



There's More to Stroke Recovery than Urgent Care and Rehab

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Neurologists and neurosurgeons saved my life. Some incredible therapists have helped me regain many of my lost capabilities. For this I am incredibly grateful. I consider myself extremely lucky to have survived a severe stroke at 53 years old, just over 9 years ago when I was in the prime of my career as a professor at Stanford University. After all, I'm alive, and after much hard work I could again live life fully independently if I needed to. I was healthy, fit, and had none of the usual risk factors. But a dissection in my left carotid artery, just at the intersection with the middle cerebral artery, completely blocked the flow of blood to the watershed area on the left side of my brain. Thus began an ordeal and journey that led me to better understand what recovery really means.

Some may recall the story of another survivor—Emilia Clarke—who told her stroke story in a *New Yorker* magazine article entitled “A Battle for My Life”. It was her personal account of recovering from 2 aneurysms, the first of which occurred just after she finished filming season 1 of *Game of Thrones*. I received from my friends and colleagues at least a dozen links to her story within a day of its appearance, because the “battle” of her title was not just to stay alive, but to rebuild a life she really wants. That's what I've been doing, and writing about, for almost 7 years.

Unlike Emilia, I still suffer from significant observable disabilities—I walk with a significant limp, have no functional use of my right hand and, most impactful, I continue to suffer from significant aphasia, a communication disorder that frequently results from stroke and other brain injuries. Aphasia can take many forms—from not understanding what you hear, having nonsense words come out of your mouth when you try to say something, or having great difficulty finding the words to express your thoughts (verbally and in writing). The last example is what I experience—a particularly cruel fate for a formerly tenured professor at Stanford University. I had earned a position after 25 years of work that allowed me to research, write, teach, and speak at professional conferences, as well as consult with companies, nonprofits, and the government on areas of my expertise. I really did love my job.

One line Emilia wrote resonated particularly loudly for me: “My job—my entire dream of what my life would be—centered on language, on communication. Without that, I was lost.” I am so thrilled that Emilia regained her speech capability and has been able to resume that life of her dreams. But the degree to which Emilia struggled with her sense of self, her sense of future opportunity, her identity as a person—even though she regained virtually all of her prior capabilities—is such a powerful example of how recovery from a stroke or brain injury involves far more than the quest to regain capabilities.

On so many scales I am incredibly lucky—access to great medical care and the insurance and economic means to pay for it, an incredible support network, and a husband, children, and extended family that could not give me more love and support. But unlike Emilia, I am unlucky in one significant respect—my ongoing aphasia did not allow me to return to the job of my

dreams. Three years after my stroke I had to accept that my ongoing disabilities would not allow me to continue in my role at Stanford, and I was forced to give up my tenured position. That hit me like a ton of bricks—in some ways it was more traumatic than the stroke itself. For my first 3 years of recovery I had an unwavering belief that if I worked hard enough, I would “recover” and return to the job I loved. All of a sudden that prospect was gone. My reality set in. It shook me to the core. “Who am I now?”

I read another article recently, “10 Tips for Your Best Stroke Recovery”, on a consumer health Web site called Everyday Health. Dr. Ira Rashbaum shared a great list including things like seeking urgent care immediately, choosing your post-traumatic care wisely, eating well, exercising, and limiting stress. An extremely helpful resource for sure, but only one of his ten tips—staying positive—was relevant to what I have found to be the equally important emotional journey in recovery.

A social scientist by training, after my “punch in the gut” experience of losing tenure, I started talking with other survivors (not easy with the challenges of aphasia) about their experience of recovery. Almost all of them described this horrible loss of identity, a sense they no longer knew who they were. This was true whether their ongoing disabilities were minimal or significant. And virtually none of them had been offered or encouraged to seek psychological counseling as part of their recoveries, despite having been treated by some of the world's best care centers.

As a professor, I had done a lot of work to understand identity, specifically in the context of my work with women and people of color as they navigated organizations that were in some way at odds with their values—with their identities. Now I am on a journey to understand the identity experience of stroke survivors, and survivors of other traumatic illnesses and events. I'm on a journey to understand my own identity—to rebuild it in the face of the disabilities I continue to have.

I hesitate to summarize in a “top tips” list my view on the question I'm asked so frequently: “How do you rebuild your identity after stroke?” First of all, I'm not done. It's an ongoing process. I haven't been able to shed from my identity some of the things in my “old life” that are no longer accessible. And, frankly, building one's identity is a lifelong process for everyone, as we all change over time. But a stroke or other trauma can certainly force the process with a greater sense of disruption and urgency. So here goes: my “top 5 tips” that reflect some of the things that have helped me the most, as well as many other survivors I have interviewed.

1. As much as I possibly can, look forward and not back.
2. Celebrate small wins; it feels good and they add up.
3. Focus on the deeper meaning and true value of the things I used to do, not just the things (or positions) themselves.

4. Enjoy the silver linings; in the midst of a horrible situation, there are things that are actually better and I need to allow myself to see and celebrate them.
5. Seek and use support. So far, I am lucky to be getting the support I need from family and friends; but I think professional counselors trained to support survivors can be key.

More than 9 years after my stroke, I'm still on my journey to redefine myself—and my identity. Some days I may still struggle with losing aspects of my old identity that I cherished, but I am also embracing new roles. Recently I co-founded Stroke Forward (strokefwd.org), a nonprofit that will provide survivors, families, and caregivers with more resources to help them navigate the journey to rebuild their identities and rewarding lives. I'm on a journey to rebuild a life of meaning and joy despite my disabilities. I'm anchoring on my desire to be a teacher, so trying to help others see a path to doing the same. I think we could give the world of survivor support a fantastic gift if we redefine recovery—not as regaining all of one's abilities, but as rebuilding a

happy and productive life, and a healthy sense of self, in the face of whatever capabilities return.

Debra Meyerson, Ph.D., is an author, advocate, and a professor at Stanford University Graduate School of Education who, among other things, researched gender and diversity issues in organizations and wrote *Tempered Radicals: How People Use Difference to Inspire Change at Work* (HBS Press, 2001). After a severe stroke in 2010, 3 years of therapy still left her with significant disabilities that forced her to give up her tenured position. With much help, including from her son, Danny Zuckerman, she wrote *Identity Theft: Rediscovering Ourselves after Stroke* (Andrews McMeel Publishing, May 2019). All author proceeds from book sales will benefit the work of Stroke Forward (strokefwd.org).

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