Personal Perspective: Marriage after Brain Injury: Staying Connected
Angela Smith & Jeannie Lengenfelder, PhD

Rose and Richard Anderson met at work in 1979 and were married three years later. They worked to purchase their first home on Staten Island while going to school at night. Their family grew, with the birth of their daughters, Maria in 1986, and Angelica in 1991. Richard worked as the bureau director for the Department of Finance, Human Resources Administration for New York City. Rose went back to work full-time in 1998 at New York University, where she still works today.

Things changed suddenly during a family trip to Point Pleasant to celebrate Maria’s high school graduation in 2004. While they were crossing the street, a car driven by an intoxicated driver failed to stop. Instinctively, Richard pushed Rose out of the way. He was struck and thrown 25 feet, landing on his head. For three weeks, he was in a medically induced coma at Jersey Shore University Medical Center, then was transferred to Kessler Institute for Rehabilitation in East Orange*. His supportive home environment enabled him to be released after 4 weeks. Richard continued outpatient therapies closer to home for more than 2 years at Rusk Rehab at NYU Medical Center (now NYU Langone) in New York City.

Although Richard had made good progress, he continued to have difficulties with speech and memory. His daughter, Maria, having seen his challenges, decided to pursue a career in speech-language pathology. It was in many ways an intimate and emotional decision, but Maria felt strongly that it was the right decision. Today, Maria runs an outpatient clinic on Staten Island — and Richard serves as a mentor for some of her patients.

Early in Richard’s recovery, he and Rose realized the importance of individual and family counseling. Talking with a therapist helped educate each family member about the changes, allow them to mourn their losses, and appreciate all that they do have. Both Richard and Rose acknowledge that they are in “constant recovery mode.” Rose said, “We have had to learn how to educate ourselves, surround ourselves with the right people, and take advantage of the resources that are available.”

A brain injury impacts not only the individual, but the marriage as well. Richard says, “My wife got it worse than me.” He notes that it’s hard for the person closest to you when you change. Rose and Richard were married for 24 years at the time of the accident, so they knew each other

* Kessler’s East Orange campus closed in 2007.
really well. Once beyond the initial ‘honeymoon phase’ of recovery, Rose knew Richard was going to be different, but didn’t realize to what extent. Suddenly, Richard’s looks and mannerisms — so comforting before — were different, and Rose had to understand the changes and his new behaviors. Thinking back to those days, Rose cites two things that anchored their marriage after the accident. The first was their old memories - Richard’s long-term memory was unaffected and they were able to draw on those shared reminiscences. The second was their children. “How we talked to each other after his injury could distress our children,” Rose noted. “Having outsiders looking at us reminded us of what we needed to work on.”

Richard also lost his senses of taste and smell following his brain injury. He didn’t count on just how much this could impact his life. “Those senses can make you feel good and help you remember things,” he said. Studies show that in the absence of these senses, there can be a lack of emotional response to things people experience. Despite his loss of taste, Richard loves to cook and cooking for others brings him great enjoyment.

When asked what she would recommend to other spouses coping with the brain injury of their loved one, Rose suggested seeking out medical services and not being afraid to try new things. She emphasized the “importance of psychotherapy in healing the biggest wound a relationship can have. Caregiver participation in that process is very important,” she says, “It keeps us connected.”

Richard emphasizes to live as best you can, let go a little and move on. Remind yourself to find something positive each day. Learn to say, “It’s ok, and it’s alright,” Richard declares, “and often it really will be alright.”

Richard and Rose have been advocates in the brain injury community for many years. They are always willing to share their experiences to help and educate others. Richard and Rose are true models, setting an example not only with their words but also with the way they live their lives every day.
Q: What is emotional processing and how can it change after TBI?
A: Emotional processing involves the ability to correctly recognize emotion in others, as well as the ability to understand one’s own emotional experience. Emotional processing is an essential component of successful interpersonal relationships. Research shows that six basic emotions are universal: anger, fear, happiness, sadness, surprise, and disgust.

Q: How common are difficulties with emotional processing after TBI?
A: Up to 39% of individuals with TBI experience difficulties in emotional processing. These difficulties are likely due to the brain injury itself rather than other factors (i.e., depression or anxiety).

