

High Country News

FOR PEOPLE WHO CARE ABOUT THE WEST

Mind over mountain

As adaptive adventure sports boom in the West, a paralyzed athlete pushes his limits.

Terray Sylvester | April 21, 2014 | *From the print edition*

Last March, Jon Arnow descended 4,400 vertical feet on crutches, from the South Rim of the Grand Canyon to the Colorado River, and then, the same day, hobbled back out. He started at dawn with four companions, following the others down the winding trail in a silent, focused lope. Strangers sometimes mistake Arnow's disability for nothing worse than a broken bone, but he is partially paralyzed from the waist down. On his right side, his nerves still stimulate, in his words, an "itty-bitty" hamstring, a quadriceps the size of another man's forearm, some gluteus, and a hip flexor just strong enough to swing his leg forward. His left leg has none of this. It is completely inert, but with a rigid brace, he can balance on that foot while he advances his crutches.

It is almost 10 miles on the Bright Angel Trail from the rim to the Colorado River, hidden among the canyon folds. The group made an unhurried descent and arrived on the riverbank before noon. They snapped a few photos and then began to climb back out. Arnow tripped. He took a few more strides and fell again. He sometimes worries about inconveniencing his able-bodied partners, and now, almost a vertical mile below the trailhead, he read desperation in their faces. One was an old friend, the others were recent acquaintances. "I've got this completely under control," he said. His muscles had gotten used to the descent, and he had to adjust. He climbed to his feet again and, later, insisted on detouring to an overlook above the river. "It was a mile and a half out, and everyone's looking at me like, 'Dude, don't do it,' " he recalls. "And I'm going, 'We're leaving nothing on the table.' "

Arnow is soft-spoken and attentive. He can appear either robust or diminutive. In 2013, *New Mobility Magazine* ran a photo of him from the waist up, wearing a tank top in the sun, flexing his right arm, biceps and deltoid surging, a contrast to his slender legs. His dark hair is beginning to gray, and he has a strong, open face without hard angles. By the time the group approached the rim of the canyon late that afternoon, Arnow was staring at his feet, measuring the final miles in short, tired increments. They stopped to rest, and one of his friends switched on a video camera, narrating for a later replay: "Less than a mile to go and this thing is kicking our butts."

"If I had one," Arnow joked.

Today, disabled adventure sports – "adaptive recreation" – are more popular than ever before. You might chalk it up to innovation; in the last few decades, injured athletes have refined the tools and skills they need to get outside. You might point to the long wars in Iraq and Afghanistan, which have disabled thousands of Americans and channeled public and private dollars toward their sports. Whatever the cause, the limits have shifted for those with physical disabilities. Organizations around the West have found ways to adapt almost any adventure sport; a disabled person can raft, surf, water ski and paraglide – if necessary, in a rig hitched directly to a wheelchair – and that list scarcely scratches the surface. Last year in Colorado, Vail hosted one of the country's first competitions for disabled rock climbers, and an Iraq War veteran who'd lost both arms in combat completed the state's prestigious Leadville 100 Mountain Bike Race. In February, adventurer Sean O'Neill became the first paraplegic to ice climb Telluride's 365-foot Bridal Veil Falls.

But for many disabled athletes, particularly those with spinal cord injuries, getting outside remains a tough and unglamorous endeavor. Arnow was the first person to crutch-hike the Bright Angel Trail – in the end, the round-trip took him 12 hours – but he is quick to note that such records may have little meaning. Partial injuries such as Arnow's, in which the spinal cord is not completely severed, are idiosyncratic, with unpredictable symptoms. "There aren't that many of me around," he says. "I had to come up with a lot of stuff on my own."

