



TBI News & Views

A publication of the Northern New Jersey Traumatic Brain Injury System

CAREGIVER CORNER

Team Dan—Caregiving for a Lifetime of Need After Brain Injury

By Justin Gelman, Research Assistant, Center for Traumatic Brain Injury Research, Kessler Foundation

On March 8, 2016, Melissa Moore took her dog on a morning walk before heading to her next shift as an OR nurse. She saw some police cars up the road but did not think much of it—until an officer approached her, asking if she knew a Daniel Moore. As she explained that he was her son, the officer delivered devastating news. Daniel was in a car accident and was being rushed to the hospital, where he was diagnosed with a traumatic brain injury (TBI).

It would be hours before Melissa could see him and even longer before he regained consciousness.

Melissa sat by his bed and played his favorite song repeatedly. Finally, after 10 long days, Daniel began mouthing the words. Despite such an encouraging sign, Daniel had a long way to go. He spent six weeks at Kessler Institute for Rehabilitation regaining strength and rebuilding skills and was finally able to return home.

Melissa transitioned to the role of a caregiver, in which her nursing background proved incredibly useful. Understanding brain injury and the care Daniel received prepared her to help him on his road to recovery.

She deftly managed his daily medication regimen that included 17 medications and ensured he never missed a medical or outpatient therapy appointment. However, Melissa stresses, “As a caregiver, I am a mother first and a nurse second.”

Melissa—and Daniel—also benefited from having a great support network, which she refers to as “Team Dan.” Melissa’s husband, Frank, with whom she had just celebrated their first anniversary, was a constant source of support and encouragement. To give Melissa a much-needed respite from her full-time job as a caregiver, her sister-in-law and daughter moved in to watch over Daniel. In so many ways, the support of family and friends has been vital to Melissa’s ability to serve as Daniel’s caregiver.

Whether it was passing his driver’s test or getting his barbering permit, Melissa has seen Daniel come a long way over the past five years. Daniel’s father even brought him into his bowling league, where he has excelled and widened his social circle. However, Melissa must still provide substantial support to Daniel in managing day-to-day activities, from finances to nutrition.



“As a caregiver,
I am a mother first
and a nurse second.”

— Melissa Moore

“It’s a lifetime commitment. You never think you’ll raise your child a second time,” she says. As Melissa and her husband, Frank, look to retire, they are well aware that Daniel will be with them and remain committed to setting him up for success. As the selfless caregiver she has always been, Melissa is looking for places that can provide Daniel with a semi-independent living situation and ultimately help him be the “Best Danny” he can be. ■

RESOURCE REFRESH

Taking Time for Ourselves and One Another—Lessons from the Pandemic

By Karen Tiseo

Six years ago, my husband John had a near-fatal motorcycle accident resulting in a severe traumatic brain injury (TBI). When the pandemic began, we realized the stress of isolation and fear of the virus affected our emotional and physical health. We used the time to nurture ourselves and reflect on our lives more deeply. My attitude about what is important to me has changed, and I have incorporated this new perspective into my life in the form of healthy daily habits.

One of my pre-pandemic habits was to drag chores that I don't like doing into an all-day event. Now I am motivated to complete these tasks quickly. Spending less time on chores leaves me time to explore new hobbies like knitting or gardening. When I'm really having trouble getting motivated, I play a game with myself—I set a timer for 30 minutes. You'd be surprised how much you get done in 30 minutes when you set that goal yourself. I even finished cleaning out the garage and basement (although it did take a little longer than a half-hour).

Staying mostly indoors for the past 18 months was a challenge. Suddenly, a simple run to the grocery became mission impossible. Planning and writing a shopping list with the items needed to prepare meals from scratch became fun. I found quick, easy recipes online. What a great way to save money and not waste food! I had some fresh zucchini in the fridge



one night and made a delicious five-ingredient parmesan zucchini quiche with lemon garlic yogurt from a recipe I found online at Spoonful of Flavor, one of thousands of cooking sites.