Q: Why is it important to study emotional processing in individuals with TBI?
A: The person who fails to accurately perceive the emotions of others could misinterpret emotions and respond inappropriately, making it difficult to maintain social relationships at home, in the community and in the workplace. Understanding the impact of emotional processing deficits is key to developing appropriate treatments.

Q: How do scientists study emotional processing?
A: Emotions are communicated through voice/tone, behaviors, body language/posture, and facial expression. Facial expression is the most common method of communication, which is why facial stimuli are most commonly used in research studies that evaluate emotional processing. The two most common ways to evaluate emotional processing are: 1. Identification: individuals are shown a picture of a face and need to identify which of the six basic emotions is shown; and 2. Discrimination: two faces are shown side-by-side and individuals need to indicate whether they display the same emotion or different emotions.

Q: Are there changes in the brain that are associated with problems understanding and conveying emotion?
A: We are currently studying how the brain processes emotions after TBI. Using neuroimaging, we study the brain activity of individuals while they perform tasks of facial recognition. We are comparing the activation we see in individuals with TBI with the patterns in healthy controls, looking at whether there are additional areas of activation in persons with brain injury.

Q: Can problems with emotional processing problems after TBI be treated?
A: Very little work has been done to treat emotional processing difficulties after TBI. Much more work has been done in autism and schizophrenia. We have developed an intervention for improving emotional processing based on the Training of Affect Recognition (TAR), a 12-session computerized intervention that improves abilities in people with schizophrenia. Our research also shows that this intervention improves emotional processing in individuals with multiple sclerosis and we are now studying it in TBI. Other strategies include having individuals generate stories based on their own emotional experiences, and using mimicry to improve awareness and understanding of their own emotions.
Are you interested in participating in Traumatic Brain Injury research?

Kessler Foundation is looking for persons with TBI to participate in research studies in the following areas:

- Problem Solving
- Processing Speed Difficulties
- Emotional Processing in TBI
- Exercise after TBI
- Quality of Life (for Caregivers)

For more information, please contact:

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Nancy Chiaravalloti, PhD • Anthony Lequerica, PhD • Jean Lengenfelder, PhD • Glenn Wylie, DPhil
300 Executive Drive, Suite 70 • West Orange, NJ 07052 • www.KesslerFoundation.org
Meet Arielle Resnick, PT, DPT, NCS, Senior Physical Therapist on the Brain Injury Unit at Kessler Institute for Rehabilitation.

Arielle has been a therapist at Kessler since she graduated from the Doctoral Physical Therapy program at The University of Medicine and Dentistry of New Jersey (now Rutgers New Jersey Medical School) in 2010. She became Kessler Institute’s first neurologic physical therapy resident in a program now accredited by the American Physical Therapy Association. Upon completion of her residency, she passed the Neurologic Certified Specialist examination and is now a board-certified Neurologic Specialist through the American Board of Physical Therapy Specialties.

While doing her clinical rotations and working with individuals with a wide range of diagnoses, Arielle found her true calling. “I always saw myself in spinal cord injury or stroke rehabilitation, but once I rotated to the Brain Injury Unit, I fell in love with this patient population, and now I never want to leave,” she said. She has brought this passion, along with her skills, to patients at each of Kessler’s campuses. Currently, Arielle works at the Saddle Brook campus.

In addition to her clinical responsibilities, Arielle is a part-time faculty member in the Doctoral Physical Therapy program at Rutgers University. She teaches courses in neuroscience, motor learning, and neurologic rehabilitation. Arielle is dedicated to the translation of didactic education into clinical practice, and loves this aspect of educating staff and students, as well as patients and their family members as they navigate through an extremely challenging time in their lives. Clinically, Arielle is involved in special programs on the Brain Injury Unit, including functional electrical stimulation for the lower extremity to improve gait, and advanced mobility rehabilitation, which encompasses multi-tasking, way finding, and community re-integration.

Arielle has presented both regionally and nationally on the topic of rehabilitation of way finding and spatial navigation deficits following brain injury.

