” she says. “People come to help from down the street. You don’t always get that out on a farm.”
GIRDLESTONE SURGERY FOR HIP COMPLICATIONS

Q. I'm 35, in my 15th year as a T8 paraplegic, and I've been having severe spasticity in my right leg for at least six months. It feels as if my sitting posture has become crooked. A set of X-rays show that my hip is chronically dislocated. My doctor recommended I see an orthopedist about getting a Girdlestone procedure, where they cut the ball and neck off my thigh bone. I'm confused and a bit scared. If I do a Girdlestone procedure, how much of the femur do they take off? If I have it done, will my hip be stable? Will I be able to use my standing frame?

— James

You raise important questions, James. The procedure is named for British surgeon Gathorne Girdlestone, who first performed it as a lifesaving measure in 1928 to remove hips that had become diseased by tuberculosis. It evolved into a last-ditch operation to combat a variety of severe complications of the hip, from non-healing fractures, to chronic dislocations and non-healing infections. A typical Girdlestone involves removing the ball and neck of the femur.

Different Conditions Call for Different Procedures

Different conditions dictate how a Girdlestone should be performed and how much bone will need to be removed, says Dr. Douglas Garland, a retired orthopedic surgeon and former director of neurotrauma at Rancho Los Amigos Rehab Center. "Ideally, if you are going to do a Girdlestone, you want to keep your trochanter [top of the femur] intact. The bone is surrounded by a huge muscle that is intrinsically attached to the pelvis. The muscle provides a cushion for the trochanter as it butts up against the wing of the ilium [pelvis] and gives the leg stability when sitting in a wheelchair," he says.

Garland says the easiest Girdlestone to perform is for a non-healing hip fracture. "Just take out the broken ball from the socket and resect the femur neck," he says.

Ask your orthopedist if a prosthetic is an option, he adds, since there have been major advances in prosthetic hips for people with SCI, and fewer Girdlestones are being done for acute, non-healing fractures (see resources).

If a Girdlestone is needed for a dislocated hip, it usually requires removing the same amount of bone as surgery for a non-healing hip fracture does, says Garland. He adds that in many cases with a dislocated hip, it is best to take it slow and see what happens, because doing a Girdlestone in a hip that has dislocated because of spasticity will likely make things worse. You will still have the spasticity, but now the spasticity will pull the end of the femur up into the wing of the ilium. By waiting, the body will over time often create its own Girdlestone as the ball of the femur, which is soft, rubs against the ilium and gets absorbed by the body. This is an option if the dislocation isn't causing complications like pressure, skin issues or pain. He adds that kids with cerebral palsy frequently develop dislocated hips, but don't undergo Girdlestone procedures. They leave them in place and do fine.

In cases of osteomyelitis, the surgeon needs to remove bone from the femur past the point of infection, says Garland. Dunn adds that because osteomyelitis is generally caused by a pressure ulcer,
Girdlestone surgery is done in conjunction with a flap. Some plastic surgeons do the entire procedure themselves, and others work with an orthopedic surgeon to make sure incisions are done to spare soft tissues for the flap.

If the Girdlestone is being done for heterotopic ossification — a condition where bone forms in soft tissue — it is important to find an orthopedist who has a lot of experience in managing HO, says Garland. As in Girdlestone surgery for osteomyelitis, femur bone is removed past the area of HO. For both osteomyelitis and HO, the surgeon must transfer the largest quadriceps muscle, called the vastus lateralis, and wrap it around the end of the femur to give the hip some stability. In the case of HO, the muscle wrap also helps prevent recurrence of HO.

A properly done Girdlestone should result in a stable hip when sitting in a chair. The femur will be an inch or two shorter, depending on how much bone needs to be resected. Unfortunately, a Girdlestone will not support standing in a standing frame or standing chair.

"Following the surgery, it is important to get a post-op seating eval because it is common for a Girdlestone to cause the pelvis to tilt to one side. This will put more pressure on the ischium on the Girdlestone side," says Dunn. "This is why a seating specialist should also be part of your team when undergoing this procedure — it is common to need specialized or custom wheelchair seating after surgery."

A Personal Example
I am a T10 para and I had a Girdlestone done on my right leg in 2000. Following surgery for a broken hip, four stabilization screws eventually pulled apart. The Girdlestone left the top of my femur intact — it was major surgery, yet by the following day, I was able to transfer into my chair gingerly and go home, where I was able to perform my own care. I had a big incision and an extremely swollen leg for weeks. It took about a week before I felt up to being in my chair all day, and several weeks for my incision to heal enough to get the staples out and be able to bathe. Two and a half months later, I was back to my normal activities, including off-road handcycling and swimming.