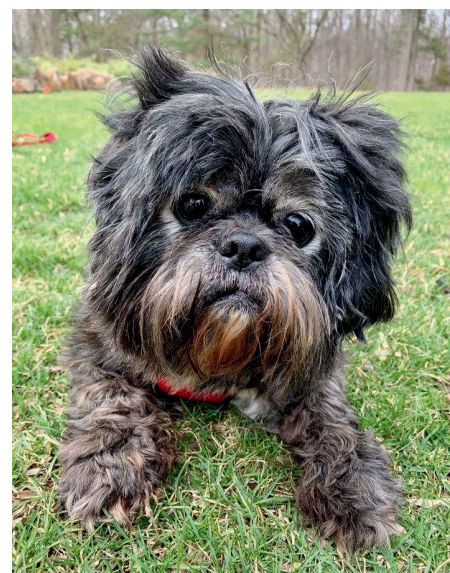
My friend Nancy taught herself how to knit during the pandemic and made a beautiful afghan and scarf, and I decided to follow her lead. Many tutorials on YouTube give step-by-step instructions on doing just about anything, like knitting a pair of socks. I'm learning and have knitted one pair so far! You can even find tutorials on how to build a birdhouse, a project you can tackle with a loved one or a friend via Zoom. I have become much more computer-literate this past year. Last week I had a computer lunch date with friends, and every Sunday, I meet with my mom and sister on Zoom.

Our family adopted a dog in March 2020 with the help of a website called

Petfinder. Walking and spending more time outdoors with John and our dog has become one of our favorite things to do every day.

I find myself taking more time to listen because I'm not always rushing around. I have caught up on many things that I never got done because I was always running errands and spending money. I'm making grocery lists and taking fewer trips to the store. All of this has given me more time for John and me to enjoy each other's company.

Although I have not lost anyone to this pandemic, my heart goes out to those who have. For me, it has been a life-altering experience. As we slowly return to "normal," I am committed to remembering all these lessons learned. But, most importantly, let's take time for ourselves and one another. ■



Harley, Karen and John's newly adopted dog.

EXPERT OPINION

Teaching About Brain Injury Through Storytelling

By Tom Grady, Director of Advocacy & Public Affairs, Brain Injury Alliance of New Jersey



Many people are not aware of brain injury, let alone able to empathize with a person impacted by it. This is why a person with brain injury, their loved ones, and their healthcare team need to think of themselves as “teachers” of brain injury in order to advocate effectively. One element of this type of teaching is storytelling.

The use of storytelling is an effective way to communicate, illustrate, and advocate. When one tells a personal story, facts are readily available, and the flow of communication is seamless. This conveys a sense of authenticity, sincerity, and honesty that can lead to increased trust—a means to build constructive relationships that benefit the brain injury survivor.

Years ago, the Brain Injury Alliance of New Jersey worked to enhance the Traumatic Brain Injury Medicaid (TBI) Waiver program. This entailed many tactics, including meeting with elected officials, encouraging others to join our effort, and testifying before budget committees in the State Senate and General Assembly.

Part of our advocacy team included a father and daughter. The daughter was unable to communicate, but the father was. Both of them joined me to testify before the Senate Budget and Appropriations Committee. I went first and spoke about what the Waiver did, its services, and why adding slots would benefit the state fiscally and, most importantly, people with brain injury. This information was certainly important to policymakers while deciding whether to approve this funding—in the amount of \$1.8 million. My presentation was half of the testimony. The other was the father presenting why the Waiver was important to people impacted by brain injury.

Their presentation sealed the deal.

The father spoke of his daughter’s brain injury journey, namely, the challenges. He also talked about the value the Waiver program provided. His story transfixed members of the Committee, clearly moved by how brain injury had affected this family.

Your story and voice can be used to teach others to be supportive of you, your family, and the brain injury community as a whole. If you need assistance in preparing your unique story, please contact me at tgrady@bianj.org.

Together, we can maximize our efforts to build awareness and understanding of brain injury and advocate for the support needed by the greater community of individuals and their caregivers.

After the hearing, the late Sen. Glenn Cunningham approached the father and daughter to offer any assistance he could provide—and he was not their senator. Their story is just one example of how storytelling can be used to advocate effectively. By the way, the \$1.8 million was approved to enhance the Waiver. ■

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Editorial

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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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