Arnow grew up in Syracuse, N.Y. At the age of 26, when he was enrolled in the Yale School of Medicine and not yet paralyzed, he was assigned a rotation in family practice in Kayenta, Ariz., a Navajo town a few miles from the buttes of Monument Valley. Until that summer, he'd slept only a few nights outside, but he joined a Utah raft trip, and hiked in the high desert and the Rockies. "Snow in the summer, and I've never seen mountains, wildflowers," he recalls. "It was an epiphany. I went back to Yale an absolutely transformed person." Intent on returning to the West, he applied for a residency at the University of Colorado hospital in Denver and, while there, made his first backcountry ski turns and learned to climb. After graduation, he partnered with a young alpinist named Charlie Fowler, who was making a name for himself as one of the most daring and dedicated climbers on the continent. Together they scaled ice routes in Canada, and put up a new line on an 18,000-foot peak in the Peruvian Andes. Arnow established himself as an ear, nose and throat surgeon in Reno, Nev. For the next 15 years, he crisscrossed the Sierra Nevada range, climbing and skiing. Each winter, he spent a week in British Columbia, hunting powder turns by helicopter.

Arnow took great pleasure in moving through remote terrain swiftly on skis. He avoided resorts, but in February 2002, he joined a friend at Alpine Meadows, a ski area in California. They rode a chair to the top of the mountain and hiked to the head of a chute called the Keyhole. The air was cool and clear. Lake Tahoe glistened in the distance. Arnow clicked into his skis and dropped in. He took two turns and yelled up to his friend, "I'm good!" He turned again and lost control.

Over the previous days, a warm front had driven rain high up the slopes. Then temperatures plummeted, freezing the saturated snow. Arnow, a powder hound, rarely sharpened the edges of his skis, and now he couldn't stop. He picked up speed. The chute forked, and he careened over the rocks in between. When he woke, he struggled to catch his breath and saw feces and blood. He'd punctured his lungs, and the lobes of his pelvis had been driven in opposite directions "like two propeller blades," ripping his colon from his rectum, and opening a wound "you could put a fist in," he says. He had cracked his sacrum and burst his highest

lumbar vertebra, damaging a bundle of nerves at the base of the spinal cord called the cauda equina. He couldn't feel his legs. When his friend reached him, Arnow deadpanned, "You know, I've skied that better."

Arnow spent 51 days in intensive care in Reno. Then he moved with his wife, Debbie, and 12-year-old son to Englewood, Colo., to be treated in Craig Hospital, a leader in rehabilitation for spinal cord and traumatic brain injuries. Craig attracts military veterans and outdoor athletes and is known for the adventures it offers – sailing, horse-packing, scuba diving and downhill mountain biking, to name a few. Due to the misery and disorientation of their injuries, patients sometimes shy away from sports, but athletics can work wonders, says Claire Cahow, one of Craig's recreation therapists. "They get away from a hospital setting and realize, 'Oh my God, life is going on out here. I need to join in.' "

Colorado was familiar ground, not only for Arnow, but also for Debbie, a nurse who had studied and worked in the Denver area in the past. Their combined medical expertise would prove invaluable in the months to come, but they would nonetheless face a steep learning curve. When Arnow arrived at Craig, he weighed 110 pounds – thin enough that his watch slid onto his biceps if he lifted his arm. His doctors had put his chance of survival at less than 1 percent, and he'd barely beaten the odds. "I was such a basket case," he says. "I was very much in pain." Cahow took him into her office and showed him videos of other disabled athletes, most notably Mark Wellman, a paraplegic who scaled the 3,000-foot face of El Capitan in Yosemite National Park in 1989. For that climb, Wellman had done more than 7,000 pull-ups, ascending ropes fixed by an able-bodied partner. It was an opening act in the era of adaptive adventure sports. "It was massive," says one writer who specializes in spinal cord issues. "That climb blew open the doors." Arnow, who had climbed El Cap six times before he was injured, wondered if he would perform such feats again.

