

An A to Z Survivors' Guide by the Most Reliable Source in Stroke Recovery – Someone Who's Been There

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"Aardvark," I say.

"Art fart," he says after me.

"Aaardddd..." I lay on the d.

"Fart"

I pull up Google Images, and my computer is a visual display of the absurdity of it all. "Look, Michael," I say laughing as I show him the crazy creatures. "There aren't a lot of aardvarks in Washington, DC, let's move on to the next one."

And then I get the look that requires no words. That reprimand over the reading glasses familiar to anyone who plays around when there's work to be done, a glance Michael perfected as a high-level television executive so eloquent with words he was asked to testify before Congress on behalf of broadcast television stations. He now has expressive aphasia, but he still knows how to make a point that will bring you around to his side.

"This is very important to me," he says.

"Aardvark," I say, this time like I mean it.

"Aardvark," he repeats with triumph.

Before his stroke, Michael was the news director for a Washington, DC, television station, so he's used to business plans. And now he's all about the business of getting better. He presented his plan today: "Learn to read the dictionary and get smarter everyday." It's been 19 months since his massive stroke, yet we're back at the beginning again, and that's how recovery works. It's as if you're on a train that moves forward and backward so you never get to your destination. Sometimes you like the ride, and sometimes you just want to get off.

People often ask me what a typical day is like. But typical days are something you have before the stroke. When one day your brilliant husband is learning to talk and one day he's learning to walk,

when a microwave is too high-tech for a gadget guru who repaired his own motherboards, when the former president of a television station can no longer read or write, there's no such thing as a typical day.

I was a sales manager for NBC in Philadelphia when this big hotshot from our Chicago station was introduced as a new vice president. He shook my hand, and an electric jolt went through my body. I walked away thinking, "What was that?"

It was (and is) the love of my life. Michael proposed on the second date, and we were married within 6 months. We just knew. And 15 years later, we still do.

I have never looked up to or loved anyone more. In addition to leading a Chicago newsroom from fourth to first place and winning local Emmy's and Addy's and accolades all over the country, Michael was a low 80s golfer, a gorgeous gardener, and a professional photographer – there was absolutely nothing he couldn't do. As much as I admired his individual talents, it was the sheer quantity of skills that dazzled me more. He drove cross-country in blizzards and hurricanes and read a map like Lewis and Clark. A big sports fan, he loved comparing notes with other fans (when he was a photojournalist, he had his camera in one hand and caught a fly ball with the other at a Cleveland Tribe game), and he'd be just as excited talking Civil War battles with a history buff or art history with a curator. His rock and roll band from back in the day was just inducted into the South Dakota

Hall of Fame. He could fix anything around the house and, yep, design the floor plans, too.

Yet, Michael always made me feel like the catch.

And that spoiling has served him well. Because now when Michael wants to go for a ride (he can no longer drive himself, so Driving Mr. Daisy it is); when he smiles and says, "Say... wanna go for a swim?" (my long ago lifeguard uses all his strength just to get in the pool); when he points to his newspaper and asks me to "read him a few bars"; when he needs me to cut his toenails or requires help in the bathroom (see also: toileting), all I have to do is flash back and remember. I don't think he ever said no to me.

The role of the caregiver (see also: caretaker) is huge. It's relentless. And while I have enjoyed some of the richest moments of my life after the stroke, I would be doing a huge disservice to all survivors and caretakers if I did not speak the truth.

A stroke is brutal. When Michael came home from the hospital, he could not speak, read, or write and that was just the beginning of our troubles. He was incontinent. That gleam in his eyes when I walked into a room was gone. The guy who laughed first and laughed hardest at all my jokes was not amused. My confidante and advisor who coached me when life got hard was now my biggest difficulty. He couldn't shower without assist, and when he insisted on doing it himself (growling no less), he fell when I left the room. He didn't know how to work his electric razor, and he needed me to shave him. It looked like something out of Psycho in our bathroom. (I don't recommend the Lady Bic for someone on blood thinners who is hairy like the Unabomber.) He needed help dressing. He couldn't eat his meal without dropping the utensils, and cutting his food was my job. He couldn't turn on his computer. He couldn't work his iPod. He couldn't handle money. He no longer knew how to work his remote. (I never did.) The man who could do everything, couldn't do anything. He combed his underarm hair instead of the hair on his head. My go-to guy was gone.

