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Now that so many people have access to smart phones with decent cameras built in, the art of photography is approachable as never before. SETH MCBRIDE talks with four quadriplegic photographers about how they got started, what equipment they graduated to, and which adaptations and tricks of the trade work for them.

Cover photo by Robert Andy Coombs
Contents Photo Courtesy of Kirk Williams
By now all the hoopla about the total solar eclipse is over and you are ready to hear the truth of what really happened that day.

My wife and I drove east through the Columbia Gorge at 3 a.m. to get to Biggs, Oregon, a tiny community of 50 people on a vast stretch of desert. We looked to the mountains 70 miles to the west. About 2,000 people were already waiting with us among a sea of vehicles. As the moon completely covered the face of the sun, a massive black shadow raced across the desert at 2400 mph and engulfed us in total blackness for a little more than two minutes. Who could ever forget that day: February 26, 1979.

That’s right, 1979. That’s when the real total eclipse happened. The one that was expected to occur on August 21, 2017, never actually happened. Maybe it was because I slept through it, or maybe it was because 38 years had passed since the real eclipse had happened and my attention span had shrunk to a few seconds in the interim. Maybe I just missed it.

The 2017 eclipse was a product of the internet, a virtual event, unreal. But the one in 1979 was undeniably real. When blackness arrived in Biggs, Oregon, a tiny community of 50 people on a vast stretch of desert. We looked to the mountains 70 miles to the west. About 2,000 people were already waiting with us among a sea of vehicles. As the moon completely covered the face of the sun, a massive black shadow raced across the desert at 2400 mph and engulfed us in total blackness for a little more than two minutes. Who could ever forget that day: February 26, 1979.

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The 2017 eclipse was a product of the internet, a virtual event, unreal. But the one in 1979 was undeniably real. When blackness arrived in Biggs, it covered everyone, including me, the only person in a wheelchair. I was often the only person in a wheelchair wherever I went in 1979. It was a different world then. There were no personal computers, no buses with lifts, no accessible bathrooms, no smart phones, no Twitter and no legalized pot. A McDonald’s burger cost 43 cents, gas had just skyrocketed from 65 cents/gallon to 88 cents/gallon and ADAPT was four years from mounting its national campaign to make public transportation accessible. When the path of totality cast its blackness over the desert for a couple of minutes, everyone was invisible and inconsequential, not just me.

It felt good being on equal footing with the rest of society for those two minutes. For a moment in time, the sun’s corona held sway over every soul, and life itself was reduced to its bare essentials: sun, moon, earth. No need to fight for the right to keep healthcare in place. No worrying about global warming, rampant racism or nuclear war. No one trying to take away our civil rights or convince us we would be better off dead.

In the darkness, though, a light was just beginning to shine. We first saw glimpses of it two years prior to Biggs when hundreds of courageous people with all kinds of disabilities gathered in San Francisco to occupy the Health, Education and Welfare federal building — to protest the government’s failure to fund the Rehabilitation Act of 1973. That bold civil rights protest was the forerunner of the ADA and arguably the true beginning of the disability rights movement as a vital force.

Just like the total eclipse of 1979, it will always be undeniably real — our corona of light shining in the darkness.

— Tim Gilmer
Linda Mastandrea is a Chicago-based disability law attorney, consultant and speaker on emergency management and preparedness issues relating to the disability community. The two-time Paralympian won 15 gold and five silver medals during her wheelchair track career. She is also a frequent New Mobility contributor, blogger at FiftyPhilosophy (where she talks about life from the perspective of a 50-something woman), and dancer. She’s currently working on a novel that deals with the impacts of an Alzheimer’s diagnosis on a tight-knit Italian-American family.

A sports-related accident left Loren Worthington a C5-6 quad 30 years ago. He is currently the marketing and communications manager at Ability360 in Phoenix, Arizona and also the publisher of LivAbility Magazine, which promotes independent living in Arizona. As a commercial and sports photographer, he recently photographed the 2016 Paralympics in Rio de Janeiro, Brazil, and is a frequent New Mobility contributor as well, having shot four covers for the magazine. He has been married for the past three years. In his off time he enjoys camping, exploring, and riding his off-road handcycle.

Luke Easterwood writes and designs experiences that make digital interactions feel and sound more human at tech companies in Silicon Valley. Privately, he enjoys creative writing, especially poetry, and dreams of one day writing a novel. Luke has been a T5-6 complete para since a 2008 motorcycle accident. He did both his inpatient and outpatient rehabilitation and therapy at Shepherd Center in Atlanta. In his free time he reads and enjoys playing video games.

David Heard is the membership/circulation coordinator for United Spinal Association and also a member of the organization’s spinal cord injury resource center team. As a database manager, he specializes in coordinating information for and about United Spinal’s hospital member program. He also researched the need for and is the sole plaintiff of the current lawsuit aimed at making the Statue of Liberty ferry accessible [see News, page 8]. He has been a C4-5 quad for more than 20 years and lives in Queens.
Remodeling Success
You can’t go wrong with tile [in the bathroom remodel], so that was a great investment. I’m so glad it turned out so well (“Finally, A Roll-In Shower,” July 2017).
Rebecca Edmonson Brown
Via newmobility.com

About Pocket Doors
I tried pocket doors, high quality ones with solid core doors, and eventually took them out. They were good when open for not taking up space, but even when closed, had zero ability to stop sound transmission, which is not what the rest of your family wants on your bathroom door.
Jeff Eddy
Via newmobility.com

Editor: The author, architect Charles Schwab, addresses this issue: “The pocket created can be an echo chamber. I specify the wall board around it to be built with fiber-reinforced Glass-Mat board that is cellulose free and more solid to block sound.”

Omission?
There is a key omission from this discussion relevant to SCI — bladder cancer from long-term use of an indwelling catheter, and/or chronic inflammation from UTI and stones (“Important, But Often Overlooked Cancer Screenings,” ParaMedic, July 2017). People who have used an indwelling catheter for 10 years or more should discuss screening for bladder cancer with their urologists, e.g., cystoscopy and/or urine cytology.

Bloody urine or pain/urgency that doesn’t resolve with culture-directed antibiotics would be very worrisome, and should prompt an additional clinic visit or urology referral ASAP. See here for technical details: www.nature.com/sci/journal/v51/n7/full/sc201333a.html
Edward Nieshoff
Via newmobility.com

Editor: See NM’s coverage of bladder cancer in our August 2016 issue (“What You Need to Know About Bladder Cancer and SCI”).

Cancer Screenings
My mother, who was an elderly obese woman, had severe paresis from the multiple operations she had for arthritis in her lower back. She was not examined because of the difficulty getting her on a table in her doctor’s office. She was left in her chair during the visits to her doctors. She was finally diagnosed with cancer, but they got it wrong. Instead of stage 3 cancer, it was more likely 1A! She was not properly watched after her operation. Sadly, I feel she was neglected. She was found unresponsive with blood pressure of only 60 systolic. She never recovered. They tried, but she was essentially found dead. … At least her misery was relieved.
Michael Langley
Via newmobility.com

Too Few Know About T4
Great article [Ervin: “First They Came for the Cripples,” July 2017]. Too few people know about T4 and how it was Hitler’s beta version of the Holocaust or that most of the “scientists” involved went unpunished and, in fact, in many cases went on to have successful academic and professional careers. To learn more visit: www.ushmm.org/exhibition/deadly-medicine/overview/. Oh, and I might add, first they came for our Medicaid …
Kevin Siek
Via newmobility.com

Women in Holocaust
Thanks for this article [“First They Came for the Cripples”]. I do cemetery research and am currently working on those who passed through Ravensbruck [Nazi concentration camp for women]. For many it was only a stopping place on the way to one of the euthanasia hospitals. The Nazis had six where they used carbon monoxide. Some of the hospitals were “insane” asylums, so they and the disabled went first.
Robert Peurifoy
Via newmobility.com

What History Omits
One of the interesting things about [Martin Niemöller’s] quote [“First They Came for the Cripples”] is that the way we remember it is actually a bastardization — because he used it often, and often changed the groups of people included, depending on his audience, and he didn’t always leave out disability. Disability is left out in how history remembers the quote because people want it to be a static concrete statement, but it wasn’t. I think that is far more telling than who came first, but rather, who history lets us forget.
Kim Sauder
Via newmobility.com

Single-Payer Cost Not a Problem
Chris Reardon has hit the nail on the head [“On Healthcare,” July 21 blog]: “If everyone joins into the single-payer pool — young and old, healthy and sick — the expensive people like me will be set off by the cheaper, healthier people. And trust me, there is a gargantuan number of healthy people compared to the number of chronically ill people like me. America has one of the largest populations — the cost of single-payer is not a problem.”
Mary Ann Barton
Via newmobility.com

Accessible Stall Competition
My experience is that while I often wait for the accessible stall, rarely is it being used by a parent and child (“Competing with Kids for the Accessible Stall,” July 13 blog). Most often it’s someone without an apparent disability changing or just enjoying the larger space. And of course, it’s maddening when I have to wait for the one stall I can use, multiple regular stalls sit empty, and the person sashaying out of the accessible stall 15 minutes later eyeballs as 100 percent nondisabled.
Bliss Temple
Via newmobility.com
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Statue of Liberty Cruise Lawsuit Moves Forward

On June 28, United Spinal Association announced a New York District Court decision that will permit David Heard, a power wheelchair user and member of United Spinal, to continue to pursue legal action against Statue Cruises, LLC, for allegedly discriminating against him on the basis of his disability in violation of the Americans with Disabilities Act, as well as the New York State Human Rights Law and the New York City Human Rights Law.

The decision, issued by New York Judge Andrew L. Carter, Jr., on June 26, denied Statue Cruises’ motion to dismiss Heard’s complaint.

Statue Cruises’ parent company, Hornblower, which has contracted to run the city’s five-borough ferry service, claimed that there was insufficient evidence to demonstrate its ferry boat service to the Statue of Liberty and Ellis Island violated the law or discriminated against Heard.

“The court’s decision to deny dismissal of this case is a huge victory for our members and all people with disabilities who struggle to access New York City’s numerous historical landmarks, including the Statue of Liberty,” said James Weisman, United Spinal’s president and CEO. New Mobility is United Spinal’s membership magazine.

“Such a powerful symbol of our country’s independence should be accessible to everyone,” said Weisman.

In December 2015, Heard, who lives in Jackson Heights, New York, and was spinal cord injured in a 1993 diving accident, purchased a round-trip ferry ticket from Battery Park in Manhattan to the Statue of Liberty. Over the course of the day Heard rode on three different Statue Cruises ferries using his 350-pound power wheelchair.

In his initial complaint Heard alleged that due to his disability and use of a wheelchair, when he first attempted to board, the gangplank was not wide enough and too steep to accommodate his wheelchair. He was then singled out by Statue Cruises employees for boarding while other ferry passengers watched, causing him embarrassment and humiliation. Statue Cruises employees then allegedly placed additional gangplanks to allow Heard to board. Heard contended they were unstable to support his wheelchair, putting him in a dangerous situation. Heard also noted that there was also

North American SCI Consortium to Meet for First Time

This fall the North American Spinal Cord Injury Consortium will hold its first meeting in hopes of establishing a unified voice regarding ongoing issues within the spinal cord injury community.