Meet Dennis Tirri, BS, Research Assistant for Traumatic Brain Injury (TBI) Research at Kessler Foundation. Dennis is a graduate of Bucknell University with a degree in neuroscience and a minor in creative writing. Currently, he recruits individuals to participate in research studies, administers neuropsychological tests, and manages collected research data. Dennis works on the Northern New Jersey Traumatic Brain Injury Model System (NNJTBIS), a federally funded collaborative project with Kessler Institute for Rehabilitation, conducting the two-year and five-year follow-up interviews of research participants with brain injury. These interviews help determine the needs of individuals and their families, and types of research studies that will help address these needs.

His other responsibilities include administrating computer interventions for a clinical trial examining speed of processing training in individuals with TBI, toward the goal of developing strategies for effective cognitive rehabilitation. Dennis is also working on a study aimed at helping to develop a measure of quality of life, specifically for the caregivers of persons with TBI, whose lives are forever changed by their experiences with persons with brain injury.

Dennis has had the privilege to work on different projects with both persons with TBI and their loved ones. “Being able to follow up with patients and their families years after brain injury has given me a unique perspective of how TBI affects so much more than just the individual. Because caregiving plays such an important role in recovery, it is imperative that we find ways to assist not only the individual, but the family as well.”

Inspired by his work in brain injury research and the people he has met at Kessler Foundation, Dennis plans to pursue a career in clinical psychology. “Psychological resilience and coping after traumatic events has always been of great interest to me, and is an area that I would like to explore further in the future.”

IN THE NEWS... Dr. Nancy Chiaravalloti, (far left) director of TBI Research at Kessler Foundation joined Rep. Bill Pascrell, Jr.’s (far right) monthly cable broadcast “To the Point,” to talk about developing effective, reimbursable cognitive treatments that improve function and quality of life after brain injury. The panel included Leonard Marshall, a former defensive lineman with the New York Giants who has signs of chronic traumatic encephalopathy (CTE) and Wendy Berk, public education coordinator at the Brain Injury Alliance of New Jersey. This thought-provoking show can be found on YouTube.
The brain injury community recently said goodbye to one of our most valiant advocates and her loss is felt by so many of us every day. Bettyjane M. Collins, RN, known to all of us simply as “Betty” passed away on February 26th, 2015, from small cell lung cancer. Betty’s official title was Cognitive Rehabilitation Program Case Manager at Kessler Institute for Rehabilitation, but to the brain injury community she was so much more. Betty was a tireless advocate for individuals with brain injury. She fought for the advancement of research, optimal clinical care, reimbursement for services, recognition of the caregivers and the challenges they face, and she always made her presence clear. Her efforts never went unnoticed.

Born in July 1948 and raised in Union City, Betty developed her interest in nursing at Union Hill High School, where she was the president of the Future Nurses Association. After high school, she attended Beth Israel School of Nursing in Newark, graduating in 1968. She began her career as a staff surgical nurse at Newark Beth Israel Medical Center before moving to St. Barnabas Medical Center as a staff nurse in surgical intensive care. Betty quickly became interested in burns, becoming one of the certified dive nurses that went into the hyperbaric chamber with patients with severe burns.

While at St. Barnabas, Betty was recruited to work at the KIM Institute. She had developed an interest in rehabilitation, and in her first position, she worked with patients with spinal cord injuries. She continued working at the KIM Institute after it was acquired by Kessler Institute for Rehabilitation.

Betty turned her attention to brain injury as a head nurse on the 3:00pm-11:00pm shift. She rose to assistant director of nursing at Kessler Institute in East Orange before moving to education in the 1990s. It certainly would not surprise those who knew her that Betty liked working in education. Betty wanted to be sure people knew what they needed to know to do their job most effectively. Although she was challenged by the transition to working much less with patients, she was beginning to find her voice as an advocate through education, both inside the walls of Kessler Institute and in the outside world.

As described by close colleague and friend, Patty Carey, PT, DPT, MPA. “Betty was a consummate educator who understood the power of knowledge. Her desire to improve staff competence and the lives of her patients and their caretakers by providing them with the information they needed was palpable. Whether she was educating colleagues as a Certified Brain Injury Specialist Trainer, presenting at the Certified Rehabilitation Registered Nurse (CRRN) review course, sharing her expertise at the Brain Injury Support Group or taking advantage of impromptu teachable moments, her passion to educate was undeniable. She is certainly missed by all whose lives she touched and taught.”

