

BACK TO SCHOOL:

Stories of Success on Campus

BY STEPHANIE D. LOLLINO

Going to college is a major life change for anyone, and it may present an especially daunting challenge for wheelchair users. Yet students who use wheelchairs frequently report they can usually find their way around accessibility problems. The main issue, they say, is figuring out how to make the “back to school” transition.

“Once you’ve set the goal that you’re going to do it,” says Kris Cichowski, founding director of the LIFE Center at the Rehabilitation Institute of Chicago, “make sure you’re medically ready. Do you have your care down? And maybe that doesn’t mean you do it yourself, but can you instruct other people? Have you put yourself out in the community? Test-



Living in a dorm helped Carrie learn to manage her care and live independently.

ed the waters? I don’t think there’s ever a time you can say, ‘Yes, I’m totally ready right now,’ because a lot of times you have to jump off and see how it works.”

Following are stories of people who took that jump and discovered they handled college just fine.

Going Away to College

Carrie, 32, C5, DePaul University, Chicago

Carrie became a quadriplegic in 2003 while attending DePaul University in her hometown of Chicago. When she was ready to return to school, she discovered her dorm was accessible and all she needed was just a little assistance. Fortunately it was easy to find.

“When I went back to school, there were all sorts of accommodations. There were people to take notes and I had a personal assistant who’d come to class with me,” says Carrie. “Teachers are willing to make accommoda-

tions — they’ll even move the classroom if needed. For taking tests, I would dictate the answers to my computer, and the professor was always OK with it. Sometimes I could email stuff in, so keeping up was much easier than you would think. It was great to be right on campus, in the city and not at home.”

Carrie’s mother, Pamela, was astounded when her daughter decided to move onto campus, especially since she had only spent one semester after her injury commuting back and forth from home: “She lived in a dorm room by herself, and her personal assistants would come and go. And then unbeknownst to us, prior to graduation, she found herself an apartment.”

Carrie has been living independently ever since.

Commuting From Home

Nick, 37, C5-6, Chicago Community College and University of Illinois, Chicago

Nick sustained his injury just as he



Commuting from home proved a good option for Nick while he finished his degree.

Visit the Campus

“I would encourage people to reach out and meet students at your prospective school, see where you’re going to live, get an idea where the dining hall is, things like that,” says Everett Diebler, 31. Everett, who has CP, attended Millersville University near Lancaster, Pa., and has a bachelor’s in psychology as well as a post-baccalaureate certification. “Be sure you know where your classrooms are going to be, check out the housing halls. These are things you might not get a sense for when you’re on a tour.”



“It was three months after I was injured that I went back to school, and my family was over 500 miles away. Now, I have a master’s degree in community economic development, and I’m going for my Ph.D.”

– Megan, 38, who became paraplegic at age 18 and attended the University of Texas at Austin

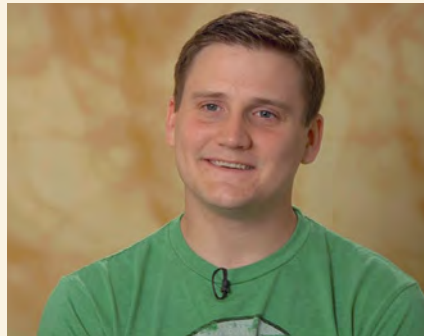
Have a Support System

“My family was within an hour away, and the Hershey Medical Center was close by,” says Paul Fogle, 31, who has a bachelor’s in public policy from Penn State Harrisburg. He has a pulmonary disability and uses a scooter for mobility as well as a ventilator at night. “If there was an emergency, I would call my family.” If your school is far from family or your own doctor, be sure to create a new support system, whether it be friends or getting support from a local United Spinal chapter or Center for Independent Living.

was about to finish high school, and he recognized college would be especially important for him. “Since my level of injury is C5-6, I knew I wouldn’t have many transferable skills to offer the marketplace without a degree,” he says.

He began school by taking it slow. “I started off at a community college because I was still becoming independent and working through some daily routine issues.” He also had a few medical setbacks but was determined to complete his degree.

By the time he started his undergraduate social work studies at the University of Illinois, “I was almost four years post-injury and completely independent with personal care and driving. I rarely utilized services from the Disability



There’s no need to rush back to school, says Patrick. Do it on your own schedule.