NASCIC was founded by 15 prominent spinal cord injury organizations in the U.S. and Canada — including the United Spinal Association Research Committee, the Canadian and American Spinal Research Organization and the Rick Hansen Institute — with the goal of providing a platform for shared goals within the community.

“We’re trying to bring together the stakeholder organizations that represent the voice of people with spinal cord injury, and we really see this as an opportunity to amplify their voices and pull them together around shared values, shared projects and shared concerns,” says Megan Moynahan, executive director of the Institute for Functional Restoration, one of the founding member organizations.

The consortium was organized by Kim Anderson-Erisman, director of education for The Miami Project to Cure Paralysis, and Jennifer French, executive director of the Neurotech Network, a nonprofit dedicated to neurotechnology, following Praxis Conference, an SCI research conference hosted by the Rick Hansen Institute in Vancouver, British Columbia, in April 2016. It was modeled after the European SCI Federation, which is made up of several individual member organizations run by people with spinal cord injuries and is focused on changing clinical care for spinal cord injury in Europe.

The plan for the consortium is to meet on at least an annual basis to put aside their individual organizational agendas in favor of working on projects in the collective interest of the SCI community: first, connecting the SCI community to clinical trials and other ongoing research, before moving on to other projects including cure versus care, independent living and employment, to name a few.

The first meeting will be held October 12, 2017, at the Miami Airport Hilton in Miami and will focus on setting up governance and membership structures as well as beginning to identify potential projects.
no place to secure his wheelchair as the ferry sailed through the choppy waters of New York Harbor.

Heard stated that he faced the same obstacles while attempting to disembark the ferry, claiming that Statue Cruises employees who attempted to help him, accidentally turned off the power to his wheelchair on two occasions.

Heard also claimed the ferry rest rooms were inaccessible and that he ultimately felt deterred from subsequently visiting the Statue of Liberty and Ellis Island as a result of the ferry’s inaccessibility.

Last year, in response to Heard’s complaint and those of other members, United Spinal Association submitted a letter to the National Park Service, which had given Statue Cruises a 10-year contract to operate ferry services in 2008, calling the accommodations “dangerous and inaccessible,” noting the “unlawful” slope of gangplanks, unstable platform pieces and inaccessible rest rooms.

In an attempt to remedy Heard’s complaints, Statue Cruises designed and implemented a new “plate wedge” with handrails, and agreed to provide its employees with further ADA training.

According to United Spinal and Heard, although Statue Cruises has identified certain remedial measures taken, it does not assert that these measures render it ADA compliant or that the alleged violations — if actually-remedied — will not recur.

United Spinal also notes that Statue Cruises entirely failed to address one of the plaintiff’s allegations — the lack of wheelchair-accessible bathrooms — asserting that the bathrooms were wheelchair-accessible already.

“We simply want to ensure wheelchair users along with their families can access and enjoy all the city has to offer. One day this will be a reality, thanks in part to members like David who are willing to bring attention to the issue,” said Weisman.

**Uber’s Big Apple Fleet Could Be 25 Percent Accessible by 2021**

It may get a lot easier to secure an Uber ride in the Big Apple if a July 12 policy proposed by New York City’s Taxi and Limousine Commission goes through. The proposed accessibility rules, which are to be reviewed at a public hearing in September, would require all for-hire vehicles to dispatch a certain percentage of their rides in accessible vehicles regardless of whether the ride request is coming from a person with a disability.

“In a demand-based system, low public demand would result in accessible vehicles basically sitting against the wall awaiting use, and as a result they would be less well-maintained, so that even when they are needed, they won’t necessarily be road-ready. Our approach keeps them in constant circulation, and always ready to roll,” says Allan Fromberg, deputy commissioner of public affairs for the New York City Taxi and Limousine Commission, which owns and operates nearly 2,000 accessible vehicles in the city.

The proposed plan will see the percentage of rides that must be accepted by accessible vehicles increase by 5 percent over the next four years, starting at 10 percent in 2018 and increasing in 5 percent increments until arriving at 25 percent in 2021.

“We think it’s a good step, but we’re obviously looking closely at the proposal to see if there are ways of making it stronger,” says Joseph Rappaport, executive director of the Brooklyn Center for Independence of the Disabled, one of the plaintiffs in a July 18 class action accessibility lawsuit filed against Uber by Disability Rights Advocates. “Uber and other transportation providers have really made it their business not to provide accessible transportation, and we think that the TLC has finally done a good job to prevent this kind of discrimination.”
“I didn’t know there was a real possibility of a real recovery after paralysis.”

From Football to Rehab to Walking

“I was always an athlete,” says Erin Saari, 33, a former member of the Halifax Xplosion, a female football team in Nova Scotia, Canada. “I’ve been playing sports since I was just a young pup.” But in August 2016 Saari’s athletic lifestyle was put on hold when she broke her neck after a dive into a pool. “I immediately knew something was terribly wrong. I was conscious and tried to stand up, but I couldn’t move my legs.”

Fortunately, her partner, Chris, was there. “When I awoke Chris was asking me if I could move or feel anything. I had sensation in most areas, but no movement. I knew I was paralyzed.” Saari was diagnosed with a C4 incomplete injury at the Nova Scotia Rehabilitation Centre. “In the first two weeks after my injury,” she says, “I was unsure of what to think. I didn’t know there was a possibility of a real recovery after paralysis.”

But like many with incomplete injuries, she began to see return below her level of injury rather soon. “After the first subtle movement of my left thigh (28 days post-injury) I thought and said out loud, ‘I got this!’” Saari’s therapists began to put her through intense rehab. “We did lots of standing as soon as I was able to, and we also did cardiovascular training to get my heart pumping like it used to. I also began using the body weight-supported treadmill to start walking again. We’re currently working on walking up and down stairs, balance and we’re tracking how far I can walk.”

With her ultimate goal of using a cane on a daily basis, not a wheelchair, she knows how lucky she really is. “I believe that I will be walking consistently throughout the day at some point, but I know that it will take a lot of time, and if I don’t get there, I know that I have tried my best, and it will have nothing to do with a lack of determination and will.”

Adaptive Sailing Gets a Joystick Upgrade

Splashelec is aiming to transform the world of adaptive sailing with its multiple-joysticks steering system. It’s configurable, so one joystick can control direction and the other operates steering with the sails and rudder. Some sailors opt for three joysticks, separating the steering components, and if you cannot use a joystick, control buttons can be used instead.

Made in France, this controller implements a “CAN interface” electronic card that gives you feedback from the boat in the form of pressure on your hand as if you were steering the boat directly. For pricing and more ways to automate your adaptive sailing experience, please visit splashelec.com.

Finally, an Accessible Tiny Home

For those interested in joining the tiny house craze, a wheelchair accessible tiny home that includes a roll-in shower option (installed on the front porch), large doorways and a bump-out kitchen is available from Hobbitat. At 455 square feet, the Blue Sky model is larger than most of their models, which cost between $45,000-$100,000, depending on options and finish. Check it out at hobbitatspaces.com/product/tiny-house-plan-3-blue-sky.
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INDUSTRY MAINSTAY
Rick Hayden

When Rick Hayden started at Everest & Jennings in 1987, it was the leading manufacturer in the rehab industry. A lot has changed since then and Hayden has been on the front lines ever since.

Behind the Smile

If you’ve had any association with the wheelchair industry, the medical industry or pretty much done anything at all related to rehab, chances are you’ve probably seen the Smile. The Smile in question is the ear-to-ear grin that splashes across Rick Hayden’s face with enough frequency to make even the Cheshire Cat and the Joker jealous. Over his 30-year career in the medical and rehab fields, one of the few constants has been the Smile. The quintessential extrovert, Hayden has no qualms about breaking out the Smile. He has used it to find success working on the manufacturer side, the dealer side, the hospital side, in marketing, in training, as a consultant, and of course, as a mentor and friend for many in and around the disability world.

Hayden, 62, joined our community in 1976 when he was paralyzed in a motorcycle accident on the heels of his 21st birthday. But he didn’t start to work in the wheelchair industry until 11 years later. After a year struggling to make ends meet as a teacher and coach, followed by a short stint with a life insurance company, he left Massachusetts for a job with rehab giant Everest & Jennings in California. The new locale and the new job both agreed with him. “I had spent 11 winters on the east coast and proven to myself I could handle them,” he says. “So when the opportunity arose, I jumped on it. The rest is history … I’m not going back.”

Hayden handled marketing for E&J for four years before taking a position in prosthetics with the Long Beach VA. When the chief of prosthetics unexpectedly left, Hayden found himself the acting assistant chief of prosthetics at one of the country’s larger VAs. “That led to an intense two years, managing a huge budget and a lot of people, so I certainly got my management experience,” says Hayden. But early mornings and long days took their toll and Hayden soon left, returning to the wheelchair

ADVICE FOR PEOPLE WITH NEW INJURIES:
Find a good urologist and a good physiatrist who have lots of experience with SCI. Those are the two docs that are going to keep you healthy and living your life.

BEST PLACE TO LIVE:
Southern California is wheelchair heaven. I know I never have to worry about inclement weather or if where I’m going is accessible.
industry with Medical Composite Technology, a new company making carbon fiber chairs.

That company was purchased by E&J, bringing Hayden back where he started. After that, he went on to start his own consulting firm, The Hayden Group, and later to work the dealer side of the business for a contract rehab company in Palm Springs. In 2008 he went to work for Colours and later, Max Mobility. Today, when he is not overseeing the Southern California Chapter of United Spinal, which he founded, he is consulting and serving as an advocate for Cure Medical, representing the company at trade shows and other events.

Just as everyone has seen his famed smile, he has been around long enough to have seen pretty much everyone and everything. “I’ve been so lucky to work in this industry,” he says. “Aside from never having to buy a chair or a cushion, I’ve had a chance to meet a lot of interesting people and become friends with even more.”

CHAIR CHAT

State of the Art

What does Hayden think about the current state of wheelchair technology? We asked him.

“It’s great that there are all of these new power chairs today that can maneuver stairs and stand and such, but they’re generally so big and bulky and they don’t do the normal everyday stuff as well. It’d be nice to see something more streamlined that does all the normal stuff and the cool stuff.

On the flip side, manual chairs have really come a long way and it has been rewarding to watch them improve. Going from the heavier folding chairs we used to have, to the lighter rigid frames of today has made a huge difference. Quads can push better and break down their own chairs, and we paras have less wear and tear on our shoulders.”

WHY I JOINED UNITED SPINAL: Before I founded the Southern California chapter, and before I became the Western Regional Coordinator, I joined because I wanted to help lead people along the right path and lessen some of their pain as they live their lives post-injury.
fell in love with Taos and Santa Fe when I first visited my brother in New Mexico in the mid-1990s. He moved to Taos on a whim and never looked back, and with each successive visit, I understand exactly why. Though I’ve remained firmly physically ensconced in Chicago, my heart belongs to Taos and Santa Fe.

