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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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PERSONAL PERSPECTIVE

Maddi Niebanck: The Fully Recovered Mindset

By Mallory Houston, Research Assistant, Center for Traumatic Brain Injury Research, Kessler Foundation

On May 30, 2017, just one week after graduating from Georgetown University, Maddi Niebanck was scheduled for surgery to remove an arteriovenous malformation (AVM), a tangle of abnormal blood vessels in the right occipital lobe of her brain. While undergoing pre-operative procedures, she developed a blood clot in her brain that burst, leading to a massive stroke. Maddi spent 15 days in ICU at New York Presbyterian before transferring to Kessler Institute for Rehabilitation in West Orange, NJ. Upon admission, she was unable to walk or use her left arm. By the time she was discharged, she had progressed to walking with a straight cane.

Although grateful to be alive, Maddi felt out of sync with all her college friends who were now working full-time. She decided to seek advice from one of her favorite professors, Eric Koester, twice named "entrepreneurship professor of the year" at Georgetown. He suggested she take this opportunity to pursue something she was passionate about, as she would likely never have this time again. Maddi credits this as some of the best advice she has ever received.

It inspired her to write her first book, "Fashion Fwd: How Today's Culture Shapes Tomorrow's Fashion." The book was important to her cognitive recovery, but also let her explore fashion as a stroke survivor no longer able to wear some of the clothes and shoes she did previously. Less than 18 months later, she wrote her second book, "Fast Fwd: The Fully Recovered Mindset," which describes her journey toward recovery. This book enabled her to connect with the brain injury community worldwide.

Writing these two books allowed Maddi to see how much she had changed during that time. She says, "I think when I shifted my perspective...and shifted my mindset to viewing my life as a blessing, that's when things started to change." Maddi follows what she calls a fully recovered mindset. This idea formed following a conversation with another stroke survivor who told her she no longer compares her recovery with how she used to do things. Instead, she focuses on how she is doing right now, an idea that resonated with Maddi. While she does not feel fully recovered, she understands that recovery is a journey. She continues to learn to adapt and is committed to the process of getting better rather than the end result.



It's okay to have bad days. Be kind to yourself and acknowledge you are constantly changing and evolving. One day – good or bad – is not going to define the trajectory of your recovery.

– Maddi Niebanck

Maddi continues to attend outpatient physical and occupational therapies. Her goals range from being able to do her hair the way she wants, to eventually living independently. Her message to other individuals with brain injuries? It's okay to have bad days. She reminds people to be kind to themselves and to acknowledge they are constantly changing and evolving. One day – good or bad – is not going to define the trajectory of a person's recovery.

As Maddi says, "that flexibility and willingness to adapt and find new ways to do things...means fully recovered. It's a mindset." ■

RESOURCE REFRESH

Support for Life at Home After Brain Injury

Brain Injury Alliance of New Jersey Support Services Team



Brain injury recovery is a process that continues long after treatment and formal therapies end. People with brain injury often create a “new normal” in which they must re-establish routines and re-learn how to complete everyday tasks at home. Help might be needed with bills, meal planning, appointments, and household tasks. But where do you turn when you’ve graduated from therapy programs, yet still have difficulty making the pieces fit together? There are services available that can improve independence and quality of life.

Contacting the Brain Injury Alliance of New Jersey’s helpline to explore available resources is a good first step. A trained professional can walk you through what services are available for your specific needs. The helpline can be reached at 732-783-6172 or info@bianj.org.

A possible resource for eligible individuals is Medicaid Managed Long Term Services and Supports (MLTSS). MLTSS can help with long-term support, such as personal care, respite, and care management. Eligible individuals over the age of 21 should contact their local Aging and Disability Resource Connection (ADRC) to apply.

Another resource is The New Jersey Traumatic Brain Injury (TBI) Fund, which may be available to help pay for home health services and personal care assistance for eligible individuals. The TBI Fund is used when insurance, personal resources, and/or public programs are unavailable to pay for services related to the brain injury. For information on eligibility or to request an application, call 1-888-285-3036.

The Personal Assistance Service Program (PASP) may be another option. To be eligible, applicants must be a New Jersey resident, physically disabled, between 18-70 years old, living in the community, capable of directing their own services, and either employed, preparing for employment, in school, or actively volunteering in the community. For more information, contact the Division of Disability Services at 888-285-3036.

One additional resource is the Centers for Independent Living (CILs), which often offer life skills workshops and other recreational opportunities. You can find your local CIL using the “Independent Living Research Utilization” online directory. ■

For questions about these resources or help finding additional information, contact the Brain Injury Alliance of New Jersey helpline at info@bianj.org or 732-783-6172.

EXPERT OUTLOOK

Resilience and Caring for Your Brain in the Age of COVID-19

By Karen Davenport, PhD, Licensed Clinical Psychologist, Neuropsychologist at Kessler Institute for Rehabilitation, Marlton, NJ

Recently while hiking in the mountains, I paused to take in the peaceful solitude of the woods and noticed a unique tree. The bark was crumbling at the trunk, most of it removed by insects or fallen to the forest floor. The top was grey weathered wood. A quick glance and one might wonder how it even managed to stay upright. Upon closer look, it had healthy branches that had found a way to an opening in the canopy. Leaves were growing with the help of the sun. This tree, which initially looked too damaged to survive, was thriving, sprouting new branches and reaching toward the sky.

This resilient tree reminded me of a gentleman named Isaac. Like the tree, he suffered many losses early in life, and later survived a brain injury. At first glance, he might look like a weathered old man.

However, upon listening to his story of adversity, it was clear that he, like the tree, was resilient. He wanted to identify proactive ways to “care for the brain” as he put it, but with the added twist of the COVID-19 pandemic impacting many of his plans. We discussed mental, emotional, and physical ways—three areas important to brain health—in which Isaac could “sprout new branches” to adapt to some of these changes.

Normally, Isaac volunteered at a thrift store. He enjoyed the mental challenge of cashiering and tracking inventory, but the store closed due to COVID-19. We decided to tap into his ability to track inventory. For cognitive stimulation, Isaac planned to take inventory of one room at a time,

in his own home. He joked that his wife bugged him about organizing his belongings, so she would probably be pleasantly surprised!

For Isaac, connecting with others was a big part of “caring for the brain” emotionally, but he became isolated from his extended family and church during the pandemic. To reconnect, Isaac called his pastor and was delighted to learn congregation members offered daily check-ins via phone. He signed up to receive phone calls every Saturday and said this would be his virtual “Church Day.” Then, he learned to use FaceTime on his phone and organized a family get-together every Tuesday and Thursday night.

Physical resilience was challenging as Isaac used a wheelchair and went to a therapeutic gym, now closed. So, he created an obstacle course of sorts, in his small apartment. His goal was to move through it twice a day.

While I have changed his name and some details to protect “Isaac’s” privacy, we both hope that sharing his story may inspire others. If you are a brain injury survivor, you are resilient! I suspect Isaac would tell you to look at the pandemic as a challenge, not a deterrent. Tap into your creativity to care for yourself and your brain. ■



“Like the tree, he suffered many losses early in life... however, upon listening to his story of adversity, it was clear that he, like the tree, was resilient.”

– Karen Davenport, PhD