My right femur is about 1-2 inches shorter than the other, barely noticeable. My right leg feels as solid as my left when I’m in my chair. The leg has full range of motion and hasn’t caused a problem, except when doing activities that put a lot of push-pull motion on the hip — for me, that means paddling a kayak. If I decide to pursue sea kayaking, I will add a quick release belt to hold my hips.

Although the Girdlestone has served me well, these days I would likely be a candidate for an artificial hip, which wasn’t an option for people with SCI until the last few years.

Resources
- “Para/Medic: Heterotopic Ossification,” newmobility.com/2018/06/heterotopic-ossification
- “Para/Medic: Fracture Risk and Treatment Options with SCI,” newmobility.com/2016/04/fracture-risk-treatment-options-sci

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“Hey! What’re you eating?” I ask.

When you’re out on a leashless walk with your favorite dog, it’s always good to monitor what she eats, drinks, rolls in or steps on. Foreign, messy or stinky things found by Ginger on our adventures have a way of coming back to haunt me later if left unchecked.

Ginger walks to a bush, reaches under some low branches and pulls backward. What the ...? She turns around chewing something, looking for approval. Well I’ll be darned, she’s found some edible berries and taken to picking her own.

“Good girl, go ahead,” I say, as she continues walking down the row picking and eating.

In our area, Saskatoon berries are quite common. The berries turn deep blue in late July and early August, looking similar to blueberries. Some years there are very few, and they are hardly worth picking. This year, the bushes are hanging heavy with them!

Being a quadriplegic, there are a few things in this world that I’m just not very good at. Take chopsticks for instance. They are great for my waistline, but for caloric intake, there are just more efficient ways for me to ingest rice. Another “for instance” would be sewing. Needles and I don’t see eye to eye. And my hands seem to develop more leakage than necessary after such encounters. Berry picking also falls into this category.

In the past, I have tried the traditional use-your-hands method. Without fingers that work, this proved to be less than efficient. I ended up with broken and squished berries all over. My hands were stained blue. My shirt was stained blue. My face was stained blue. My dog’s back was stained blue from petting. You get the idea.

I was hoping to find a way to get in on this berry-picking thing, but so far Ginger has out-produced me by about 20 to one. I even tried Ginger’s direct method of eating from the branch. I wheeled right into the bush, grabbed a branch in my teeth and wheeled backward. It seems a dog’s physiology must differ from a human’s in the mouth area, as she enjoyed a clean mouthful of berries, but I ended up with leaves, bark, spiders and other icky bugs, plus a few berries.

I needed a solution, and trusty Google was game to help. A quick search on berry pickers produced lots of units for sale with “fingers” that strip the berries off of bushes. If I was to believe the rave reviews, I would have to buy a new freezer to accommodate all of the berries I would come home with. The problem is, with three-week shipping to our area, the harvest would be finished before I could start!

About this time, my uncle calls. “Any Saskatoons at your place?”

“Yes,” I reply. “The dog has been eating them. There are lots there, come and get ‘em!”
“Thanks! Be right out!”

A little while later he pulls up to the bushes. Ginger and I head over to visit, and I see he already has an ice cream pail full!

“How did you do that so fast?” I ask.

“Look at this,” he says, pulling out a berry picker — the same one I saw online.

I ask him where he got it and he says at the hardware store for five bucks.

“Here, you can have it, I’ve got enough berries already,” he says as he pulls away.

I wheel up to the bush and try the picker. My hands still don’t hold it well. So, like anything new, there is some trial and error. I try pulling the picker upright. The fingers catch a branch and I promptly drop the device on the ground.

“Oh shit,” I say. The picker might as well be on the moon. I’m thinking that my picking is done, but then Ginger prances over and stands over it. I guess one good thing about training your own dog is that she responds to your customized commands. Apparently cursing means “Dad dropped something … again.”

I laugh. “Would you pick it up please?”

Ginger sets the picker in my lap and returns to her berry picking. I’m back in business!

A new strategy is in order. I hold the picker with two hands as safely as possible, and gently rake the underside of a branch. Slowly peering inside, I’m pleasantly surprised … there are berries there! I rake a few more branches and feel the picker getting heavy. It’s working, there’s actual production! I turn back home to get a pail — this is gonna be fun! Soon I’m back raking the branches. I have a pail full in no time. Ginger has even quit picking her own and is looking for handouts.

