

Learning Curves

Preparing patients for challenges and opportunities post-rehabilitation

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How do patients learn? This question is often overlooked in medical rehabilitation, yet persons with chronic and progressive disabilities face enormous learning challenges. They must not only integrate a flood of new information, but also negotiate the challenges of layered learning: relearning, unlearning or adapting what they already know in order to re-establish their lives.

Learning how to care for the body and manage disability and chronic pain are complex learning curves. I think of the process as concept education: they are learning how to respond to their medical needs on a moment-to-moment, day-by-day basis, entering a world of new concepts.

Practitioners should explore the best way to teach these concepts in order to maximize their patients' abilities to integrate them into their daily lives.

Concept Education

The remarkable story of Ken Kunken, Esq., offers insight into the complex journey of layered learning for persons with disabilities. Kunken, now 58, suffered a spinal cord injury (SCI) during a college football game in 1970. He has lived with quadriplegia for 38 years. He currently serves as a deputy bureau chief for the Nassau County district attorney's office in New York, supervising 26 assistant district attorneys.

"Every step of adjusting to life outside the hospital was challenging," Kunken said of his process of learning to manage his disability. "There were so many challenges... my physical care, how to work with an attendant, how to go back to school, how to take notes and take tests. I felt there was very little encouragement."

Kunken did not simply want to survive, he wanted to succeed. The learning curve, however, was more than he expected. Even learning to respond to his body's needs was a trial-and-error process.

"I had to constantly learn more about what my body is telling me, what I need to do to care for it," he explained. "I had to learn how to be attuned, how far I can push myself-that would not jeopardize my health while not being fearful to push myself to more."

For example, Kunken, like many individuals with SCI, found learning to regulate his body temperature difficult. "I remember being in class shivering and sweating, I would be either cold or overheated."

Clinicians should listen and respond to each patient's individual needs, feelings and concerns, he suggested.

"Medical professionals do know a lot-but patients also know what is happening inside their bodies.

Communication needs to improve in this area."

Exploring Potential

After Kunken was discharged, he began the process of rebuilding his life. He remembers an article in a rehab magazine that described the limitations he would face due to his SCI.

"[It] was accurate and described me to a T-except for careers," he recalled. "It said that I would be able to sell magazine subscriptions over the telephone. Years later, my doctors could not believe what I accomplished. It was a

compliment, but also upsetting. Why were they surprised? Why are they not expecting more for their patients? More people could do what I am doing."

Before he became a lawyer, Kunken worked as a rehabilitation counselor providing vocational counseling and placement to severely disabled individuals. He found that many others with disabilities also were not encouraged to explore their career potential.

"As a rehab counselor. I was exposed to what disabled people are able to do," he said. "I would encourage doctors to come and see what disabled people can do, so they can include it in their treatment planning-to better help prepare patients during the rehabilitation process."

Kunken strongly advocates rehab treatment teams check in with patients about their life goals. He believes it can be a powerful connection for patients to see that the skills they are learning in rehabilitation can lead to bigger goals.

"Helping patients find life goals they can work toward and envision will also help them through their rehabilitation. When patients know that there is a future out there, that they may be able to live independently, they have something to look forward to. It can provide motivation to work through tough moments."

Striking a Balance

The most challenging issue to negotiate when contending with disability is the delicate balance between dependence and independence. In almost every domain of his life, Kunken had to define what it meant to preserve his independence.

"When I started working [as a rehab counselor], I first had an attendant," he explained. "It started to pose problems in counseling sessions with clients, and it took away from privacy. I had an employer who encouraged me to be independent for eight hours a day without an attendant; it was a gift."

As a law school student, achieving independence required ongoing adaptations. Despite these challenges, Kunken was able to complete law school in three years and pass the bar exam. He has carried this sense of interdependence into his current role as a supervising attorney.

"I have had to learn how to verbalize my needs. In my current role, I do not have an attendant; my staff-from secretaries to interns-assist me."

Kunken notes that the key to discovering interdependence is exploring what you can confidently do on your own, and to ask for help when you need it.

Deborah Links, MA, educator and learning specialist, added that in the process of learning, it is important to help patients feel safe so they can venture out to places where they have not been. The goal is for patients to express, without fear, "I need help with this," rather than, "There is something wrong with me."

Social Learning

Social learning-learning how to adapt in work, social settings and relationships-is essential to wellness. Clinicians need to incorporate discussions about social issues and options into the treatment plan.

