



Value of Specialty Rehabilitation Initiative Maximizing Rehabilitation Outcomes and Reforming Lives

The value of maximizing rehabilitation. Across the spinal cord injury and disorders (SCI/D) community, the United Spinal Association and our partners support maximizing individuals' health and functional rehabilitation outcomes in order to increase their independence. Increased independence furthers education and employment opportunities and enhances the ability of individuals with SCI/D to integrate more fully into communities and to contribute to the economy.

Across the country, SCI/D rehabilitation programs vary greatly in the quality of services they can provide individuals living with SCI/D in order for them to maximize their health and independence. Lower quality of services may result in increased hospital readmissions, secondary chronic diseases (diabetes, hypertension) and a decrease in quality of lives.

Value of Specialty Rehabilitation Partners

- Academy of Spinal Cord Injury Professionals
- American Spinal Injury Association
- Brain Injury Association of America
- Center for Medicare Advocacy
- Christopher and Dana Reeve Foundation
- Colorado Acute Long Term Hospital (CO)
- Gaylord Hospital (CT)
- Harvard Medical School/Massachusetts General Hospital (MA)
- Kessler Foundation (NJ)
- NIDILIRR's Model Systems Knowledge Translation Center (Washington, DC)
- National Spinal Cord Injury Statistical Center, University of Alabama at Birmingham (AL)
- Mount Sinai Hospital (NY)
- National Coalition for Assistive and Rehab Technology
- National Multiple Sclerosis Society
- Paralyzed Veterans of America
- Shirley Ryan Ability Lab (IL)
- Spina Bifida Association
- TIRR Memorial Hermann (TX)
- United Spinal Association
- University of Minnesota, Department of Rehabilitation Medicine (MN)
- University of Pittsburgh Medical Center (PA)
- University of Texas Medical Branch, Galveston (TX)

Surviving Modern Rehab: A Tale of Two Injuries,
United Spinal Association's New Mobility Magazine, 10/18

<http://www.newmobility.com/2018/10/surviving-modern-rehab-a-tale-of-two-injuries/>

“.....Edie Perkins was the only person on the unit with a spinal cord injury, and the only one in her age group. She had a private room, ate meals in her bed. There was little social contact with other residents, most of whom were elderly and had had strokes. “The staff, they cared, they wanted to help me. Even though they were nice, they didn't seem to have experience with some basic things about SCI.”



Edie Perkins at home

You'd think a rehab hospital in a major metro area would have the rudiments of neurogenic bowel and bladder care down. Perkins said she was transferred to a commode, expected to urinate on her own, and to move her bowel unaided.Perkins wondered if her urologist had any SCI-specific training. “He kept getting mad at me for having to pee so much at night. This required a nurse to cath me, which they often neglected to do. In the morning I would have 1,000-plus ccs of urine. The doctor told me not to drink so much water. I learned later that people with edema would retain a lot of fluid in lower extremities, and therefore urine output increases at night. Seemed strange that a urologist wouldn't know that.”

The urologist also put Perkins on antibiotics in advance of her having any symptoms of infection. This made her nauseated and interfered with physical and occupation therapy. Getting her full allotment of therapy time was another struggle. “Usually what would happen is the nurses would neglect to get me up and ready for PT/OT. They would leave that to the first therapist to appear,” says Perkins. “It would infuriate me. We'd waste a whole session with the PT changing my diaper, putting my pants on and getting me into the chair. So I made a stink. The administrators responded well enough to my pushiness. But it was still hard to get nursing to comply.”

....When [her facility] deemed her rehabilitated, she wasn't close to being ready for home. **Her HMO approved Perkins to enter [a Transitional Living Center] — not full rehab services, but good prep for getting back home. Besides having a board-certified SCI doctor she trusted, Perkins discovered another key thing community. She was met there by peer mentors**[from a chapter of United Spinal Association), and [another individual with SCI] who she would see again at [the facility's] peer support program. **“It was so moving, so motivational to have these guys wheel into my room,” she says. “I always had a sort-of vision that I'd become independent. I hadn't lost hope. But I had no idea what that looked like.** These cool guys zipping around, they were the first people I'd met who looked comfortable and cool in a wheelchair.”

[United Spinal chapter representatives see] SCI newbies all the time. “There's no denying it, these folks are devastated. But we are there for them,” **“We share our testimony: We're married, have homes, jobs, we've got responsibilities and lots more things planned. We do what we can to exert positive energy.”**

.... **[Edie] got valuable advice about the new lifestyle, and also about dealing with such things as spasticity and pain. “These guys were so much more helpful with some medical issues than the actual doctors were.”**