Victims of traumatic spinal cord injuries can spend months or years in denial, fighting the finality of their loss, sometimes searching in vain for a cure. When someone loses the ability to walk, "there's a clutching that goes on," says Candace Cable, a disabled rights advocate and athlete who has won a dozen Paralympic medals. After damaging her spine in a car accident in 1975, she isolated herself

from family and friends, bewildered and depressed. Eventually, she found camaraderie and self-confidence in athletics. She hadn't been a competitive athlete before her injury, but she went on to help pioneer the sport of wheelchair racing, won the women's wheelchair division of the Boston Marathon six times, and became the only American woman, disabled or otherwise, who has taken an overall title in World Cup Nordic skiing. When she met Arnow, he impressed her with his unflinching appraisal of his injury. She lives near Lake Tahoe, as does Wellman. The day after Arnow returned from rehab, he called both of them. "He was looking at the problem and saying, 'Hmm, OK, let's just see how we can make this work for me,' " Cable recalls. "He fully understood the ramifications."

In 2001, Barry Corbet, a paraplegic journalist, delivered a speech at Craig Hospital describing those with spinal cord injuries as "conquerors of the ordinary." Corbet had been an accomplished climber before he broke his back in a helicopter crash in 1968, and the comment was a riff on the title of a classic mountaineering book, *Conquistadors of the Useless*. At Craig, Corbet spoke on a topic most of his audience already knew too well: For those with damaged spinal cords, daily life demands the navigation of many minutiae, some dangerous. Bowels and bladder become unruly, prone to obstruction, infection and other sudden, unpleasant surprises. Skin ulcers can develop in a matter of hours if a person without sensation rests too long in one position; if infected, they can be lethal. Circulatory problems crop up. Sexual function may fail. "We find adventure in reaching the unreachable object, in scratching the unscratchable itch," Corbet said. "We find it every time our equipment breaks down or an attendant doesn't show up. Our conquests are ordinary as dirt – but they are adventures and it helps if we see them that way."

Just before his accident, Arnow had been planning to ski the *Haute Route*, a multiday journey over the glaciers of the French and Swiss Alps. When he returned from rehab, he found his duffels waiting for him, not yet unpacked. Now, simply getting out of bed demanded the finesse of a rock climber. He could maneuver around the house without a wheelchair, but it was a precarious undertaking – a stumble from room to room, braced on a countertop, a wall, a cane. At the same time, he was becoming acquainted with neurogenic pain, a

chronic condition that can afflict those with damaged spinal cords. Arnow's lower body, otherwise numb, tingled and burned with a severity that defied drugs, and, sometimes, description. He searched for motivation, telling himself he had to set a positive example for his son, but still, the pain isolated him, forcing him to close his medical practice, and leaving him curled in bed for long hours, cut off from his family. The mountains offered solace. "I loved skiing as much as anyone can love skiing," he says. "It was damn important to get back on snow."

Arnow didn't miss a season. In the winter of 2003, he drove to Alpine Meadows, the site of his injury, to train with Disabled Sports Far West, a nonprofit based beside the resort's bunny hill. It was an auspicious, if humble, place for a new beginning. The organization began half a century earlier, when a group of injured World War II veterans, members of the 10th Mountain Division, took to the slopes at small resorts on Donner Pass, above Truckee, Calif. For balance, amputee skiers back then wielded heavy steel outriggers – essentially crutches fitted with sawed-off ski tips. With the Vietnam War, participation surged. "It was crazy," recalls Kirk Bauer, who joined as a participant after losing a lower leg in Vietnam and has since become director of the national nonprofit Disabled Sports USA. "You were scrounging for equipment. You were scrounging around for donations. We were making up the ski teaching methods as we went." In its early days, the group was called the National Amputee Skiing Association. Its model proved popular, and offshoots spread to other ski towns, then elsewhere across the country.

Disabled Sports USA now serves as an umbrella organization for 109 chapters, many of which run year-round, offering more than 40 sports to clients with cognitive and physical disabilities. The military continues to have an outsized effect on disabled athletics as well. Veterans represent a small portion of the active disabled population; even though Disabled Sports USA recruits directly from military hospitals, veterans typically account for fewer than 5 percent of its 60,000 annual clients. But each war nonetheless drives participants, and dollars, toward adaptive sports. It can be tough to wrestle top-notch prosthetics – let alone recreation gear – from private insurers, but the Department of Veterans Affairs is

more generous. For manufacturers in what is, at best, a niche market, its contracts create "a buying power that is second to none," Bauer says. The VA and other government agencies also support innovation in adaptive technology.