The confluence of Spanish and Mexican history, architecture and food have come together to create something uniquely New Mexico. The stunning Sangre de Cristos, the piñon scented air, and the abundance of adobe construction remind me that I’m not in Kansas (OK, Chicago!) anymore. Green chile tops everything — and endless sunshine, blue skies, men wearing cowboy hats alongside women in jeans, tank tops and hiking boots without a business suit or sheath dress in sight. The stress just melts away.

True, both cities have their challenges when it comes to accessibility, but much has been done right to enable a wheelchair user to have a great visit. Join me, won’t you?

**TAOS PLAZA AND TAOS PUÉBLO**

Taos Plaza began as a Spanish fortified walled plaza in the late 18th century to keep out armed invaders. It was the central meeting place in the Taos Valley for socializing, trading, and community events. Today a ring of shops surrounds a park, anchored by the Hotel La Fonda de Taos. Shops feature Northern New Mexico goods like leather, pottery, jewelry and artwork. Curb cuts surround the plaza and ramps serve various levels, but take care, some of the ramps are pretty steep.

From May to the end of October on Saturdays the plaza comes alive with the local farmers market. Dozens of vendors sell local produce, flowers, prepared foods, fabulous breads, gelato in flavors like watermelon or milk and honey, and wonderful face creams and lip balms made with local herbs and flowers. Try a delicious breakfast burrito filled with eggs, potatoes and green chiles while you browse.

The rich history of Taos is everywhere. Thanks to the Spanish heritage of the region, Catholicism has an equal place alongside the Native American spiritual traditions, and a key piece of Catholic history is Our Lady of Guadalupe Church (Nuestra Señora de Guadalupe), just west of Taos Plaza. Built between 1801 and 1802 as a Franciscan Mission of San Geronimo parish at the Taos Pueblo, it has since been rebuilt and is still an active church with daily masses in English and Spanish.

Next, visit the Kit Carson House and Museum. Designated a National Historic Landmark in 1963, it is now a museum dedicated to Carson’s life and contributions to New Mexican culture. Built in 1825, the museum served as Carson’s home from 1843 until his death 25 years later. Today, the four-room house contains original artifacts, period furnishings, and photos of Carson and his family as well as letters and documents from his life. Admission is $7 for adults, $6 for seniors and $5 for kids. The house is accessible for wheelchair users and those with limited mobility.

For a glimpse into the Native American cultural traditions of Taos, visit Taos Pueblo. Over 1,000 years old, the Taos Pueblo consists of five stories of adobe construction, with living spaces built one on top of another and no electricity or running water. Home to the Tiwa Indians, the Pueblo currently houses about 150 people, with a few hundred more maintaining homes there for the ceremonies. Though many of the ancient buildings are not accessible to wheelchair users, there is a walking tour through the Pueblo, and the grounds are packed dirt — relatively easy to navigate on wheels. You can take a guided tour or wander the grounds on your own. Pueblo residents
To get your day started, try Michael’s Kitchen, a locally owned favorite since 1974. They have delicious huevos rancheros, but one of my favorites is the Poor Man’s Eggs Benedict — eggs with shaved ham, chile and cheese on a toasted English muffin. And grab a cream puff from the counter bakery for later.

At the Taos Diner, try Copper John’s Eggs — two eggs scrambled with green chiles and cheese, home fries and a homemade biscuit, and bottomless coffee.

At lunchtime, head to another Taos institution, The Alley Cantina, located in the oldest building in Taos, with two original walls from the 16th century structure still remaining. Here locals and tourists alike enjoy live music, pool tables and shuffleboard, and an outdoor pet-friendly patio. You can’t miss with the green chile cheeseburgers or green chile stew, served with a huge flour tortilla for dunking.

For a dinner of quick, inexpensive Mexican food, you can’t beat Guadalajara Grill. My favorite is the Guadalajara shrimp, marinated in butter, chile and garlic salt, served with rice, beans and tortillas. Their burritos, tacos and enchiladas are delicious, too.

If you feel like something a little fancier, head on over to Lambert’s of Taos. Built in typical Southwestern adobe style, Lambert’s has a beautiful outdoor patio with the main level fully accessible. Try the green chile stew appetizer, or if you want something lighter, the watermelon salad is amazing. For dinner, fresh trout or duck breast are delicious. A wonderful wine list and delectable desserts like seasonal fruit cobbler or housemade ice cream make this one of my favorites.

NEARBY DAY TRIP

If you get the itch to absorb natural beauty, drive west on U.S. Highway 64 from Taos to the Rio Grande Gorge Bridge. This 1,280-foot long span hovers 650 feet above the Rio Grande, with stunningly breathtaking views of the mountains and the river below. Dedicated on September 10, 1965, it is the second highest bridge on the U.S. highway system and the fifth highest in the United States.

The bridge was famously featured in the films Natural Born Killers and Twins. It has concrete sidewalks on both sides to allow pedestrians, including wheelchair users, to cross. There are several lookouts for viewing and photo opportunities, and at the end, you’ll usually find several vendors selling handcrafted leather brace-
Taos has accommodations to fit every budget. Here are two possibilities:

El Monte Sagrado Resort is a high-end luxury property with gorgeous grounds and wonderful amenities, including the Anaconda Bar where you can enjoy cocktails and a light bite, as well as an award-winning restaurant, De La Tierra. A full-service spa will leave you pampered and relaxed, or you can enjoy a dip in the pool. Accessible accommodations can be found across room types and price ranges. My favorite is the Native American Suite, a room with a private balcony overlooking a babbling brook in the center of the property that just whispers you to sleep.

The Sagebrush Inn is a more moderately priced accommodation, with typical Southwestern knotty pine architecture and Mexican style furnishings. Here you can enjoy a complimentary breakfast, dinner at the Sagebrush Grill or happy hours and live entertainment in the Cantina make this a great spot to spend your time in Taos. There are five wheelchair accessible rooms, but only one has a roll-in shower.

The Rio Grande Bridge is the second-highest in the U.S. Highway system.

ON TO SANTA FE

When you’ve had your fill of Taos, take Highway 64 south to visit historic Santa Fe, the state capital, about an hour-and-a-half drive. Like the rest of New Mexico, here you’ll find Mexican, Spanish and indigenous influences in architecture, art, food and culture.

Once you arrive, enjoy a late breakfast or lunch at Tia Sophia’s, a local, family owned institution since 1974. Whether you order my favorite blue corn huevos rancheros or a breakfast burrito of eggs, bacon and green chile, your breakfast comes with a basket of sopapillas — pillowy breakfast breads served with butter and honey. Coffee is strong, delicious and plentiful.

Then it’s off to the Georgia O’Keeffe Museum. Born in 1887, O’Keeffe is widely renowned as one of the most influential artists of our time. Her career evolved from realism to abstraction, and she ultimately became enthralled with the architecture and landscape of New Mexico. She spent much of the 1930s and 1940s living and working in the state, finally settling in Abiqui in 1949. She continued to live there, traveling and painting, until her death at the age of 98 in 1986.

The O’Keeffe Museum houses her entire collection — 981 works: paintings, drawings, sculptures, sketches and photographs. The museum also features photographs taken of O’Keeffe by other photographers, giving an outside perspective into the life of this vitally important artist and her place in New Mexico history. Adult admission is $13, students $11. The museum is accessible to wheelchair users and those with limited mobility.

Next stop, the Loretto Chapel. The history of the Chapel dates back to 1850, when Bishop Jean Baptiste Lamy was appointed by the church to spread the faith in the New Mexico Territory. The Sisters of Loretto opened The Academy of Our Lady of Light (Loretto) in 1853, a residential school for girls. The Chapel was built in 1873, incorporating both local sandstone as well as stained glass windows imported from France into the stunning example of Gothic architecture.

Though the entire Chapel is gorgeous, to me the most striking feature is the “Miraculous Staircase.” Said to have been constructed around 1877, the 33 steps rise over 20 feet tall, making two complete 360-degree turns with no visible means of support. It is closed to foot traffic. Today, the Loretto Chapel is both a museum and a wedding destination.
THE PLAZA AND MORE

Don’t miss a chance to stroll around Santa Fe’s Plaza, where you’ll find dozens of indigenous artisans selling silver and turquoise studs, cufflinks, hammered leather bracelets, amethyst pendants, and more. I’ve done lots of Christmas shopping in this very spot. You’ll also find many galleries on and around the Plaza featuring pottery, sculpture, photography, painting, and artists more than willing to share their stories with you.

When you need a break, visit “Santa Fe’s Famous Cart” for a Frito pie. You’ll get New Mexico chili poured inside a bag of Fritos, topped with sour cream and shredded cheese that you can eat as you stroll. Heaven in a bag!

Next, head to The Museum of Indian Arts and Culture, created from the merging of The Museum of New Mexico (founded by anthropologist Edgar Lee Hewitt) and the Laboratory of Anthropology (founded by John D. Rockefeller). The Museum is known for having the most complete collection of indigenous New Mexico ceramics anywhere in the world, as well as millions of archaeological artifacts. It pays homage to the past but also welcomes the future of indigenous art through featuring current artists like Jody Naranjo, a Pueblo potter from Santa Clara, and Frank Buffalo Hyde, a painter and sculptor whose works represent the span of Native American culture from the ancient to the modern. Admission is $7 for NM residents and $12 for non-residents.

At day’s end, stop in at one of my Santa Fe must-visits, La Boca, for some tapas and a drink. My favorites are jamon iberico, a traditional Spanish ham made from acorn and olive-fed black pigs, manchego cheese, bacon wrapped dates, fried Brussels sprouts and patatas bravas, potatoes in spicy tomato sauce. Order a glass of Spanish cava (sparkling wine) and settle in for a live music set. You’ll hear everything from Spanish guitar to country to jazz.

If you want something more traditionally New Mexican, head to The Pink Adobe. Opened in 1944, the Pink Adobe was named for the color of the adobe used to build it. I love the warm colors and kiva fireplaces — it’s like having dinner at a friend’s house. While you can enjoy terrific salmon or steak, I prefer the native New Mexican favorite, Enchiladas Pink Adobe, which comes with your choice of red or green chile, rice, beans and posole.

When you’re ready to turn in, there are many lodging options to choose from. Two of my favorites are right near or on the plaza: The Rosewood Inn of the Anasazi is a gorgeous luxury accommodation. Located walking distance to galleries, museums and dining, it offers accessible Southwestern style accommodation, several dining options from casual to fine dining, and a lovely patio where you can people watch and enjoy a drink.

If you prefer to be right on the plaza, the La Fonda On the Plaza is the place to be. The site has continuously hosted an inn since the 1600’s. There’s some rumor of ghost appearances — not so unusual for New Mexico — but I hear they’re friendly. The spacious guest rooms feature kiva fireplaces, hand-painted furniture and art from local artists. The Bell Tower Bar on the rooftop is my favorite place to enjoy a stunning Santa Fe sunset.

Whether you enjoy art, history, dining, or outdoor activities, Taos and Santa Fe are perfect vacation destinations. Beautiful weather, abundant sunshine, and friendly people no matter where you go are sure to leave you heading home relaxed, refreshed and ready for your return to the Land of Enchantment.

