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RESILIENCE AND DISABILITY IN THE TIME OF COVID-19

Listen to our renowned rehabilitation researchers discuss the impact of COVID-19 on people living with disabilities and learn how you can participate in a study from home. Visit our website at kesslerfoundation.org/covid-19#participate for more information.

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CAREGIVER CORNER

Finding Hope After TBI

By Angela Smith, Senior Research Coordinator, Center for Neuropsychology and Neuroscience Research, Kessler Foundation

On July 3, 2011, Joan Enker's life as a busy wife, mother, grandmother, and caregiver to her aging parents changed in an instant. During a family trip to upstate New York, a young driver struck her husband, Warren, while he was on an errand to purchase additional folding chairs for his family to watch the holiday fireworks display. The trauma was compounded by the fact she had no idea what happened until he failed to return. After several desperate hours of searching, Joan learned Warren had been medevacked to a local facility, but because of the severity of his injuries and the increasing fog, he had been taken by ambulance to Westchester Medical Center.

After three weeks, Warren, a well-known colorectal cancer surgeon at Memorial Sloan Kettering, in Manhattan, was transferred to Kessler Institute for Rehabilitation in West Orange, where he spent seven-and-a-half weeks before transitioning back home to Teaneck, N.J.

Joan remembers how difficult it was to leave home during those early years. "I was very uncomfortable leaving him alone," Joan said. "You are left with residual trauma that keeps you from stepping out." Joan gradually recognized the importance of making time for herself, and she

now takes watercolor classes, does yoga, and socializes with friends.

Their youngest daughter, Aliza, moved back home two years ago and was able to be there this past March when Warren became sick with COVID-19.

At the emergency room, a familiar story played out as they told Joan she could not stay with Warren. However, as his strongest advocate, she has learned to never take no for an answer.

"He has a very complicated medical history as well as anxiety, and there was no way I was going to leave him," she said.

After Warren's discharge from the ER, Joan and Aliza became symptomatic as well. Joan credits Aliza's cooking, along with "time and Cheez-Its®," in helping her care for Warren despite her own struggle with the coronavirus. Lessons learned from prior health emergencies, particularly the importance of having a well-established medical team, also aided their recovery. When the pandemic began, Joan was concerned with Warren's susceptibility, but knowing they had a good support network in place helped her remain calm.

Practicing mindfulness-based stress reduction has taught Joan to cope with caregiving pressures. "I am reactive

by nature, but having the tools to find calmness when I am ready to explode is so important," she said.

In addition, she is a firm believer in the value of education: "Do your homework; know what resources are out there and use them," she said.

She and Warren read "Over My Head" by Claudia Osborne, MD, the memoir of an accomplished physician who sustained a brain injury. "The more tailored the experience is to our situation, the more helpful it has been," she shared.

Joan recommends understanding the brain and the changes that happen after injury. Learning about neuroplasticity in "The Brain's Way of Healing" by Norman Doidge, MD, was a turning point for her and Warren. "It's very difficult to pull hope up from your feet if you don't have something to help you find the way," she said. ■



EXPERT OUTLOOK

Returning to Work After a Brain Injury

By Thomas Shea, PsyD, Vocational Counselor, Opportunity Project



Opportunity Project members, Andy and DaVante, are recognized for their successful employment as part of the 2019 Disability Employment Awareness Month celebration.

Returning to work after a brain injury is an important part of the rehabilitation process. For some, obtaining paid employment is an important milestone in recovery and an affirmation of hard work.

During the past 26 years, Opportunity Project, an internationally recognized Clubhouse model program, has helped over 600 people who have experienced a brain injury. As a vocational counselor at Opportunity Project for the past five years, I have assisted more than 30 people with brain injury return to paid employment.

Those who survive a brain injury may face lifelong physical, cognitive, social, and/or emotional challenges. Most experience mental fatigue. For this reason, we counsel our members to build their stamina through volunteering and encourage them to start work on a part-time basis.