When Kessler Institute reorganized its education department, Betty transitioned yet again to become a case manager in the Cognitive Rehabilitation Program (CRP). According to Betty’s daughter Meghan, the transition was difficult initially. For the first time, Betty was working with outpatients, and she did not feel as connected to her patients. More significantly, the insurance certification process was frustrating. Betty would often be asked, “What body part are you trying to get pre-certified?” Anyone who knew Betty knows that this attitude did not sit well with her. In typical Betty style, she would reply, “It’s a patient I am working with – not a body part.” She found her niche by taking what she learned in education and applying it to the insurance representatives she interacted with on a daily basis. Betty’s dedication to her patients was no more evident than in her leadership of Kessler Institute’s support group for persons with brain injury and their caregivers. She led this group for 25 years, most recently with her co-facilitator, Christina Klymasz, MS, OTR/L, CBIS.

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The Brain Injury Alliance of New Jersey (BIANJ) recognized Betty’s contributions on many occasions. Among these many honors were the Founder’s Award in 2006, the Lifetime Volunteer Commitment Award also in 2006, BIANJ Support Group Leader Award in 2009 and the BIANJ Community Pillar Award in 2011. As Barbara Geiger-Parker, then president and CEO of the BIANJ, describes Betty: “Betty was one of the most committed advocates for people with brain injury and their families that I know. Quite frankly, she was a force to be reckoned with. In addition to her work at Kessler Institute, Betty was extremely active as a volunteer with the Alliance, helping in many ways to improve the quality of life for those affected by brain injury. She was always willing to help out, especially through her support group leadership and work on the Advocacy and Public Affairs Committee. We owe a debt of gratitude to Betty, who is sorely missed.”

Although we all knew and loved Betty because of the energy that she devoted to the brain injury community, Betty’s first love was her family. As her daughter, Meghan has said, “My mom was always about family – her family was so important to her.”

Betty married Dennis James Collins, an East Orange police officer, on June 17, 1979. They raised their children, Meghan, 33, and Dennis, 35, in Nutley. Meghan explained that Betty and her dad balanced each other out. “Dad was laid back, into sports, and read the paper on Sundays, while Mom yelled at him to do the laundry. She was type A, he was type B. Mom was refinishing furniture, while Dad was screwing in a light bulb”. They loved to have fun and both liked to gamble. Dennis was Betty’s other half. He passed away from cancer in January 2003, at age 54. It was hard for Betty to accept that he was gone, but she went on – working every day and continuing to serve her patients well. The pride of her life, her granddaughter Sierra, was born to Meghan and her husband in 2014.

In 2001, Betty’s two worlds met. In that year, Meghan, 19, sustained a concussion in a car accident. Betty brought Meghan to see the psychologists at Kessler Institute. She used the resources available to her to help her daughter – and experienced what it was like to be on the other side. This experience inspired her to advocate for families. In fact, Kessler Foundation recently initiated a line of research focusing on the families and the optimal means of providing the support that they need. Betty was an advocate for this work and an important part of its initiation.

When asked about her mom’s style at home, Meghan replied, “Mom was always tough – at work and at home. You couldn’t stop mom from doing what she wanted to do.” Meghan explained that her mom was hard on her and that “made me a better person. She was hard on me because she saw potential.” But Betty was also fun – both at home and at work. Betty loved to take road trips with her family – she would pop a tape in and sing the whole way. John Denver ... Dolly Parton... AC/DC... traveling to various destinations... Florida, Colonial Williamsburg, Toronto, and the St. Lawrence River. She loved her life and her family and it showed in the way she cared for those around her. She adored animals of all kinds, and will always be remembered for lining her pockets with birdseed and food for the deer that frequented the West Orange campus.

So, who was Bettyjane Collins? Betty was a force of nature. She could be a hurricane or tornado, whipping you into shape, or a calm breeze that relaxed you and put things into perspective. Betty was tough, but with a soft interior. And Betty was humble... very humble. Everyone would agree that Betty always told it like it was, and you always knew where you stood with her. Her energy was contagious, and she held us all to a high standard... her family, her friends, her patients, and her colleagues.