Head to the Pink Adobe for the restaurant’s signature enchiladas, which come with — of course — green or red chiles.

RESOURCES

IN AND AROUND TAOS:
• Taos Plaza, 800/732-8267; taos.org/what-to-do/landmark-sites/taos-plaza
• Taos Pueblo, 575/758-1028; www.taospueblo.com
• Farmer’s Market, www.taosfarmersmarket.org
• Our Lady of Guadalupe Church, 575/758-9258; ologtaos.com
• Kit Carson House and Museum, kitcarsonmuseum.org.
• Rio Grande Gorge Bridge, taos.org/what-to-do/landmark-sites/rio-granegorge-bridge/
• Millicent Rogers Museum, 575/758-2462; millicentrogers.org
• Michael’s Kitchen, 575/758-4178; michaelskitchen.com
• Taos Diner, 575/758-2374; taosdiner.com
• The Alley Cantina, 575/758-2121; alleycantina.com
• Guadalajara Grill, 575/751-0063; www.guadalajaragrilltaos.com
• Lambert’s of Taos, 575/758-1099; lambertsoftaos.com
• Hotel La Fonda de Taos, 575/758-2211; www.lafondataos.com
• El Monte Sagrado Resort, 575/758-3502; elmontesagrado.com
• The Sagebrush Inn, 800/428-2636; www.sagebrushinn.com

IN AND AROUND SANTA FE:
• Santa Fe Plaza, www.nps.gov/nr/travel/amsw/sw53.HTM
• The Georgia O’Keeffe Museum, 505/946-1000; okeeffemuseum.org
• Loretto Chapel, 505/982-0092; www.lorettochapel.com
• The Pink Adobe, 505/983-7712; thepinkadobe.com
• The Rosewood Inn of the Anasazi, 888/767-3966; rosewoodhotels.com
• La Fonda on the Plaza, 505/982-5511; lafondasantafe.com
Whether you’re a quad or a para, cooking after a spinal cord injury is going to be different and possibly frustrating. The big changes, like accessing counters and cook surfaces, cutting safely and being vigilant about heat, are obvious. But that’s just the beginning. With the right tools and techniques and the willingness to learn and adapt, what at first may seem like a task can become a passion.

Trying to get back in the cooking groove proved frustrating for Minna Hong after she sustained a T12-L1 SCI in a 1999 automobile accident. “Cooking was something I took a lot of pride in before my injury, so I wanted to get that back,” she says. “But when I first came home after discharge, it was just me and my two kids. They were 6 and 8 at the time of the injury, and I had to kind of think about how to utilize this energy and how can I be as efficient as possible?”

Discovering a simple technique that allowed her to flip food in a pan in a new way helped her realize she would be able to adapt and succeed. “It was one of those pivotal points in my life where I thought, ‘Oh, it is different, but different isn’t bad.’ And I think that specific act kind of helped me solidify that.”

Unlike Hong, cooking wasn’t a big part of Bobby Rohan’s life before his C5-6 injury as a teenager, and it didn’t become one immediately following his injury. “I relied on my friends. I would grab food at a friend’s house, or I had a roommate who cooked,” he says. Getting married and getting a barbecue grill changed that. “I thought, I can do that,” he says. “I didn’t have to worry about chopping and I can just grab it off the counter, take it outside and put it on the barbecue.” Rohan liked the idea of helping out his wife and providing delicious food. He found some simple grill utensils with rubbery grips to help him handle them and got to perfecting his technique. A few years later his wife gave him a Traeger smoker (combination smoker/oven/barbecue on wheels). The Traeger uses wood pellets of various flavors (mesquite, apple, cherry, etc.) that feed automatically into a firebox by way of an electric augur.
Minna’s Crab Fritters

1 pound blue crab meat
2-3 tablespoons mayonnaise
1 teaspoon Dijon mustard
1 clove garlic (minced)
Salt and white pepper to taste
1 egg (for dredging)
Panko (for coating)

Mix mayo, mustard, minced garlic and salt and pepper. Toss the crab meat in the mixture, then dredge in egg and coat with Panko and fry using canola oil. Serve fritters on top of a small portion of sauce and garnish with avocado and orange slices. Serves eight.

Sauce:
3 oranges (juiced)
1 lemon or lime (juiced)
1 orange, sliced, without membranes
1/2 of firm avocado sliced (16 slices lengthwise)
Thinly sliced jalapeño to taste

Mix all the ingredients except the sliced oranges and avocado and set aside in the fridge.

“I didn’t know what the difference would be,” he says. “Once I started using the Traeger, I just fell in love with it. It seemed like it was just easier. It doesn’t seem like it gets as hot, so I didn’t worry about burning myself as much. I like the hobby of sitting around a smoker for six to eight hours or 12 hours, depending on what I was cooking, and getting it just right — so it’s really juicy and flavorful.”

Crockpots are another quad favorite for their combination of ease and flavor. New Mobility contributor Tiffany Carlson, a C5-6 quad, owns two and uses both often. She is a huge evangelist for their use and vouches for the crockpot’s ability to handle all kinds of dishes and sauces. “They just come in really handy when you’re in the mood to cook a lot of food easily, and well,” she says. “They also are an easy way to cook because it’s all ‘low and slow,’ the safest way to cook as a quad. I don’t mind high heats but crockpots are stress-free.”

GETTING THE RIGHT SETUP

Whether you’re using a crockpot, getting ready for a BBQ or simply cooking a meal, having a safe place to cut and prep your food is critical. An accessible counter you can roll under is great, but a secure lap tray with a cutting board can work just as well, if not better. “Even though I can get under my counter, cutting on my lap works way better,” says Carlson. Hong recommends finding a cutting board with a lip to keep juices from running onto you. Hong also prefers the added leverage she gets from prepping on her lap, along with the added mobility. “Having everything ready in front of you so you’re not rolling back and forth is important. Knowing the three points of your kitchen is important. One roll to the sink. One roll to the cook top and one roll to the refrigerator — like in a triangle. That’s really, really important.”

Just like using the lap tray instead of an accessible counter, Hong sees benefits in not having the most state-of-the-art accessible kitchen. “Let’s say my house was just completely ADA compliant — which it’s not — the minute I step out of that environment, I feel like, ‘Oh my God, I have to relearn everything again.’ It would be great if everything in the world was accessible, but it’s not.”

The one accommodation Hong made — and highly recommends — is removing cabinet doors below the sink so you can roll under it and wash produce and such. “That’s huge, but it’s an easy thing to do.”

In addition to the right tools and a good setup, cooking in a chair takes a lot of planning. For quads like Rohan and Carlson, a part of that is figuring out if you will need any assistance and how to maximize it. When he needs to move heavy pieces of meat on the smoker, or if a fire gets out of control, Rohan knows his sous chef (his wife) has his back. Carlson has become a master of managing her attendants. “PCAs can help me prep in the morning and put it on low before leaving, which I love to do when feeling the lazy bug,” she says. “I’ll also make a list of what I need my caregiver to help me with before leaving, like cutting or peeling certain vegetables or opening certain packages that are just too annoying to do on my own.”

If certain tasks are too annoying, Hong recommends considering ways to skip them altogether. “Ask yourself, what is the most efficient way of doing things? Like me, I wouldn’t want to spend time shredding carrots or something like that. I’d just buy a bag of carrots and use the scissors to cut the bag — how much are you willing to do and how much time are you willing to spend? It’s about division of labor and division of time.”

Despite the extra time and effort it requires, most wheelchair chefs seem to agree the benefits go beyond simply enjoying a tasty meal. What started for Rohan as a novelty has become a passion. He is looking at getting adaptive knives and kitchen gear to help him take on more of the prep. He is also expanding his repertoire with new recipes and ideas. “The reward of watching everybody eat something you made — and something you know is good — is huge,” says Rohan.

Hong also draws great pleasure from sharing her food with friends and family, but points to more personal benefits. “I feel like cooking helped bring some of my identity back,” she says. “Regardless of whether it’s cooking or something else you were passionate about, sometimes people have a tendency to turn that part of their brain off after they are injured, and if something like cooking can help them jumpstart it, that’s great.”

Cooking with the Traeger grill is easier, and there’s less of a burn risk, says Bobby Rohan. Plus the food is juicy and flavorful.
Bobby’s Smoked Shrimp

Ingredients:
- 2 pounds large shrimp, about 18-24
- 3-4 sausage links — spicy works great or go sweet
- 1-3 tablespoon basic rub*
- ¼ cup parsley, chopped
- 1-2 jalapeno peppers, chopped
- Juice of one orange
- Juice of one lemon
- 1 stick of butter

Two hours before you plan on eating, cut up the sausage into bite-sized pieces. Peel, de-vein and wash the shrimp. Put the shrimp and sausage into a disposable baggie, then add three tablespoons of rub, jalapeno pepper, and half the parsley. Using your hands, mix together and marinate in the refrigerator for two to 12 hours. When you are ready to cook, melt the butter, add the orange and lemon juice to the butter, then pour over the shrimp adding another sprinkling of rub. Heat your cooker to 250 degrees. Put the shrimp mixture into a disposable aluminum pan. When the cooker is ready, cook for 45 minutes to an hour, closing the lid. Make sure to check at the half hour mark. The shrimp are fully cooked when they are pink. Garnish with the remaining parsley and serve. You can also cook this in your oven or on your barbecue, but I prefer a smoky flavor taste.

Basic Rub Recipe

Ingredients:
- 1 cup dark brown sugar, unpacked
- ½ cup paprika
- 1 tablespoon coarse black pepper
- 1 tablespoon chili powder
- 1½ tablespoon garlic salt
- 1/2 teaspoon cayenne red pepper

Mix all the ingredients together, making sure to get any lumps out. This recipe makes two cups. Store in a sealed container; you can also store in the freezer. This recipe is great for beef, pork, fish and veggies.
When it comes to cooking, David Doc Robertson has a simple motto, “If I can cook it, anybody can cook it.” Coming from a celebrity chef or your standard TV chef, that might seem a little cliché. But coming from Robertson, a C5 quad who zips around the kitchen in a power chair, it takes on more meaning. “I’m not your normal everyday chef — I’m not even a chef — but I do have a need to eat,” he says.

Robertson cooked for himself when he first got out of rehab at Rancho Los Amigos back in the ’70s, but over the years he slowly relinquished his chef hat to his wife, and then, after a divorce, his son and attendants. The loss of independence rankled him. “I’ve had aides go away and tell me, ‘Yeah, I’ll be back in time for dinner around five or six,’ and they show up around midnight,” he says. “When I get hungry, I want to eat right then, not when somebody is ready to fix it.”

Moving into a new apartment with a bigger kitchen that could accommodate his power chair proved to be the catalyst to get Robertson back to cooking. In 2015 Robertson started filming a series of simple how-to videos and posting them to YouTube. Over the nine episodes of “Kickin’ It in the Kitchen,” Robertson shares gritty and practical ideas to empower quadriplegic viewers to take back their kitchens. “The whole purpose is to show what people can do when they’re hungry,” he says.