Sit-skiing gear was rudimentary until 1985, when a paraplegic Stanford-educated engineer, Peter Axelson, invented the monoski – a molded seat designed to clip into a ski binding. By the time Arnow began relearning his turns at Alpine Meadows, paraplegic skiers could keep pace with their able-bodied partners. Modern monoskiers cinch themselves in with knee and chest straps and wield light outriggers for balance. Aggressive shock absorbers buffer against bumps; some companies sell custom seats. Says Cahow, the Craig Hospital therapist: "You gotta have a good fit for a butt, just like you'd want a good fit for your ski boot."

Arnow started monoskiing hard. "Jon took to it like nobody I've ever seen," says Bob Vogel, one of his instructors, a freestyle skier and stuntman who injured his spine in a ski crash in 1985. "He was skiing all the super-extreme terrain." Arnow used the widest skis he could, and relearned how to arc through powder, where outriggers drag in the deep snow, and monoskiers must balance and turn largely without them. Once, he flew back to British Columbia, chartered a helicopter and thudded into the Selkirk Mountains to carve turns in spring conditions.

Again, his passion came with a price: Monoskis can be hard on the spine. Their shock absorbers can't cushion the largest jolts – such as the jumps Arnow took from cornices – and when the suspension bottoms out, a skier's sitz bones and spine absorb the force. "You get this violent pounding," says Vogel, who reinjured his own spine while monoskiing. By 2009, Arnow had crushed vertebrae above and below his original injury. His surgeons fused his spine from his pelvis to the middle of his back, removing his ability to bend at the waist and making it impossible for him to fold into a monoski. Years earlier, Vogel and others had advised him to take it easy, to preserve what mobility he still possessed. Arnow saw this as pessimism. "Come on. Let's go. Use it up," he had said. "You're going to fall apart sooner or later."

The surgery was a mixed blessing. His original accident had left him bent at a 30-degree angle from the waist, making it hard for him to balance on his feet. Now, for the first time in seven years, he stood upright. He could crutch-hike.

Most media coverage of adaptive sports follows a predictable plotline: An athlete suffers an accident, struggles with his injury, and overcomes it. It's a story for which Arnow has little patience. Triumphant narratives don't square with his experience, which is riddled with setbacks. His pain has never ebbed. He has tried many remedies – opiates, acupuncture, massage and meditation – but he has come to believe that the best solution may be a simpler one. "You can talk about drugs all you want, but it turns out that distraction is what keeps your spirits up to go another day," he says. "And the outdoors stuff has been my great distraction."

In 2009, after his second major surgery, he learned to crutch-hike. He had been training his upper body since his accident – handcycling, poling a Nordic sit-ski on cross-country trails, lifting weights in his garage – but dry, unpaved ground presented a new challenge. "You ask really ridiculous things from your arms," he says. In part, he wanted new tools. He contacted a Canadian company, SideStix, whose co-founder, Sarah Doherty, was the first single-leg amputee to summit Alaska's Mount McKinley. SideStix crutches can be fitted with tips of various shapes for sand and snow. Some models include shock absorbers to minimize the strain on wrists, elbows and shoulders, which, in many paraplegics, succumb to arthritis, carpal tunnel syndrome and other ailments. Arnow talked his way onto the SideStix product testing crew, promptly wore out an attachment shaped like an over-sized ski-pole basket and convinced the company to redesign it. Then he took his crutches snowshoeing. In the summer of 2010, at the age of 53, he completed the 165-mile Tahoe Rim Trail, a circumnavigation of the heights around the lake. He was the 1,166th person to do so, but the first to make the trip on crutches.