“You didn’t share yours very well,” I say, “but then I guess you did save me when I dropped this thing.”

I pour a scoop on the ground and she readily gobbles it.

Berry picking has since become another season to look forward to. Now I watch closely to see if it is going to be a good one or not. I had never really considered it as a hobby before!

Frequently Asked Questions

What are Saskatoons?
They are a species of serviceberry that grow on bushes in clusters like grapes, only smaller. They grow wild in our area, but are also planted.

What are they good for?
The berries are great for jams, pies, ice cream syrup, and some people make wine out them. Because the juice is dark blue or purple, it is said to be full of antioxidants. I love them alone or sprinkled on cereal, and they make great raisins in a dehydrator. The bushes make a perfect hedge. They produce suckers and spread well, which is good if you want them to spread. Coyotes love to eat them, and then bushes sprout from their scat.

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I often hear people who are outside of the white, straight, uncrippled male demographic complain about how, when they were kids, they rarely saw characters that looked like them in movies and on TV shows. That sure was the case when I was a kid. Watch reruns of those nostalgia TV shows like Andy Griffith and the like, and you’ll see what I mean. They are so blazing white that binge-watching may well burn your retinas. And there sure as hell weren’t any cripples in Mayberry — not even begging on street corners.

I hear these same people say they really wish they had seen a lot more characters that looked like them in movies and on TV shows. They say this would have made them feel better about themselves. But not me. The only characters who looked like me in movies were Tiny Tim and bitter old Potter from It's a Wonderful Life, and the only cripples on TV were telethon poster children. I wanted to see a whole lot less of them. That would have made me feel better about myself.

Apparently, things aren’t much better all these years later, at least not in the movies. The Annenberg School for Communication and Journalism at the University of Southern California has a project called the Annenberg Inclusion Initiative. Every year they watch the 100 most popular movies of the previous year and make note of the number of characters in these movies that are outside the white, straight, uncrippled male demographic. The report recently issued about last year’s most popular movies says that only 2.5 percent of the 4,454 characters with speaking roles reviewed were crippled. That’s down from 2.7 percent in 2016. Forty-one films in 2017 did not feature a single speaking character who was crippled, and 78 movies did not include any female crippled characters. Only 14 movies featured a crippled character that was a lead or co-lead at any point in the film. And most of the crippled characters that did appear in these movies were otherwise straight, white and male.

Even when I do see crippled characters in movies and on TV shows, they still don’t look anything like me. I imagine it’s because these crippled characters aren’t likely to be played by real cripples. Suppose, for some bizarre reason, some big-time Hollywood director wants to make a movie about me. Who’s going to play the leading role? You know damn well it isn’t going to be a cripple who looks anything like me. It’s probably not going to be a cripple at all. It’s probably going to be somebody like Tom Cruise.

Now to try to prevent something like that from happening, I could insist that the actor who plays me has to look as authentically crippled as I do. The big-time director would say, “No problem,” and then do like they did in the movie Forrest Gump. The character Lieutenant Dan became a double leg amputee — so they cast Gary Sinise in that role and chopped his legs off using special effects.

The big-time director would probably special effects the hell out of Tom Cruise until he looked as authentically crippled as I do. That amount of special effects is the equivalent of a million dollars of plastic surgery. Or maybe they’d film Tom Cruise through a circus mirror lens that’d make him look like he has a quad belly. Tom Cruise might not win the Oscar for best actor, but the movie will surely win a special effects Oscar for pulling off the amazing feat of making Tom Cruise look like me.

If they’d done this last year, that would have brought the number of movies featuring white, straight crippled male characters playing the lead or co-lead up to 15, a whopping .34 percent of the 4,454 characters with speaking parts. And Tom would have won that Oscar.
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CLASSIFIEDS

DECEMBER 2018
HAPPY HOLIDAYS!
We asked you to show us your merry ways. Thanks for sharing, and best wishes for a wonderful New Year from New Mobility!

Clockwise from top left, photos were submitted by NM readers Jenna Hammerly, Bonnie Malcolm, Jessika Kattah and Reinaldo Maiz, Jack Spencer, Kristie Lent, Tammy Cameron Stay and Raul Martinez. In the middle of the “clock”: NM superfan Tom Turner and his sister, Laura.

PLEASE REMAIN SEATED

EXCUSE ME, CAN I JUST SAY THAT YOU ARE AN INSPIRATION.
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