Robertson does this without the fancy accoutrements TV cooking shows have accustomed viewers to want. His kitchen, while spacious, lacks any accessible modifications, and he doesn’t use any specially-made adaptive equipment. “You don’t have to have all those things and do all that fancy stuff to make a good meal,” he says. His most trusted tool is a spatula he found in a 99-cent store. He uses the spatula for everything, including a replacement for a knife. “I tried using knives, but they are really difficult without your hands,” he says. “Then I discovered this spatula and its sharp end worked a lot easier.”

Robertson uses his trusty spatula for

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everything from dicing vegetables to flipping eggs to stirring pots. The only tool he may use more is his mouth. He uses it to open jars and containers, peel vegetables and tear bread for a bread pudding recipe. He knows using his mouth in place of a knife may seem unsanitary, but he explains that when you are cooking for yourself, and you are hungry, sometimes getting the job done is the most important thing.

Watching Robertson cook, it becomes clear that getting the job done is his specialty. To crack eggs he simply drops them into a pan, then picks out the shells with a fork. To make cleaning easier, he lines pans with aluminum foil. When he can’t reach the controls for his stove, he busts out a long stick to push the buttons. No matter the obstacle, he seems to have a solution.

He has that same focus on practicality when it comes to presentation. “I’m not going to be like the other chefs and say, ‘oh that looks beautiful.’ I’m not going for beautiful, I’m going for tasty.” This becomes clear watching the satisfaction on Robertson’s face as he bites into the savory sausage-and-egg sandwich he has made at the end of one episode.

Part of that satisfaction comes from having invested the time and effort to make the food. And make no mistake, it is not easy. Robertson edits his videos down to the essential steps but admits that cooking as a quad takes a lot of time and planning. “Just getting things out of the refrigerator takes a lot of time, and that’s assuming everything is where it’s supposed to be,” he says. He makes sure his son knows where he wants key ingredients left so he can get to them when he is alone. “It can be frustrating.”

ALWAYS BE SAFE
Being safe is also critical. Robertson remembers eating tacos at home on his first leave from the hospital. “We hadn’t had tacos since I was injured,” he recalls. “So my mom made me some tacos, and I had a hand splint that I put on, and I held them up and fed myself. It never did occur to me to set them down, and then when I was finished eating, I had giant-sized blisters on my fingers.” Today he is extra careful to avoid burns and other injuries. He only uses pots and pans with non-conductive handles and rarely uses more than the two front burners at the same time. To tend to the food cooking on the stove, he uses a grilling fork with a long handle that allows him to keep his hands away from the heat. Regardless of how many burners he uses, Robertson always keeps the fire low. His biggest safety advice is to know your limits. “Safety has to be your main concern,” he says. “Don’t try to cook too many things at once.”

After years of eating food the way other people liked it, Robertson is loving being able to enjoy his meals just how he wants them. “I know exactly how I want to make my eggs and how I cook my sausage,” he says. “It definitely tastes better.” Earlier this year he moved beyond YouTube to record a regular 30-minute show for a local TV station titled “Kitchen Independence.” With a slightly more polished presentation, Robertson continues to show the same indefatigable approach to conquering the kitchen, and he still sports his trademarked yellow polo shirt. “I figure if Tiger Woods can wear red every Sunday, then I would wear the yellow.”

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I think I look good in yellow.”

So far the show has been well received. “I guess they liked it, because they’re currently re-running it right now,” he says. He hopes the show and his videos will encourage more quads to try their hands, however limited they may be, in the kitchen. “I want to show that the more you know, the more you learn, then the more you can do for yourself,” he says. He’s looking forward to filming a second season, with the hope of inviting some celebrity chefs. His dream would be to challenge chef Bobby Flay, the host of Beat Bobby Flay on Food Channel, to a quad cook-off. “Have him come do what I do?” asks Robertson. “I don’t think he could do it.”

Robertson hosts a local television show called, “Kitchen Independence,” where he shares techniques and recipes he’s honed over the years.

Doc’s Coachella Chicken

1 cup baked chicken
2 tablespoon olive oil
1 cup rice, cooked
2 tablespoon onion
2 tablespoon bell pepper
1/3 cup water
½ teaspoon salt

This dish is mainly for leftover poultry. It will surely prolong a store-bought cooked chicken or a good turkey during the holidays. Debone the chicken. The poultry should already be seasoned. Adding more seasoning is optional — according to your taste. Lightly sauté onion and bell pepper in the olive oil, using your favorite frying pan. Add chicken and water. Then stir until warmed. Serve over warmed rice.

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There’s something about beautiful photographs that can make you stop and appreciate the world in a way that’s difficult to do in real time. They can transport you, tell you about other places and people in a way that words simply cannot. But there is certainly a difference between a picture and a quality photograph. A quality photo focuses your gaze on a bead of sweat on an athletes’ chin as she musters all of her body’s coiling energy to return a tennis shot. A picture shows cousin Andy with half his arm cut off standing in front of the world’s largest ball of twine.

Nowadays technology has advanced to the point where you can take quality photographs on even the most common devices. For those with limited function, there has never been a more accessible time to get into photography: all you need is a willingness to try, to practice, and an eye for the world.

If you’ve ever wanted to take better photos, and who hasn’t, you’ll be glad we talked with four photographers with quadriplegia — Loren Worthington, a sports photographer; Robert Andy Coombs, a portrait photographer; Kirk Williams, a drone photographer; and Kary Wright, a nature/landscape photographer — about how they do what they do.

How to Get Started

If you’re just getting started with photography, the specific gear and type of camera you use doesn’t matter a whole lot. Given the price of high-level camera equipment, it’s best to start simple and make sure that photography is more than a passing interest before you invest in thousands of dollars’ worth of gear.

“The art of photography is two parts. One is the technical side of how you set up your camera, but the other part is the composition: where are you going to be, what are you going to put in the foreground, the background itself, and all of that,” says Worthington. “It doesn’t matter if you have a $400 camera phone or $4,000 equipment.”

Williams repeats the old photographers’ maxim — “the best camera is the one that’s on you all the time.” Like any skill, photography requires repetition to get better, which means taking lots and lots of pictures.
The best camera to learn on is one that you can carry with you, access and operate most easily. That can be a phone, a simple point and shoot, or even a GoPro. As you learn what you do and don’t like to shoot and get more comfortable composing photos, that’s when more specialized gear can help improve the functionality and quality of the photos you’re taking.

All of the photographers we talked to started the same way: they just began taking photos of the stuff that they were already interested in. Coombs says he

“I have a unique perspective as far as how I want the photograph set up and what we want to say collectively, visually.”

Robert Andy Coombs

Coombs has what might be called a pro-quad aesthetic, which can be seen in this image celebrating the positive side of being surrounded by helping hands.
became intrigued when he started taking photos in high school and found it came easily to him. “I just had an eye for photographing people specifically,” he says.

Worthington was working in marketing for the vacation resort industry and often worked with photographers as part of his day job. When he first got interested in photography, he wasn’t necessarily interested in one style or type of photography, but more as a functional challenge. “At first, it was really about how was I going to get the camera to work? Because a camera requires a lot of finger dexterity to be able to control the settings, I was pointing the camera at anything, literally, and basically modify-
ing it and trying to get it to work for me.”

He spent the first two years taking photos of his dog, anything around his house, just trying to hone the techniques he would use and getting better at composing photographs.

Williams started with photography before his accident. He was big into mountain sports, skiing and biking, among others, but found that he wasn’t quite talented enough at any of them to make it as a professional. He started bringing his camera with him and taking photos of his favorite activities in hopes that photography could be a way to make a living still doing the things he loved. After he sustained a spinal cord injury in a mountain biking accident, his first thoughts were whether his right finger was functional enough to still use the camera shutter.

Wright lives in rural Alberta, Canada, and started with photography and videography after he sustained a C5-6 spinal cord injury in a car accident. It began as a way of recording the landscape and nature around his home. He discovered that a rack used to hold a hunting rifle steady on his power chair worked just as well to hold a video camera stable. From there, taking photos and videos became a natural extension of his various outdoor adventures. For those wanting to get started with photography, Wright has simple advice: “Just do it,” he says. “There’s always a way. If you can’t hold the camera, talk to everyone you know. I get advice from as many people as I can, because people come up with such good ideas if you let them.”

From the Ground

For those with limited hand function, operating the dials and switches to adjust the settings on a regular camera can be difficult. Fortunately, there are a couple of ways to make cameras easier to adjust and operate.

Coombs is a portrait photographer and C4-5 quad who has just enough hand function to be able to operate his phone with his right hand, but not enough to operate the buttons on a camera. When he is shooting in a studio setting, he often has assistants help him with setting up things like lighting and a tripod, but he needs to be able to do all the shooting and camera adjustments on his own. To do this he uses a software called Capture One, which tethers his camera to his laptop so that he can control all the settings and even the shutter from his laptop. He then uses a Jouse2 mouse, which lets him control the cursor motion with a mouth joystick and the button operation via sip and puff. With this system in place, he has total camera control without needing to use his hands at all.

“Capture One software has been used for years by commercial photographers,” he says, “so that they can immediately see the images they’re shooting in a
large format to know whether or not they have what they need. So that technology has been with us for a while, it’s just not very well known if you’re not in the photography community.”

Even though the software is primarily used by professionals, Coombs says it’s easy to use and works with a wide variety of cameras. You just need to go to Capture One’s website to make sure it’s compatible with the camera you have or are looking to purchase (see resources).

Coombs’ specialty is photography that focuses on disability and sexuality. Given the sensitive nature of this work, there are times where it’s more comfortable for Coombs to shoot one-on-one with his subjects. “I’m photographing people in my community, so I have a unique perspective as far as how I want the photograph set up and what we want to say collectively, visually,” he says.

In settings where Coombs doesn’t have any assistance, he uses a Sony A7R2 camera. The camera has WiFi, which allows him to sync the camera to his smartphone and do all of the adjustment and operation from the much easier to use touch screen. WiFi is becoming more and more common in cameras, from high-end DSLRs down to simple point and shoots. If you have limited hand function and are looking to get a dedicated camera, purchasing one that is WiFi-enabled can save you a lot of hassle with adaptations and figuring out how to mash buttons with your knuckles.

Worthington, a C5-6 quad, took to photography 10 years ago, 20 years after his spinal cord injury. Sports had been a big part of his younger life (he was injured
sliding into third base while playing baseball), and as he started learning photography, he found himself naturally gravitating towards sports photography. The problem with sports photography is that you have to be able to react quickly to the action to be able to get any decent shots. Even with a ton of practice, he simply couldn’t shoot fast enough with his quad hands. “That’s what made me realize I could use what’s called a remote trigger with my mouth in order to be able to go as fast as the sports in front of me. I hold the camera up and I’m looking through the eye piece, but my index finger is not triggering the camera, I’m triggering it with my tongue. You know, the tongue is remarkably fast and it’s very sensitive. … In sports, you’re constantly half-touching the trigger in order to get the shot, as it’s evolving, to focus, and then when the time is right, you’re pushing it all the way to get the shot, and I could never do that with my hand function. So the remote trigger is the biggest adaptation I made.”