Arnow has never reopened his surgical practice, but in 2011, he began working again, this time as a consultant for Nevada Social Security Disability Insurance, a position he still holds. He also applies his medical expertise on an online spinal cord injury forum run by Rutgers University. He is a moderator there, and one of his threads, a simple prompt urging others to share their workouts, has drawn more than half a million hits and created a large community of similarly disabled

athletes. Arnow is also well known for his posts on chronic pain. He has become something of an expert on the topic. In early February 2012, he acknowledged the 10th anniversary of his accident with an unusually downtrodden post. "There has been so much pain, daily pain, that makes getting through each 24 hrs a huge challenge," he wrote. "Not one in 3,650 days has ended well and peacefully. ... I am so beat down from the chronic pain, and all the meds to manage it."

Exercise exacerbates Arnow's pain, but the endorphins it generates help him cope. "Maybe there is a fine line that is just the right amount," he says. "I have not found that yet. I'm unlikely to." Crutch-hiking is particularly painful, due to the strain it places on his legs. These days, he has almost completely given it up because he has found a replacement: kayaking, which is, usually, easier on his body. He must fight his fused spine to sit upright in the boat. On one outing, in 2013, he spent five hours paddling the San Francisco Bay; afterward, he realized he had developed a 1-inch pressure sore on his left buttock. (Without gluteus muscle for padding, his skin had been sandwiched between his ischial bone and the hard plastic seat and, of course, he hadn't felt it.) Cursing his carelessness, he cut a hole in the kayak seat and stitched in a neoprene hammock for his sitz bone. He has purchased several boats since and added padding in each.

Arnow would like to become a proficient saltwater paddler, then head to Baja, and up the Inside Passage to Alaska. For years, he moved, while outdoors, at a faster pace than his family. Lately, he has begun to hope that Debbie, his wife, will join him on the water. He often studs his posts on the Rutgers forum with pictures of his trips – the play of shadows on the canyon walls above flatwater on the Colorado River, winter light on the tufa formations of California's Mono Lake, a geyser in Pyramid Lake in northern Nevada. In December of 2013, he took a photo as he paddled beside a curtain of icicles on the east shore of Lake Tahoe. He posted it with a note: "So beautiful. I don't feel disabled for a change."

Before dawn on the first day of 2014, Arnow met Mark Wellman, the famous paraplegic El Capitan climber, at a boat launch on the north shore of Lake Tahoe. Wellman has made a career delivering inspirational lectures and educating people about adaptive sports. He spends part of his time towing a portable climbing wall around the West, using pulleys to help people climb out of their wheelchairs. "It's

pretty cool to see a kid that was born with cerebral palsy, that's trapped in a body that doesn't work, and they might not be able to speak, but they've got a big smile on their face and their parents are crying because they've never seen them do something like this," Wellman says.

After Arnow's accident, the two became friends and frequent outdoor partners. Now, they stuffed their kayaks with camping gear and set out, paddling the shoreline. It was a warm weekend in a mild winter, and the water was calm – "absolutely glass," Arnow recalls. The weather remained that way for the next two days, and although they'd camped by kayak only once before, they moved efficiently and independently. In the evenings, they nosed onto beaches, spread tarps between their boats to keep out the sand, and feasted on smoked salmon and crackers. They slept beneath the stars. Each morning, they woke before dawn, brushed the frost from their sleeping bags and pushed onto the water. The trip was another milestone – the first paraplegic kayak circumnavigation on Lake Tahoe – and the lake was deserted on the New Year's holiday. They had it all to themselves.

This story is part of an [April 2014 special issue of the](https://www.hcn.org/issues/46.6/) (<https://www.hcn.org/issues/46.6/>) HCN (<https://www.hcn.org/issues/46.6/>) magazine devoted to travel in the West (<https://www.hcn.org/issues/46.6/>). Terray Sylvester is a former HCN intern. Originally from the Lake Tahoe area, he now lives in Berkeley, Calif., where he travels mainly by bicycle, dodging car doors and potholes, dreaming of peaks.

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