We are all better people for having had Betty in our lives.
Residents Leroy Lindsay, MD, and Larry Lai, MD, and postdoctoral fellow Giselle Vivaldi, PhD, presented findings from their studies utilizing data collected by the Northern New Jersey Traumatic Brain Injury System (NNJTBIS), in collaboration with NNJTBIS investigators Anthony Lequerica, PhD, and Nancy Chiaravalloti, PhD, of Kessler Foundation, and Irene Ward, DPT, and Neil Jasey, MD, of Kessler Institute for Rehabilitation.

Dr. Lindsay discussed how the way a patient performs transfers at discharge is a predictor of the need for supervision at 1-year post-injury. Dr. Lai presented an analysis showing that individuals who reported having a concussion prior to their TBI had higher levels of depression and lower satisfaction with life at one-year post-injury. Dr. Vivaldi showed the impact of bladder dysfunction on disability and community participation among individuals with TBI. All three studies were also presented in Dallas at the American Congress of Rehabilitation Medicine in October 2015.

Kessler researchers presented their findings at the International Neuropsychological Society 43rd Annual Meeting in Denver, Colorado in February 2015. Joshua Sandry, PhD, (co-authors Drs. Nancy Chiaravalloti, John DeLuca & James Sumowski) presented their poster on cognitive reserve and long-term memory impairment. Drs. Sandry, Chiaravalloti and Kathy Chiou, PhD, discussed performance differences and predictors of learning after moderate and severe TBI. Dr. Chiaravalloti and Anthony Lequerica, PhD, shared their research on the relationship between disturbed sleep and executive functioning after TBI. Glenn Wylie, DPhil, and Ekaterina Dobryakova, PhD, presented on two aspects of working memory: capacity (the amount of information that can be held in working memory) and manipulation (how accurately one can reorganize the information while it is in working memory).

Other researchers presented at the Cognitive Neuroscience Society’s annual meeting in March 2015. Starla Weaver, PhD, and Dr. Wylie presented neuroimaging findings on how the brain functions during multi-tasking in individuals with TBI. Dr. Wylie (co-authors Helen Genova, PhD, Drs. DeLuca and Chiaravalloti) talked about how brain imaging can help us understand cognitive fatigue after TBI. Drs. Chiu, Genova, and Chiaravalloti presented a poster showing how ability to learn after moderate to severe brain injury is associated with the pathways that transmit information throughout the brain enabling brain cells to communicate with one another (white matter).
Joe Concato teaches others about life after traumatic brain injury.

Communication is important in all relationships. How many times have we heard this from counselors, talk show hosts, and everyone else who provides advice?

When thinking of communication, the spoken and written methods that require action are almost always the first that come to mind. Do not forget that communication is taking place whether or not we are actively participating.

Consider the difference between walking into a room with a spring in your step and a smile on your face as opposed to trudging along with a defeated look. Body language speaks loudly. Remember, too, that listening is an important and sometimes overlooked aspect of communication. Communicating with someone who has a brain injury is very different from anything you have ever experienced.

You may feel overwhelmed, frustrated and confused about what to do to have your loved one understand you. Be aware that your loved one may also feel overwhelmed, frustrated and not know what to do.

Joe Concato teaches others about life after traumatic brain injury.

**CAREGIVER CORNER: Communication is Key**

**Joe Concato**

To effectively communicate with your loved one, you need to lay the groundwork:

- Establish and maintain open lines of communication with professionals who are involved with care. (including case managers, counselors, medical teams, therapy teams)
- Understand your loved one’s condition, their deficits and the strategies they are being taught to overcome them.
- Ask questions.
- Do your own research.

More focused communication about your loved one’s condition will be necessary, as well as both short-term and long-term plans and goals. This should first take place between you and the professionals using the established open lines of communication. During this dialogue, they can provide you with information to share with your loved one and the manner in which it can be done.