Another challenge that Worthington had with sports photography was being able to hold the camera and move in his chair at the same time. He uses a manual wheelchair in his everyday life, but turned to a power wheelchair to give him a more mobile, stable
platform to shoot from. This solution would turn a challenge of shooting from a wheelchair into an advantage over his nondisabled peers.

“With the power chair,” he says, “I just let go of the joystick and I’m a human tripod. A big moment for me was that I realized that when I’m in this power chair, I can get where I want to be and take a photo holding it in one hand and driving with the other, and because the power chair is heavier, my shots were better because it’s more stable.”

“As you start doing more photography, you want better gear, and with photography, that typically means bigger and heavier,” he says. “A lot of my sports shots I take with a really heavy lens, and a lot of sports photographers will use what’s called a monopod, so the weight of the lens is transferred down to the ground.”

For sports photographers, picking up and moving all that weight is a hassle, but for Worthington, a simple adaptation made him and his gear more mobile than a walking photographer could hope to be. “I built a mount on the bottom of the footrest and the monopod sits on top of that so that I can move the chair with the lens balancing on top of the monopod, which is on the chair … I have nondisabled friends who are envious.”

From the Air

As the technology advances, drones are becoming easier to use and cheaper to purchase, making them increasingly functional for photographers of all abilities. One of the limits of photographing from a wheelchair is that all your photos are coming from the same perspective: three feet off the ground.

Nondisabled photographers can hold a camera up high, flatten out on their belly, or climb on top of a table to get the right angle for their shot, options that for a quad are difficult, if not impossible, depending on your level of function.

Today’s drones are so stable, easy, and precise to fly that you can hover at just about any height, quickly moving wherever you need in three dimensions to play with the angle you’re shooting from. Whether you’re wanting to get an aerial photo of a house for real estate purposes, a panning video of a mountain bike trail, or a close-up of uncle Phil’s bald spot, drones have you covered.

Williams, a photo/videographer and C6-7 quad, runs Birds Eye Optics, a company that specializes in drone work. He was pursuing a career as an adventure and action sports photographer before he had a mountain bik-
ing accident that resulted in a spinal cord injury.

While Williams was at Craig Hospital doing his re-
hab, some Colorado University students helped make
an armrest camera mount so he could have a stable
platform from which to shoot, and after talking with
Worthington, he started using a shutter remote that he
could operate with his mouth. "I kept buying the cheap
ones, though," he says with a laugh. "Apparently if you're
hanging out with one in your mouth, watching a sports
game and waiting for that special moment to shoot, if
your mouth's open the whole time, you end up drooling
quite a bit, which ends up shorting these things out left

"If you can't hold the camera,
talk to everyone you know.
I get advice from as many
people as I can, because
people come up with such
good ideas if you let them."

Kary Wright

Wright enjoys
the thrill of
the high-angle
drone shot.

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and right. So I probably went through 50 of them.”

He had a setup that was functional for him to take photos, but his biggest issue was with the limited height of the camera. Coming from a photography background, he knew the kind of photos he wanted to be taking. “I saw these angles of how I wanted to get the shot, but I couldn’t get there,” he says. “I ended up handing people my camera, setting up the aperture, and saying, ‘Can you be in this position and see how the light is hitting that person over there? Can you put them in the bottom right corner of the frame?’ I was essentially framing the picture but giving the camera to someone else to actually execute the image.”

It was a frustrating way to take photos, because he didn’t feel fully involved, and more often than not the photo would come back just slightly off from what he’d wanted. After a chance encounter, and nudges from a few different directions, Williams started to research drone photography as a way of expanding his field of view. Just over three years ago, when he bought his first drone, the technology was just starting to become mainstream. He bought a Phantom 1 (first-generation recreational drone) and quickly realized that drones could provide him with the shooting perspective for which he’d been searching. From there he made the conscious decision to learn how to use and invest in high-end drones that could carry professional quality cameras on them because he wanted to make a career out of it.

Since then Williams has done a variety of professional shoots with his drones — from a project with the U.S. Olympic archery team to real estate shoots, car commercials, and “weird music videos.” One of his favorite projects was a short film, “Boundless,” that he shot and produced to change public perceptions of people with disabilities by featuring gorgeous footage of adaptive athletes in their element. As a film, it’s a testament to both Williams’ skill and artistic vision as well as the power of drone technology to shoot from unlimited perspectives.

Of the photographers we spoke with, three of the four use drones as a part of their gear. Compared to other high-end camera gear, drones are relatively inexpensive. You can get a good, easy-to-fly drone that takes stable HD video and quality photos for anywhere between $500-$1,500.

Wright uses a Mavic Pro drone for landscape video and photography. The drone’s ability to shoot in 4k video has an additional benefit outside of superior video quality. “With the new cameras going up to 4k in video mode,” he says, “all of a sudden you can take a screen shot and zoom in on it on your computer, and you have a still photo that’s really good quality.”

Wright will do a flight entirely in video mode, and he’s still able to pull good still photographs from the footage. For both Wright and Williams, the only modification they needed to be able to fly a drone with control was to add extenders to the joystick levers. Wright also uses an app called Litchi, which allows the drone to track objects, essentially giving it autopilot.

A World of Cameras

It used to be that if you wanted to learn photography, you bought a still camera. If you wanted to learn videography, you bought a video camera. Such was the case when Wright first started learning the visual arts 30 years ago. He attached his first video camera to an adapted gun mount on his power chair and started filming. He has expanded his arsenal as new technology becomes available, and now he has a camera for every occasion.

For a regular video camera, Wright uses a Panasonic model 7000. His biggest requirements in a video camera are long media and battery life, so that if he goes out hunting or camping (or both) and does a lot of shooting, he doesn’t have to worry about running out of space in the middle of the trip. With the model 7000, Wright says he gets a full four hours of shooting time, more than enough for whatever he needs.
In the summer, Wright spends as much time as he can flying a glider that he operates with hand controls. While up in the sky, he uses a few different tools to get shots from a bird’s-eye view. One is a Contour GPS, an HD action camera that he can place anywhere inside the glider with a suction cup. He turns it on before he gets towed into the air and films the whole flight. He then uses Adobe Premier to edit the raw footage into engaging video. Wright also uses a Ricoh Theta 360 camera, a small iPod-sized device that takes 360-degree photos and video with a single push button. Because he doesn’t have the function to hold the device out of the glider and push the button, Wright will maneuver into a position he wants and have his flight mate (he flies a two-person glider) hold the camera to snap the photo.

While Williams spends a lot of his professional time flying octocopter drones that can carry heavy DSLR cameras, he also highly recommends a few hand-held camera options. One is the Osmo, a handheld video camera mounted on gimbals that keep the camera flat no matter how you move it. The stabilization is so advanced, he says, that you can mount the camera on your wheelchair and you’re essentially a rolling camera dolly. “It’s just cool. It gives a very cinematic feel to a family vacation.”

Today, technology has advanced to the point that operating a camera with limited hand function doesn’t have to be a hassle. Whether by touch screen, mouth, or voice, you can adjust and shoot a camera without ever lifting a finger. Photography has never been a cheap hobby, but you can now take crisp photos and HD video on a phone that’s already on you all the time. Whatever your function or interests, there’s never been a better time to take a shot at recording the world around you.

Resources
- Adobe Premier (editing software), www.adobe.com/products/premiere.html
- Capture One (software), www.phaseone.com/en/Products/Software/Capture-One-Pro/Highlights.aspx
- Contour GPS (HD action camera), contour.com
- GoPro Hero 5, shop.gopro.com/cameras/hero5-black/CHDHX-501-master.html
- Jouse3 (mouse, most recent version), www.compusult.net/assistive-technology/our-at-products/jouse3
- Litchi (software), flylitchi.com
- Mavic Pro drone, www.dji.com/mavic
- Osmo (handheld video camera), www.dji.com/osmo
- Panasonic Video Cameras), shop.panasonic.com/cameras-and-camcorders/camcorders
- Phantom 4 Drone (newest version of Phantom series), www.dji.com/phantom-4
- Ricoh Theta 360 camera, theta360.com/en
- Sony A7R2 (camera), www.sony.com/electronics/interchangeable-lens-cameras/ilce-7rm2

Consult your healthcare professional to learn how our JACO² robotic arm can help you.
Music was the catalyst for so many of my interactions growing up, and it’s still important to me today. But music changed, as did everything else, in 2008, during the fall semester of my senior year in high school.

Heading to my school’s talent show to play the drums in “That’s What You Get” by Paramore, I lost control of my motorcycle. My speed was around 50 miles per hour when I fell to the side in a black-out, slid several yards into a ditch and slammed my back against a tree.

Now, as a T5-6 para, I can’t use my left foot to hold the high hat closed, or my right to press the pedal that strikes the bass drum. While I haven’t given up on playing the drums, my priorities have shifted, and I’ve invested more time exploring music venues as a listener, rather than a player.

INACCESSIBLE MUSIC VENUES

I listen to eclectic genres — math rock and ska punk varietals — and the venues these ne’er-do-wells haunt are generally cramped and standing room only, often inaccessible.

I call ahead and ask if there’s an elevator to a balcony so I can get an acceptable viewing angle. I ask if the bathroom is accessible, or if there might be help to make it to the bathroom during the show if I need it. Despite existing in an age where extensive information on most things — such as the price of the peach Bellini served during happy hour — can be found with a single Google search, elbowing myself into the purview of those who manage music venues is unnecessarily exhausting.

Not too long after my injury I chose to forfeit attending a show due to its basement location in a pizza joint. There would have been no way for me to attend, other than strangers hooking their elbows under my armpits and knees, hoisting me down the stairs, as someone trailed behind them carrying my chair. I had already bought my ticket. The venue managers were aware of my disability. No one informed me, nor did the information appear on a website anywhere, about the basement sans elevator issue.

“...
backs and be trampled over? Or is there see a show, should I expect to see sweaty expectations: if I pay $50 for a ticket to policing standards that establish realistic London. We need consistent communi-
ment of the music they host for all peo-
music venues that facilitate the enjoy-
tent has been at least considered before go somewhere. They know their perspec-
try to identify which cabs are accessible.

BLACK CAB MODEL FOR VENUES

The accessibility of music is an impor-
t and expansive issue, but we can take small steps to get there. In London, I can hail any black cab and get inside via a small ramp that takes seconds to unfold on the curb. The speed at which I can get inside the cab is worth the extra cost in fare for me, and I would choose a black cab over the bus or underground every time. I don’t have to research the likelihood of a wheelchair lift breaking, or try to identify which cabs are accessible. Every single one is, and wheelchair users know what to expect when they decide to go somewhere. They know their perspective has been at least considered before they pay extra to ride in a black cab.

Which brings us to my dream: small music venues that facilitate the enjoyment of the music they host for all people, regardless of physical ability, much like black cabs do for wheelchair users in London. We need consistent communication standards that establish realistic expectations: if I pay $50 for a ticket to see a show, should I expect to see sweaty backs and be trampled over? Or is there a place to the side where I can see and hear without being in the way? We don’t need to try and make every single music venue perfect for all people. That’s impossible. But what we can do is help people like me navigate live music choices in an informed manner without hours of work.