A person seeking paid employment must have the knowledge, skills, and abilities to perform the job. Their success is more likely if they have a job coach onsite to help them manage the transition. Additionally, it is important to have a supervisor who recognizes the value in an employee who has returned to work and understands the daily challenges that employee faces.

Despite having the proficiencies to carry out job requirements, some individuals with brain injury may find their supervisor is not satisfied with their performance. Often this is caused not by the individual's inability to do the work, but by their inconsistent work performance. After a two-month learning period, a person who is performing well may suddenly have difficulty with their job responsibilities and make errors in tasks they previously mastered.

Carry-over learning from day to day is difficult. Sustained effort can be exhausting and may require a change in the work schedule every few weeks (e.g. reduction of hours). Maintaining attention and concentration, especially under stressful conditions, can negatively affect work performance.

For some, shifting from one task to the other and returning to a previous task without reorienting can be another challenge due to gaps in short-term memory. Employers pay their workers to perform consistently and accurately. Finding companies who will accommodate some of these deficits in exchange for committed employees who work hard every day to bring success to their company is of utmost importance. ■



Thomas Shea, PsyD, Vocational Counselor, Opportunity Project

NURSE'S CORNER

Preventing Illness, Developing Preparedness, and Reaching Out During a Pandemic

By Kari Kaminski, RN, BSN, CRRN, and Agata Buczek, RN, BSN, CRRN, Kessler Institute for Rehabilitation, Chester Campus



Although the spread of COVID-19 has begun to wane in many areas of the country, the importance of staying vigilant and following state and local precautions remains a high priority for all.

The COVID-19 pandemic has affected everyone in ways we never could have anticipated. These unprecedented times have added an extra burden to brain injury survivors and their caregivers. It's important to prevent becoming infected, plan for what to do if you or someone in your family becomes ill, and know how to reach out for help to prevent increased stress, anxiety, and isolation.

As we receive new information regarding the virus, it is imperative that we stay well-informed about the latest guidelines in order to remain safe and healthy.

What can you do to help prevent contracting and spreading COVID-19?

- Stay at home as much as possible.
- Practice social distancing; stay at least 6 feet away from others.
- Avoid gatherings of people.
- Frequently wash your hands with soap and water for at least 20 seconds.

- Avoid touching your face, mouth, nose, and eyes with unwashed hands. For those with brain injury who may have restless hands, try squeezing a stress ball, using a fidget spinner, doodling, or playing a game on a handheld device.
- When handwashing is not available, use a hand sanitizer with at least 60% alcohol.
- Clean and disinfect frequently touched surfaces. If you use an assistive device such as a wheelchair or cane, frequently clean all areas that you touch.
- Wear a mask or face covering over your mouth and nose when in public.

What can you do to reduce feelings of isolation and anxiety?

- Stay connected with family, friends, and community through use of technology and video conferencing.
- Check in with your doctors through telephone or video conference. Many medical offices provide services via telehealth platforms. (Do not delay medical care!)
- Build a normal daily routine to regulate sleep cycles. Adequate sleep is imperative for proper immune function and anxiety reduction.
- Practice mindfulness by journaling, meditating, or focusing on deep breathing. Caregivers can also benefit from these practices.
- Exercise daily, even if it is only light stretching or taking a walk around the block, as this helps improve circulation and reduce anxiety.
- Do not neglect proper nutrition and adequate hydration. Eat plenty of protein-rich foods, fruits, and vegetables, and drink plenty of fluids. ■

Additional Resources

If you live in New Jersey, you can visit the state Office of Emergency Management: Special Needs Emergency Preparedness Registry at <https://www13.state.nj.us/SpecialNeeds/Signin?ReturnUrl=/SpecialNeeds/>

Registering will help first responders plan and provide efficient service to those who need it most in times of natural disasters and other emergencies.