Voices of Recovery: A Family Physician’s Experience of Aphasia

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Tom Gilbert

Prior to my stroke, I was a family physician for 25 years. During the 2 years preceding my stroke, I worked with Larry Culpepper, MD, MPH, in the new Department of Family Medicine at Boston Medical Center. The department was well underway with 18 residents, three fellows, a large undergraduate program, and a growing faculty. In August 1999 I had a week-long vacation in Maine. That Monday evening, our daughter, Carrie, and a nephew joined us on North Haven. The weather was perfect so it was easy to have houseguests.

However, when I awoke on Tuesday morning, I did not feel well. I had a severe headache unlike any I had had before. After the rest of the group went out for a sail, I tried to lay down upstairs. Right away I found I could not raise my right arm or leg into the bed. I could not speak appropriately either. When Peggy, Carrie, and Jake got back 2 hours later, I was conscious but slipping fast. I was having a stroke.

I had a massive brain hemorrhage. A cavernous malformation of vessels deep in my brain had burst. The stroke affected the left side of my brain and the right side of my body. As I left the island, I lost consciousness. I was flown to the local hospital in Maine and then taken by helicopter to the Massachusetts General Hospital.

Larry Culpepper

Peggy called. Tom was comatose and being MedFlighted to MGH. I joined the neuro-radiologists that evening as they explored his brain virtually, identifying the bleed, but uncertain as to its cause—vascular malformation? Cancer? I could interject a sense of Tom and his humanity onto the screen images and take away information to translate for Peggy and his children, Carrie and Dan, who I had known for many years—since my own daughter babysat for them. Possibly most important, I could bring to Peggy, driving down from Maine, the sense that someone who knew him was with him and that the MGH team was both highly professional and highly caring.

Tom's and my life had woven together over the years, since we first met at the University of Rochester residency in 1975, both exploring new life roles as family physicians. Later at Brown we were colleagues who shared much—I led Tom in developing his research skills, and he led me in clinical and educational realms. In 1998 Tom delighted me when he agreed to join our fledgling department at Boston University. He brought the outlook of a midcareer family physician who approached patient care with the depth of understanding of the human condition that only years of rural practice—delivering babies, serving as the local coroner, and all in between—could instill.

Over the next 6 weeks the severity of Tom’s expressive and possibly cognitive damage became clear. He had a dense left hemiplegia, and I thought it impossible that he would ever walk again. I weakly encouraged Peggy that it was too early to predict the long term. I had no idea what the outcome would be or if Tom would even want it. I echoed the conventional teaching, that it would be 6–12 months before we'd know Tom's new “steady state.” And as those time marks passed, I thought there would be little further progress beyond Tom’s marginal ability to communicate and relate, his inability to read or write.

Peggy Gilbert

When Tom emerged from a weeklong coma, he was speechless and floppy as a rag doll. Seeing him that first week in the ICU hooked up to every machine imaginable, I couldn't envision a positive prognosis. In fact, I asked his doctors whether we should discuss pulling the plug. Tom and I laugh about this now but I was serious. I underestimated Tom’s resilience and strong will to survive and my own ability to be helpful to him.

One of the biggest adjustments following Tom’s stroke was the change in our relationship. Instead of being equal partners in a marriage, I became “the boss.” Tom was in such a
NARRATIVE ESSAY

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Tom Gilbert

I was disoriented and in a fog for much of the first 2 months that I was in rehab. It took two physical therapists to roll me over or get me into a sitting position, and I needed to be tied into a wheelchair. I could not keep both eyes going in the same direction. I couldn’t swallow correctly so my food had to be blended and thickened. I was given medications that I thought I never would have to take because I never imagined being so ill. I could not produce many words, and those that I could were difficult for others to understand.

As my recovery progressed, I became aware of how isolated I had become. My inability to process information at a normal speed meant that I had difficulty following conversations and responding in an appropriate manner. My limited speech made it extraordinarily challenging to communicate. For example, my observation that Peggy’s car inspection sticker had expired resulted in 20 minutes of gestures and “yes” and “no” responses before she understood my point. Multiply this exchange by hundreds throughout the day to understand my exhaustion, frustration, and depression. It seemed that my former self was alive and well in a maze inside my brain, leaving only a simpler version of Tom communicating with the outside world. My family knew that I understood so much more than I could say. When they read me supportive emails from family and friends, I would respond appropriately. Humor helped us survive. Peggy tells me that one of her happiest moments was when I said her name correctly. However, when she asked me her last name, I responded “Christmas.”

I had to re-learn everything—to speak, to read, to write, and to operate a computer. Like other stroke victims, I made a gradual recovery. We returned to Maine the next summer, and I learned to ride a recumbent tricycle. My family helped me get in and out of boats so I was able to sail again too.

Each month, Peggy and I attended the Aphasia Support Group at Spaulding Hospital. At first I was in a wheelchair unable to say much, but in time I became much more engaged. Interacting with other stroke victims and their families gave us hope for the future.

I continued to receive speech therapy at home. My therapist encouraged me to get out and interact with the greater community as much as possible. My first volunteer position was shelving books in the local public library.

Peggy Gilbert

When I started paying our bills, I was horrified to discover how much Tom had been spending on the boats. Assuming that he would never be able to sail again, I asked our children if I should sell our small sailboat, Patience. Carrie and Dan were adamant that selling Patience would kill their father. How right they were! We are convinced that the dream of sailing Patience again was instrumental in his recovery. His physical therapist developed exercises that applied to boating. One year after his stroke, Tom was at the helm again. While he could not name the parts of the boat, he could sail as well as he always had.