Some online ticket purchasing platforms provide the option to purchase ADA tickets, but detail about what ADA means for that specific venue or show is usually completely lacking.

I’ve been left to figure out how to fit physically back into the live music scene: its raw nature, the energy of the fans, the collective experience of both artist and audience in one place at one time, the messiness, the potential for chaos. These attributes that enthrall me now terrify me as well. To reduce the grittiness would be to reduce the enjoyment of the experience for anyone else, but all I ask is that artists and venues pay attention to the accessibility of the physical space where music is played — and then to care about how the information is portrayed and transmitted.

People without disabilities have venue preferences of course: They want strong drinks, or a dance floor that doesn’t get too hot. Or they want the crowd to be as close to the stage as possible. I don’t have preferences; I have requirements. If it’s standing-room only, I can’t see. If the bathroom is between me and a sea of people, I can’t use the bathroom. And due to my disability, I’ll probably end up pissing myself as a result. It’s hard to admit, but it’s happened before: seeing my favorite band in a shitty venue with no regard to accessibility, and I have to listen to this amazing music knowing I’m sitting in my own urine. Thankfully the beer I got drenched in was more pungent and covered the smell.

Regardless, though, there’s something to it that keeps me going to concert after concert. I think it’s the way the bass grabs my ankles and shakes every bone in my body. Hyperactive amps screeching, inside jokes between songs, the extended and drawn-out buildup crescendo to a climax that makes your head spin. The crowd surges and favorite-song-sing-alongs. The temporary tinnitus. Synchronized lights and the shredded set-lists you linger for when the music stops. I keep going to concerts for the thrill. For the love and sake of music that lives. For everyone.

UNITED SPINAL’S Accessibility Services Program

United Spinal Association runs an Accessibility Services program with the exclusive goal of making the built environment — including music venues — more accessible to people with disabilities. This team of professionals includes certified accessibility specialists, plan examiners, attorneys, architects and code enforcement officials who help property owners and designers to meet state and federal accessibility requirements.

If you know of a venue or development that is being planned in your community and want to make sure you can enjoy it along with everyone else, feel free to let the planners know that United Spinal’s Accessibility Services can help make complying with access guidelines a whole lot easier. Accessibility Services is about helping ensure accessibility compliance right from the start, as well as bringing existing spaces up to code so that everyone has equal access.

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

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

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

CALIFORNIA
- Dignity Health - Northridge Hospital Medical Center, Center for Rehabilitation
  Northridge, CA; 818/988-8500
- Rady Children’s Hospital San Diego - Division of Pediatric Rehabilitation Medicine
  San Diego, CA; 858/576-1700
- Santa Clara Valley Medical Center
  San Jose, CA; 408/885-5000
- Sharp Rehabilitation Center
  San Diego, CA; 858/939-6709
- Sutter Rehabilitation Institute
  Roseville, CA; 916/878-2588

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

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

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

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

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

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

ILLINOIS
- Marianjoy Rehabilitation Hospital
  Wheaton, IL; 800/462-2366
- Memorial Medical Center
  Springfield, IL; 217/778-3302
- Schwab Rehabilitation Hospital
  Chicago, IL; 773/522-2010
- Shirley Ryan Ability Lab
  Chicago, IL; 312/239-1000

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

IOWA
- Childserve
  Johnston, IA 50131; 515/727-8750

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

KENTUCKY
- Cardinal Hill Rehabilitation Hospital
  Lexington, KY; 859/254-5701
- Frazier Rehabilitation Institute
  Louisville, KY; 502/874-7490
- Gateway Rehabilitation Hospital
  Florence, KY; 859/426-2400

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

MASSACHUSETTS
- Spaulding Rehabilitation Hospital
  Charlestown, MA; 617/573-2770

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

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

MISSOURI
- Ability KC
  Kansas City, MO; 816/751-7812
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<td>VCU Spinal Cord Injury Rehabilitation</td>
<td>Richmond, VA</td>
<td>804/828-0861</td>
</tr>
<tr>
<td>WASHINGTON</td>
<td>University of Washington Harborview Medical Center</td>
<td>Seattle, WA</td>
<td>206/221-7390</td>
</tr>
<tr>
<td>WISCONSIN</td>
<td>The Spinal Cord Injury Center at Froedtert and The Medical College of Wisconsin</td>
<td>Milwaukee, WI</td>
<td>414/805-3000</td>
</tr>
</tbody>
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**Organizational Members**

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

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

- NextStep - Atlanta
  - Alpharetta, GA; 770/722-4239

- NextStep - Kansas City
  - Overland Park, KS; 913/451-1500

- NextStep - Orlando
  - Sanford, FL; 407/571-9974

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

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

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

- Project Walk - Spinal Cord Injury Recovery Center
  - Carlsbad, CA; 760/431-9789

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

- Push to Walk
  - Oakland, NJ, 201/644-7567

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Interested in becoming a hospital or organizational member? Please contact Nick LiBassi at 718/803-3782, ext. 7410 or nibassi@unitedspinal.org
In my June Motorvation, I covered accessible powerboats for fishing, an activity that appeals to a passionate, but relatively modest population. Recreational boating is even more popular, and boat manufacturers have stepped up to fill the growing need by introducing accessibility to many of their models.

Accessibility can be achieved by adding access ramps or lifts along with controls that are operable while seated in a wheelchair. Stability Yachts even offers some larger catamarans with a unique elevator that extends the width of the stern of the boat and can be used for everything from loading wheelchairs to lowering swimmers in and out of the water.

Pontoon boats and catamarans often provide the most stable platforms, especially when loading and boating while seated in a powered mobility device. Tom Dennett, a C6-7 quad from Stuart, Florida, says it’s not necessary to lay out a huge wad of money for an accessible pontoon boat. Dennett originally purchased an older pontoon boat that was no longer usable, stripped it down, reinforced it and has now readied it to hit the waterways. The modifications of the craft, now named The Islander, were performed by Tim Clark of Accessible Boatworks in Port St. Lucie, Florida. The company is currently completing a modular lift that will be mounted on the front of the deck to make it possible for wheelchair users to be lifted out of their chairs with a mesh Hoyer lift sling and lowered into the water for swimming or scuba diving.

John Bevins, a para from Berthoud, Colorado, knows quite a bit about vehicles that float thanks to his experience of owning and restoring numerous Amphicars. Bevins has restored dozens of them; several of the Amphicars he once owned are available at Walt Disney World in Orlando, where park goers can ride in them on the Disney World waterways. The only modifications required to allow Bevins to drive the Amphicar were hand controls that he constructed.

The size of the Amphicar means that he can only haul three passengers, so Bevins recently elected to purchase a used pontoon boat, a 26-foot Ercoa with a 90hp Yamaha outboard that would host even more friends and family members. “Since it’s a former rental, it is pretty rough for now. It’s going to be a man cave when we’re done.”

Modifications are pretty minimal thus far. Initially Bevins didn’t need to do anything but lift the captain’s seat off its pedestal so he could sit at the controls in his wheelchair. The front gate was 32 inches wide, so he was able to roll right onto the bow of the boat. The side gates are currently 26 inches, so he plans on making them wider for side entry; he pointed out that many newer pontoon boats have wider side gates as a standard feature.

While he will be adding a ramp or gang plank, he explained that “getting
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aboard is easy, as I pop a wheelie, place my front wheels on the deck and pull myself on board.” Bevins also has an opinion about the ideal type of watercraft for someone who uses a wheelchair and needs stability. “By far the one type of watercraft that is almost always accessible is a pontoon boat,” he says. “I’ve been on several and they all were easy for me.”

Most pontoon boats have the capacity to safely accommodate several wheelchairs at once; Mark Johnson, director of advocacy at Shepherd Center in Atlanta, is a C5-6 quad who owns a 20-foot Sun Chaser pontoon boat. The only modification needed for him to access and operate it is to remove the pedestal seat behind the steering wheel so he can remain seated in his power wheelchair while driving the boat. A small ramp allows him to quickly roll aboard, at dock level.

Bob Swiney, a sales representative for Sunrise Medical, lives in Dallas. His “man cave” is his lake home on Table Rock Lake in Missouri. The home, accessible dock, 26-foot Sea Ray powerboat with an open bow and 25-foot pontoon boat and jet ski that he has available there make the seven-hour drives from his home to the lake well worth the trip. Swiney is paraplegic, so he has installed a powered lift on the dock that can hoist him into boats, onto the jet ski, or into the lake for a swim; the pontoon boat can be accessed directly across a ramp from the dock.

26-foot Sea Ray powerboat with an open bow and 25-foot pontoon boat and jet ski that he has available there make the seven-hour drives from his home to the lake well worth the trip. Swiney is paraplegic, so he has installed a powered lift on the dock that can hoist him into boats, onto the jet ski, or into the lake for a swim; the pontoon boat can be accessed directly across a ramp from the dock.

Miami Shake-a-Leg President Harry Horgan shows how easy it is to sail from his wheelchair.

Boats of All Kinds
When it comes to versatility and the ability to operate different types of boats, it is unlikely that anyone surpasses Captain David Gaston, adaptive sports coordinator of the Community Sailing Center in Galveston, Texas, now called Sea Star Base Galveston. Prior to his 1979 injury that resulted in paraplegia, Gaston was a commercial diver on oil rigs in the Gulf of Mexico. Shortly after being discharged from rehab, he was back on the water operating power boats.

In his current position, Captain Gaston introduces people to water sports using all types of boats. He has earned instructor certifications in everything from kayaks and sailing vessels to power boats and recently completed the course for his Coast Guard license as a Master for 100-ton boats. It helps to have access to plenty of powerboats, along with a quality facility for training. Gaston says, “Through my nonprofit I have a 50-foot Gulfstar motorsailer, a 39-foot Aquaventure catamaran sailboat with twin diesels, a 25-foot...
Proline Sportfisher, a 20-foot Sea Ray sportboat, a 20-foot pontoon boat, and a 14-foot Jon boat with a 25hp motor. Many of his students are also disabled, so Gaston’s experience and skills serve as examples of what is possible once they are aboard a boat of virtually any type. It is not surprising that those who prefer to drive vehicles fast on land would seek out similar opportunities on the water. Ricky James was a motocrosser before becoming paraplegic, then became an Ironman world champion, NASCAR driver, off road truck racer, and X games silver medalist. On the water he prefers to drive the family’s 20.5-foot Bahner open bow boat with a 454-cubic inch Mercruiser engine and out drive. That boat reaches speeds of about 65 mph, and didn’t require any modifications to make it accessible for him to drive.

Midnight Express Boats, located in Miami, has recently introduced a 39-foot high speed cruiser that is capable of reaching 65 nautical miles per hour. One of the owners of the company is paraplegic and designed the boat with an access ramp and seats that are hydraulically operated to raise occupants to the proper level for maximum visibility and ease of operation.

Gemini Catamarans offers a boat of similar size that is capable of operating at high speed under power or by sail. The Gemini Freestyle 37’s cabin and deck are on the same level, which allows wheelchair users the ability to access all of the boat’s features. Harry Horgan, president of Shake-A-Leg Miami, has driven this boat and says it is easy to access and operate from his wheelchair.