"I believe that rehab professionals need to become experts on how to live in the world," Kunken stressed. "Not just what kind of exercises to do, but what types of recreational activities are doable with a disability? How can patients be more involved in social settings? It would have been helpful to meet some role models, not just [for] school and work, but [in] social and personal life."

Kunken had to learn to adapt interpersonally in different realms. Socially, he had to stretch himself. In the classroom, he had to put in extra effort to adapt his learning style.

"I used to sit in the back of the classroom," Kunken related. "I had to switch my learning style and sit in the front of the classroom and raise my hand and learn to be more verbal and ask questions. It was a difficult adjustment. Now, I give speeches in front of audiences of 250 and feel comfortable."

When he became an attorney, Kunken needed to adapt his social skills to yet another realm—the courtroom.

"In court, I had to find ways to also bridge a connection. It took some getting used to. I would talk without notes. I would focus on engaging the jury with eye contact," he explained. In the end, "I had to learn how to be myself. If I acted comfortable, then everyone else got comfortable and focused on my ability, not my disability."

Learning Coping Skills

Chronic, progressive or even temporary disabilities create stressors that constantly shock the mind-body system. Coping involves an ongoing learning curve to manage the stress.

"I had to find new ways to relieve stress. Before my accident, I relieved stress through athletics," Kunken said.

"After my accident, I had to find ways to relieve stress through my mind... It was an adjustment to stay at home and read or be verbal instead of being part of a team and playing on the field."

Even when patients find new mechanisms to manage stress and anxiety, coping is still a daily effort, one that often needs to be relearned every day.

"At night I would dream I would be up on my feet and active, and then in the morning, I would not be mobile again. It was a daily challenge for me," Kunken admitted. "It is a lot easier to keep and maintain friends when I can keep a good attitude. Every day I would say to myself, 'Am I going to enjoy it or not enjoy it; am I going to have a good time or not a good time? Am I going to find positive things and not negative?'"

Ongoing learning requires endurance, so it is important to foster this capacity in patients, Links added.

"Every day we are alive, we are making choices of how we choose to see ourselves," she said. "Whatever has transpired in the past is background—we can't change it. It is important to teach people how to be in the present, being present is a full-time job."

Learning Hope

It is also important to remember that hope is not a given. However, it is a lesson that can be taught. Kunken strongly believes that rehabilitation professionals are in a position to teach patients how to have hope.

"After my injury, I felt that the medical team I worked with wanted me to be realistic about my injury," he said.

"They took away all my hope. My rehab took the path of 'now let's bring your fork to your mouth.' My family and I were doing everything we could to stay hopeful. Medical professionals need to remember that hope is a great motivator."

Continual education and goal setting were two strategies that helped Kunken refuel his hope. He took great lengths to advance his place in the world through education. He holds a bachelor's in industrial engineering and operations research and a master's in arts counseling and student personal administration, both from Cornell University. He went on to earn a master's in education in psychology and rehabilitation from Columbia Teachers College and his law degree from Hofstra University.

Challenging patients-especially patients with complex disabilities-to get involved with new activities is essential, Kunken stressed.

"I realized I had to make the most of my mental abilities, especially since I lost my physical abilities. I refueled on hope by setting new goals. Once I mastered a task, I would then go on to the next challenge. I enjoyed rehabilitation counseling, but I wanted a new challenge, which is why I went to law school. I had the feeling there was more. Goals helped me to feel hopeful."

Links shared that clinicians can further help and encourage patients by supporting their efforts to set and accomplish goals.

"[Rehab patients need] champions, those individual connections that help patients recognize the potential in themselves," she continued. That support is "not only limited to scheduled visits, but [also in the] partnerships that exist in between sessions."

Kunken is now embarking on a new learning curve, the most satisfying one of all, as a husband to his wife, Anna, and father to his three sons, Timmy, Joey and James. His accomplishments in every aspect of his life serve as a reminder that by working through all kinds of learning curves, rather than letting challenges derail progress, patients can lead meaningful and highly productive lives.

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Resources

- Department of Education Office of Special Education and Rehabilitation Services

www.ed.gov/about/offices/list/osers/rso/index.html

- CBS-TV News Segment on Ken Kunken

<http://wcbstv.com/health/Ken.Kunken.Rockville.2.235723.html>

- Learning Styles Self Assessment

www.ldpride.net/learning-style-test.html

- Ken Kunken

For consultation or information on lectures/presentations, email Ken at kkunken@aol.com. His website, www.kenkunken.com, is currently under construction.