As an inpatient at the rehab hospital, Tom took his first steps—but this time with a cane. I can still picture his physical therapist holding onto the wide white strap around Tom’s waist and hear her periodic words of encouragement: “Excellent, Dr Gilbert.” She was the only therapist who did not use Tom’s first name. At a time when so much had been taken from us, it felt affirming to have someone acknowledge Tom’s previous life. Approximately 11 months after his stroke, we hired a driving instructor trained to work with disabled adults to give Tom a series of lessons and take him to the driving test.

With the driver’s license, Tom’s freedom had been restored. One day, I came home from work and Tom was not there. I panicked, thinking that he had been in an accident, and his limited and halting speech would cause others to assume he was drunk or developmentally disabled. At 6 pm, Tom drove in with a grin on his face. He had decided to drive to Rhode Island to get a haircut! Like a distraught parent, I told my husband that he had to leave me a note when he was leaving the house. The next day, I returned home to find a note. It said: “Tom will be back.”

Tom became eager for a new challenge. His speech therapist encouraged him to find a volunteer opportunity. Tom’s first job was shelving books at a local library. I mentioned to our family doctor that a part of me thought it might be demeaning for Tom to be shelving books. He rightfully responded: “Think of this as therapy, Peggy.”

The following year, Tom volunteered in the step-down unit of a local hospital. A year later, a social worker who remembered Tom from his inpatient days invited him to participate in a new peer visitor program at Spaulding Rehabilitation Hospital. The staff on the stroke floor welcomed him and directed him toward...
families that would be receptive to visitors. Eventually Tom started a similar program at BU Medical Center. It has been stimulating for him to have a venue to utilize his strong listening skills and model his positive attitude. He visits patients 3 days a week and has been an inspiration to many families.

Larry Culpepper
Every spring Tom and Peggy disappeared to Maine for 3 months. And every fall I was amazed at the new Tom that returned and the stories of his and Peggy’s Maine island adventures. He still could not write or use a computer, and I still wondered how much his expressive limitations reflected internal thought limits. But Tom was dogged in finding his new adult life. Every few months there were stories of Tom stretching his physical limits and then patiently paying the consequences, often waiting up to hours for assistance. These events also were very powerful and eloquent communications from Tom about his determination and disregard for limits accepted by his “providers.” I was blown away when he showed up at our front door for drinks one day unassisted except for his cane—at the top of 14 steep South End brownstone stairs.

In the first couple of years, I made it a point not to terminate Tom’s status as a member of our faculty. We discussed that while he did not anticipate returning to his prior clinical role, that he had new contributions to make to our teaching program and research group. He tried being the experiential teacher of students in our medical student clerkship and rejoined our research seminar group. In recent years, his progress has been more subtle but no less powerful—from showing up but dozing through research seminars to alert participation to insightful questions based on deep experience. Over the years, he has developed a presentation on his recovery that he and Peggy give together. It has framed vividly the error of conventional teaching of the static nature of stroke recovery. It put in context the evolving story we were experiencing with Tom and Peggy. It is also angering given the benefit Tom has shown, possibly from long-term therapy, and the penny-foolish very time-limited therapy benefit available to most. Aphasia is fluid, cognitive engagement expands, social, intellectual, and family relationships remodel, stairs are to be climbed. Life is to be reclaimed.

Tom also has returned to research, developing a collaboration with other stroke families. Through this work he has educated many as to the nature of post-stroke life—that it evolves and continues and can be intensely rewarding. He and Peggy also demonstrate the strength of family and the human potential to share and grow through it.

Peggy Gilbert
Tom still confronts tremendous challenges on a daily basis. Since his right side remains compromised, it takes him extra time and effort to get dressed and to walk. He tires easily and benefits from an afternoon nap. For some reason, he cannot remember something unless he writes it down. I find this particularly frustrating. Since spelling is difficult for him, I often help him with email and other correspondence. However, he continues to make progress in surprising ways. This past year, for example, he began reading novels again. It has been a delight for us to read and discuss the same books.

We are aware how fortunate we are. We have a supportive family, caring friends, and the financial resources to set the terms of Tom’s recovery. We have consciously decided to keep putting ourselves in situations that will allow us to be the full versions of who we were before the stroke.

Tom Gilbert
As I reflect on my medical career, I have no regrets. The year before medical school, I shadowed an oncologist at BU who taught me that doctors cannot always cure patients, but they can always treat them with dignity and compassion. My mentor encouraged me to spend time with patients, to listen to their stories, and to share a bit of myself as well. Learning to listen well had a huge impact on my approach to medicine. Making time to connect with my patients gave me a better feel for the stresses at work and at home that might interfere with their ability to follow my advice. Ironically, I didn’t give lots of advice; if you let your patients talk, they often come up with solutions! Now that I am a patient with aphasia, physicians sometimes avoid talking with me and direct comments to Peggy. Sometimes I wish they would sit back and ask me to tell my story.

While I am no longer a practicing physician, I believe that I am using many of the skills that I developed over my years in practice. As I make my rounds on the sixth floor at Spaulding or the seventh floor at BMC as a volunteer in the peer visitor program, I listen to the patients and their family members. I answer their questions and share my experiences. Because I no longer have time constraints, I can spend as long as is necessary with these individuals. As a result, they do not feel rushed and are better able to communicate. Our relationship is different than that of a physician/patient; we are equals navigating the trail to recovery.

Aphasia Resources
Aphasia Resource Center
Boston University, Sargent College
635 Commonwealth Avenue
Boston, MA 02115
www.bu.edu/sargent/aphasia

American Stroke Association
www.strokeassociation.org

Their own words Website
www.bu.edu/aphasiareflections/
Additional Resources


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