Resources Office and only experienced one issue with one of my classes being scheduled on the second floor without an elevator. By the next day, the classroom location was moved.”

Nick continued to commute from home. Since the majority of his classes were all within a half-block radius, living on campus offered no extra convenience. He earned a bachelor’s as well as a master’s degree in social work.

It’s OK to Take Your Time

Patrick, 29, C5-6, Drexel University, Philadelphia

Patrick sustained a C5-6 injury at age 21, and as he was still recovering six months post-injury, he decided going back to college full-time was too much. “I tried pushing around every day, and I was like, I’m not ready for this.”

He took an online class to start, and by the next term went back to classes as he was stronger and felt more confident.

Also, he had a reliable support system on campus. “My mom actually works at my college,” says Patrick. “So she would come to help me whenever I needed. It was wonderful. I graduated with a degree in business and engineering. I know it sounds weird, but with having the accident, so many more opportunities have opened up for me. I think I have more opportunities now than before.”

Jack, 67, T12-L1, University of Illinois

Jack became paraplegic many years ago at the age of 26 just as he was about to graduate from college, and he agrees with Patrick that having a spinal cord injury can change the course of your life, inadvertently leading to unexpected possibilities. “I broke my back two weeks before I graduated from undergraduate school,” he says. “I had a job waiting for me in Aspen, Colo., as a surveyor and land planner. I often tell people that if I had taken that job, I’d probably be a



Jack credits his SCI with changing his career path from ski bum to architect.

burned-out ski bum bartender in Aspen right now, as opposed to a professional with my own business.”

After earning his bachelor’s, Jack went back to graduate school to get a degree in architecture.

Figure Out Your Care Before Classes Start

Molly, 25, C5-6, Stanford University and University of Michigan

Since Molly became a quadriplegic at 15 while still in high school, she began learning how to handle her care in a classroom right away. “My sophomore year I was part-time,” she says. “I did two classes in the hospital in the fall, and then three in spring. Then my junior year, I went back pretty much full time.” She went to summer school, determined to graduate on time, so it’s no surprise she tackled college head-on as well.

“Basically, I decided I was going to go where I wanted to go to college and then figure out the accessibility part later,” says Molly. “I went to California with my mom specifically to look at schools.

Have an Assistance Plan

As Molly discovered, most colleges and universities offer no help securing personal assistance services or aides. Therefore, it is best if you have your services in place before you show up on campus.

If you receive personal assistance services, speak with your current service coordinator and let them know where your school is located. Some Medicaid-funded programs will allow you to keep your services uninterrupted even in other states, and will help you to coordinate with a local agency.

Paul says he already had personal assistance set up and just needed a large enough living area to accommodate his aide. “Penn State has pretty conducive housing arrangements for folks needing attendants,” he says. “My dorm room was like an apartment suite, so there were four single bedrooms, one common living area, a kitchen, bathroom and living area. It was pretty big.” His attendant did not get a bedroom, but since she was on duty at night, it didn’t matter. “She hung out in the living area and it worked,” he says.



Locking down your plan for hiring caregivers can relieve the stress of being away from home, says Molly.

I liked Stanford, so I applied and got in.” Two weeks before the term began, Molly pulled into town, moved into her dorm and began learning to live on her own.

It turned out managing her daily care was more stressful than she had anticipated. “I was hoping Stanford could help me find caregivers, or could at least suggest some agencies or help me advertise,” Molly recalls. “They basically said that was not a service their office was going to provide; they weren’t going to help with that.”

After dealing with a series of incompetent caregivers, Molly found a way to do many tasks for herself. “There were a couple of days where no one showed, so that meant I couldn’t get out of bed, couldn’t get dressed, couldn’t go to class. You can imagine living 2,000 miles from home, not knowing anyone or having any friends and starting classes, how hard that was. That was really stressful.” Her solution: “I stopped using the caregiving agencies and advertised on campus to hire grad students or their spouses.” That was the magic combination. Once Molly discovered a reliable pool of responsible people she could train to be her caregivers, getting on with school became her main focus. However, since they were not eligible for payment from government programs, she had to pay them out of her own pocket.

Molly finished college and will start medical school at the University of Michigan this fall.