Informal communication with your loved one about daily activities and common interests is good. Keep the following in mind:

- Be positive and encouraging in all words and actions.
- Do not show frustration or any negative emotion.
- Learn to recognize when your loved one is beginning to feel overwhelmed or frustrated and do not ignore the signs.
- It is acceptable to provide assistance when your loved one may be on the verge of frustration.
- With input and direction from the professionals, it is also acceptable to delay assistance and challenge your loved one to use their strategies.
- Decide between these approaches on a case-by-case basis.
- Do not participate in any communication as if your loved one is not present.
- Make sure that all who communicate with your loved one understand and consistently follow the same guidelines.

When sharing this information with your loved one:

- Ensure only those who are necessary are present.
- Share aspects of the discussions that led to decisions.
- Be prepared for questions.
- Indicate that decisions, plans and goals are based on the current situation.
- Make it clear that the situation will be re-evaluated and plans and goals will continue to be adjusted.

You and your loved one are both re-learning how to communicate. The information provided is meant to help you with all that you need to do. How well you communicate will influence the paths you travel together.
John DeLuca, PhD, welcomed more than 100 individuals with brain injury, their families and caregivers to “Taking Care of Yourself after Brain Injury.” This consumer conference was sponsored by the Northern New Jersey TBI Model System, one of 16 federally funded centers for TBI care and research across the U.S. Dr. DeLuca, senior VP of Research at Kessler Foundation, leads a diverse team of scientists dedicated to improving the lives of people with disability.

Jeannie Lengenfelder, PhD, introduced the day’s speakers, underscoring the importance of taking a proactive role in maintaining one’s physical, psychological, and emotional health after brain injury. Dr. Lengenfelder, an expert in the impact of emotional processing deficits, is assistant director of TBI Research at Kessler Foundation.

“Loss & Grief after Brain Injury” was the topic of the keynote address by Constance Palmer, LCSW, a teacher, counselor and therapist with more than 30 years’ experience. Palmer is the director of Imagine: A Center for Coping with Loss, in Westfield, NJ, where individuals and families learn practical strategies for coping with death and life-altering injuries. “Why is life like a box of dominoes?”

Nancy Chiaravalloti, PhD, thanked the attendees for supporting the Foundation’s research by participating in clinical studies. Volunteering for research accelerates the pace of discoveries that improve the quality of life after brain injury for individuals and their caregivers. Dr. Chiaravalloti is director of TBI Research at Kessler Foundation and project director of the Northern New Jersey TBI Model System.

2015 TBI CONSUMER CONFERENCE:

Missed the 2015 TBI Consumer Conference?

Listen to the podcast series of all of the speakers at https://soundcloud.com/kesslerfoundation/sets/2015-traumatic-brain-injury
Taking Care of Yourself after Brain Injury

As a young professional, Catherine Brubaker survived a violent attack resulting in severe brain injury. Brubaker, the founder of HopeForTrauma.org, travels the country to raise awareness and empower individuals with her message of self-advocacy. Hear this gripping story of recovery and follow Brubaker's journey through the stages of grief to a life of advocacy for people and their caregivers coping with the aftereffects of brain injury.

“Optimizing Brain Injury Recovery” provided useful strategies taught by Bill Gallagher, PT, CMT, CYT, of EastWest Rehab. Gallagher, a holistic physical therapist, treats pain and disability with a blend of Eastern (yoga, qigong, tai chi chuan) and Western (osteopathy, Feldenkrais, myofascial release) practices. Relax during our podcast recording of Gallagher’s meditation workshop, and learn about his novel approach to maximizing function and minimizing pain.

“The Brain & Nutrition” was a fascinating, informative session by Ernest A. Ehrhardt, IMD, NMD, who learned the benefits of tailored nutrition after his own serious brain injury. Dr. Ehrhardt, an award-winning Naturopathic Medical Doctor, practices at the Ehrhardt Center for Integrative Medicine. Which foods and supplements support brain healing? What foods benefit memory? Listen to this podcast to learn more.

A panel discussion led by the popular Michael “Mike at the Mike” Greenwald, EdM, was an opportunity for individuals to share their thoughts and experiences on “The Importance of Volunteering”. Listen to the podcast, which features audience members sharing their perspectives on the benefits and challenges of taking advantage of volunteer opportunities.

You can listen to each speaker on Kessler Foundation’s Soundcloud Channel at https://soundcloud.com/kesslerfoundation/sets/2015-traumatic-brain-injury