There are many options for wheelchair users and others who want to get out on the water but do not want to go to the trouble or expense of owning a boat. The larger boats used for harbor tours and similar local sightseeing have become more accommodating since passage of the Americans with Disabilities Act. Most cruise lines or ferryboats are also accessible. Fishing charters operating out of major seaports may have a few boats that can accommodate mobility devices, but it is smart to call ahead to check availability.

In order to find a facility that is practiced when it comes to loading wheelchairs onto watercraft, it is helpful to seek out charter or rental opportunities through disability-specific organizations like Sea Star Base Galveston or Shake-A-Leg Miami. As an example, the latter organization charters a powerboat called the Pilar, the same name as the late writer Ernest Hemingway’s boat, which accommodates four passengers using wheelchairs plus their friends. Similar organizations can be found in many major metropolitan areas with nearby navigable waterways; a recent internet search for “disability boating” resulted in almost three million entries.

As should be obvious after reading the above, the world of boating — of all types — is open to people with disabilities as it has never been.

Happy — and safe — boating!

Resources:
• Accessible Boatworks: accessibleboatworks.com
• Gemini Catamarans: www.geminicatamarans.com
• Midnight Express Boats: midnightboats.com/news
• Sea Star Base Galveston: www.ssbgalveston.org
• Shake-a-Leg Miami: www.shakealegmiami.org
• Shepherd Center: www.shepherd.org
• Stability Yachts: www.stabilityyachts.com
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Captain David Gaston powers along in his 14 foot Jon boat.
Q. I’m 53 and in my 20th year as a T4 paraplegic. A few of my friends with spinal cord injuries have been dealing with cardiovascular disease, which has ranged from coronary artery disease requiring angioplasty and stent placement, and in some cases bypass surgery, to peripheral artery disease in the legs that has required surgery to bypass narrowed arteries.

Is there a higher incidence of cardiovascular disease in people with SCI? Are there specific risk factors and/or symptoms? Are there tests to check for this that I should ask my doctor for? What are the treatment options? Are there ways to lessen chances of developing this?

—Joni

Let’s start by defining cardiovascular disease and peripheral artery disease. Both refer to a systemic condition, sometimes called arteriosclerosis which, according to mayoclinic.com, involves “the buildup of fats, cholesterol, and other substances in and on your artery walls, which can restrict blood flow.” When this build-up, or plaque, occurs in arteries of the heart, it is called cardiovascular or coronary artery disease, and when it affects the legs, it is called peripheral artery disease. Since both diseases usually stem from the same underlying conditions, if you have one, you should ask your doctor to check for the other.

In the past, the leading cause of death in people with SCI was due to renal (kidney) complications. But thanks to advances in urological management, this is no longer the case. The flipside of this is now that life expectancy has increased, cardiovascular disease is the second-most common cause of death for people with SCI — behind respiratory complications — according to a study published in the June 2017 International Spinal Cord Society. The odds of a person with SCI developing cardiovascular disease are 2.72 times greater than in the general population, according to a study published in the August 2013 issue of Neurology that looked at a cross section of 60,000 individuals in the Canadian Health Care system.

Risk factors for CVD and PAD include a family history of heart disease, diabetes, lack of exercise, high blood pressure, and being overweight — especially fat around the mid section. Also, dyslipidemia — high levels of LDL (“bad”) cholesterol and a decrease in HDL (“good”) cholesterol — and a diet high in fats, and smoking or use of any form of tobacco. Symptoms for CVD are often silent and may be masked in people with higher level SCI who lack sensation to feel chest pain or shortness of breath, explains Kathleen Dunn, a recently retired clinical nurse specialist and rehab case manager. Dunn says unexplained chest pain and/or arm pain (not joint pain) especially if it is in the left arm, should be reported to a physician. This may mean going to the emergency room for an EKG and cardiac marker evaluation.

Since high blood pressure is a risk for CVD, checking blood pressure is important and should be part of an annual physical — or annual “wellness exam,” which is 100 percent covered under Medicare but must be asked for by name. Dunn says because dyslipidemia is also a risk factor and more common in people with SCI, starting at age 40 you should ask your physician for a cholesterol test — Medicare will pay 100 percent for this test every five years when ordered by a physician. She also suggests asking your physician about an annual EKG. Medicare covers 80 percent of this procedure.

If CVD is suspected, your physician may order additional tests, such as a stress test, to see how your heart responds to exercise. In people with SCI this is done using a medication called thallium, which raises the heart rate without exercise. Other tests include an echocardiogram — an ultrasound of the chest that shows detailed images of the heart; cardiac catheterization, in which a catheter is inserted into an artery in your leg or arm and threaded to the heart to measure blood flow; and/or a cardiac MRI or cardiac CT scan. None of these tests are painful. All are done while you are conscious or minimally sedated.

Similar to CVD, symptoms of PAD can also be masked by SCI, since the most common symptom is transient pain and/or cramping in the legs. Other PAD symptoms are frequent sores on the legs or feet that are slow to heal. But even then a PAD diagnosis can be missed, because these can also be caused by venous insufficiency (reduced return blood flow), which is common among people with SCI, explains Dunn. Testing for PAD is simple and painless. An ankle-brachial index test involves measuring systolic blood pressure on the arm and the ankle and calculating a ratio between the two numbers. The ratio will indicate the degree of disease — none, mild, moderate or severe. Follow-up is critical since disease progresses over time. Other options to test for PAD include Doppler ultrasound, magnetic resonance angiogram, or CT angiography — injecting contrast material into the bloodstream and doing a CT scan.
The treatments for CVD and PAD are similar, beginning with lifestyle changes — stopping use of all tobacco products, proper diet, exercise and weight management, managing diabetes if you have it, and reducing stress. Treatment may include taking medications to manage cholesterol and/or high blood pressure, and blood thinners. When an arterial narrowing is suspected, one treatment is angioplasty — a catheter is threaded to the affected artery where a Foley balloon is inflated, flattening the plaque buildup and reopening the blocked area. In some cases, angioplasty may be followed immediately by insertion of a stent designed to keep the opening clear. Where extensive arterial disease is present, bypass graft surgery may be performed — a major operation involving grafting harvested or artificial arteries or veins to bypass the diseased area.

The best way to avoid or mitigate arterial disease is through lifestyle changes. Start with healthy eating. A healthy diet can lower LDL (bad cholesterol), raise good HDL (good cholesterol), reduce inflammation, lower blood pressure and even help strengthen arteries, says New Mobility nutrition guru Joanne Smith. According to Smith, who has an excellent YouTube video on the subject [see resources], a healthy cardio diet includes foods high in fiber, such as nuts and seeds; whole grains; plentiful fruits and vegetables; and healthy fats contained in cold water fish, such as salmon, herring and halibut; also, avoid processed foods.

It is also important to keep your body at its ideal weight. Although weight loss is more difficult for wheelchair users, a good place to start is to read Smith’s column — “SCI and Weight Loss” — in the December 2014 issue of New Mobility [see resources]. Last but not least, if you have arm movement, aerobic exercises or activities will help. In the July 2017 issue of Neurology, a review of 211 studies done between 1980 and 2016 found that moderate upper body aerobic exercise of 20-40 minutes for two to three times a week improves cardiovascular health in people with chronic SCI. The study found it also improves muscle strength, body composition — and speaking as “a survey of one” — it is a great motivator and mood elevator.

**Resources**
- Cardiovascular Disease & Nutrition Youtube video: www.youtube.com/watch?v=wunMybPK3I0&feature=youtu.be
- Cardiovascular disease and spinal cord injury: www.ncbi.nlm.nih.gov/pmc/articles/PMC3776463/
- Craig Hospital Information about your heart: https://craighospital.org/resources/your-heart
- Atherosclerosis/arteriosclerosis: www.mayoclinic.org/diseases-conditions/arteriosclerosis-atherosclerosis/home/ovc-20167019
- Eat Well, Live Well: Weight Loss — More is Less: www.newmobility.com/2014/12/weight-loss/
This is why Thoreau retreated to Walden Pond: “I went to the woods because I wished to live deliberately,” he wrote, “to front only the essential facts of life, and see if I could not learn what it had to teach, and not, when I came to die, discover that I had not lived … I wanted to live deep and suck out all the marrow of life.”

Well hell, who wouldn’t want to do that? And the way to do that, Thoreau wrote, is, “to live so sturdily and Spartan-like …”

That ain’t so easy when you’re crippled. But I’ll give it my best shot. Thoreau lived in a house that he built himself. Not me. I’m retreating to an accessible cabin that was built by a bunch of volunteers on a campground in a state park in Wisconsin called the Bong Recreation Area (named after Richard Bong, a World War II flying ace and recipient of the Medal of Honor … so stop thinking what you’re thinking). And it’s barely accurate to call it a cabin. Yeah, it looks like a cabin from the outside, with its sturdy log construction. But inside there’s a refrigerator and cooking burners and a microwave and a sleeper sofa and two beds and a roll-in shower and air conditioning and a whole bunch more.

This is Walden for cripples. Thoreau wrote, “Simplify, simplify. Instead of three meals a day, if it be necessary eat but one; instead of a hundred dishes, five.” But that ain’t so easy either. Because the more crippled you are, the more impossible it is to travel light. Every night I sleep hooked up to a CPAP machine I call the Breathe-a-tron 3000. I don’t know what the real name of it is, but that’s what I call it. My doctor says if I sleep without it I might stroke out or have a heart attack and die. So even though my Breathe-a-tron 3000 is a big, bulky pain in the ass to lug around, lug it with me I must. I can’t suck out all the marrow of life if I’m dead.

I also have to bring a battery charger for my wheelchair. And the cabin is 99.9 percent BYO, so we have to bring sheets and towels and cooking utensils and plates and bottle openers, etc. Mercifully, the cabin is well stocked with toilet paper. I imagine Thoreau wiped himself using stuff like oak leaves or dead chipmunks. If that’s what you have to do to successfully suck out all the marrow of life, no thanks.

So between my wife Rahnee and me, our accessible cripple van is packed full with our stuff. Our poor assistants bring a small suitcase and backpack each. They sit cozily on the back seat. And still I’m upset that there isn’t enough room for me to bring my shower chair. There’s a shower chair at the cabin, but it’s a rickety old rolling commode. It’s uncomfortable as hell. But if I bring any more stuff, I’ll have to tie it to the roof like the Beverly Hillbillies. So I guess I’ll have to rough it come shower time.

Thoreau stayed at Walden for two years and two months. The Wisconsin Department of Natural Resources allows the accessible cabins in their state parks to be reserved for a maximum of four days and nights. So if I’m going to suck out all the marrow of life, I have to do it fast.

During my time at Walden for cripples, I read a lot. I try not to think about what time it is. I take cigar walks, meaning I roll around the campground smoking cigars. I do some things I can’t do in the city, like just be still and listen until none of the sounds I hear are manmade. I lie with my eyes wide open when I first go to bed at night so I can see the pitch blackness. I do some things I can do in the city, too, like eat a lot of food and drink a lot of beer.

I don’t know if I sucked out all the marrow in life per se. But after four days and nights, I felt generally content. Maybe that’s the best a cripple like me can do.
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