Nico, 21, C3-4, University of California at Berkeley

Nico, who is quadriplegic as the result of an injury at age 15, is having a fantastic caregiving experience at college. He is in the Disabled Students’ Residence program offered by the University of California at Berkeley.

His mother Audrey says, “It really is

the best thing that has ever happened to him, and to us, because they take care of everything that worried me about sending him to college. It has been so wonderful because he is encouraged and enabled to do things himself, and for better or worse, there’s always a responsible adult around in case he needs one. At this point, we are so happy that he is there and that he is feeling independent. He has a peer group of other students who have major disabilities. They’re all intelligent kids, they’re all getting on with their lives, and it’s kind of like this whole band of young people, who are like, “OK, so I got a problem. What’s your problem?”

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For parents like Audrey, watching their kids discover newfound independence at college is profoundly rewarding.

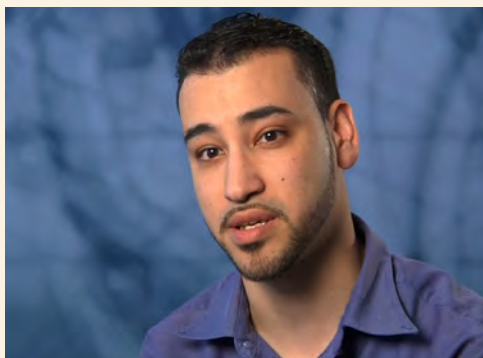
Stephanie D. Lollino, executive editor of FacingDisability.com, is a television producer and writer who has worked with the website since its inception. Her extensive background in research, media and creative communication turns the task of improving the lives of others into a dream job. “Making people aware of SCI and everything that goes along with it is something I’m really proud to be a part of.” For more information from FacingDisability.com on going back to school, visit www.facingdisability.com/spinal-cord-injury-videos/education

Resources

- **Centers for Independent Living**, www.ilru.org/projects/cil-net/cil-center-and-association-directory. Located nationwide, CILs are a great resource for finding personal assistants, learning the accessibility of a new city and more.
- **FacingDisability.com**, www.facingdisability.com/spinal-cord-injury-videos/education. Although primarily operat-

ing as a resource-packed website, FacingDisability.com has other programs as well and can be reached by phone at 312/284-2525.

• **United Spinal Association**, 800/404-2898; info@unitedspinal.org, www.unitedspinal.org. United Spinal has hundreds of chapters and support groups across the country that can be tapped as part of your support system.



Joel, 34, sustained a T11 injury during high school and wanted a college with a schedule that would enable him to work full-time while going for a degree. He decided on Northeastern Illinois University and discovered, to his relief, that accessibility was not an issue. "As long as I was able to enter and exit buildings, classrooms and the all-important washroom — I was OK," he says. Later Joel attended Dominican University for grad school and visited the campus beforehand to make sure it met his requirements for accessibility.

Get to Know the Office of Disability Services

It's best to meet with your school's Office of Disability Services a few months before you're due to show up on campus. This is when you'll discuss what accommodations you'll need, such as ensuring all of your classes are held in accessible buildings. The school will ask for medical documentation, and usually a letter from your doctor or a copy of your high school individualized education plan will do the trick.

"If you set up a meeting with the Office of Disability Services before you start classes and talk about accommodations you might need, then before the semester begins you get the accommodation letter that spells out what you're eligible for and you take it to your professors," says Everett.

This is the meeting where you ask for a note taker if you think you'll need one. "I used note takers in big lecture hall situations," says Everett. He says there are two ways to get one. Either the university will provide one, or

you may pick a classmate. "Then that person gets paid through the Office of Disability Services. So they are taking the class as they normally would, but get a little bit of money." That's a sweet deal for a struggling student.

If you plan to live on campus, arrange to meet the school's housing staff at the same time you meet with Disability Services. Not only does this allow you to ensure your needs are met ahead of time, but it also gives you an opportunity to establish a rapport for when things go awry.

Everett did everything right, met with the appropriate people, and still found himself in a building where he could not access the laundry facilities. "The washers and dryers were down steps into the basement and that didn't work," he says. But it was an easy fix, especially since his accessibility needs were well-documented, and he was quickly moved to a building with an elevator right to the laundry area.

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