It's surreal when you're discharged from the hospital. Impossible to fathom you're on your own. There's this huge disconnect between you and the powers-that-be who say you're ready for home. To be fair, the hospital staff/insurance

company compared Michael to when he arrived (near dead), so they were pleased with his before and after. We had a different before and after in mind, so we were nothing short of horrified with extreme makeover: disability addition.

"Michael made a cup of coffee today" said his occupational therapist days before discharge.

"Seriously? He made coffee?" I was highly doubtful knowing his new skill set.

"Well, he forgot the water..."

Um, with all due respect to occupational therapists, that's not making coffee. That's making a fire. Don't try that at home.

But of course, he did. And watching him try to fill the carafe with his left hand (his once dominant right dangling forgotten by his side), measure his coffee counting "one, eight, eleven," drool running down his chin because he was concentrating so hard, didn't conjure up a barista. But I had to relax. Okay, not relax, but not have his 'n her strokes with every cup of Joe.

Slowly, and I mean slowly, we found our way. We couldn't have done it without the kindness, compassion, and unwavering support we receive from Michael's medical team. I love Michael's primary doc, the one *after* the stroke, and I adore the neurologists at George Washington University Hospital who saved Michael's life.

But it's rehab (in our case outpatient speech rehab specifically) that shapes the quality of the life that's been saved. Thanks to divine intervention (a television anchor/former colleague shared our case with a board member at National Rehabilitation Hospital [NRH]), Michael and I found ourselves in the inimitable care of Patty and Paul at NRH in Washington, DC.

Michael was a man of few words when he was discharged from the hospital. He had global aphasia – scoring FIM* 1, the lowest of the low, so speech therapy was our lifeline. Talk about a team effort. Patty and Paul double-teamed Michael, and they double-teamed me. They not only taught Michael how to talk after the stroke, but they also taught me how to listen. They had this magical way of making me a part of it, even when my part was staying home. Michael loved owning his lessons, and

*FIM™ is a trademark of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.

I absolutely adored the break. It was the only time I ever felt he was in better hands than mine. Patty and Paul would call me with progress reports, and they didn't talk in FIMs; their enthusiasm was contagious. "He was a rock star today," "He called a restaurant CHIC!" I loved hearing the results at home, too.

I heard Michael practicing on the couch, "More, More, Maur-eeen," I don't know who was more excited when he finally spit it out (Michael, Patty, or I), but it was the first time he'd said my name in 5 months and it was worth the wait. And that's not the biggest payoff from speech therapy.

For months after the stroke, Michael was trying to tell me someone owed him money. Since most of the handouts were all in the family, I just waved him off. But he kept trying another way to get it across. Think Charades when your partner can't get any of the clues. One day he wrote down \$12,000.

"Someone owes you twelve thousand dollars?" I asked, thinking it was like my birthday when he said I could spend "300 million."

"YES!" he said, with such force that I believed him.

He marched into his study and was clearly dismayed to see I had cleaned his desk. (And by clean, I mean I tossed it all in a trash bag and threw it out. I was overwhelmed by all the paper.)

"Rats," he said softly, drawing out every letter.

"What are you looking for?"

"Back."

He was rifling through his briefcase. Somehow I figured out he was looking for his day planner (book). Last year's to be exact. I retrieved it from another room and handed it to him. He paged to July and pointed to the date where he'd written "Adorama /\$12,000." I Googled Adorama, and it was a camera shop in New York. I was beyond excited with my guess: "You sold your cameras before the stroke, and you never got paid!!!!!!!"

It was like the world champs of Charades. He hugged me. We were jumping up and down. But not as high as we jumped 2 weeks later when the \$12,000 check arrived.

It's like life on steroids. The good stuff is so much better, and the bad stuff is so much worse. They say if you don't get it back in the first year, it's probably not coming back. Ask any stroke survivor and they will tell you they continue to improve forever. But in year 1, you learn to walk and talk again; whereas year 2, the improvements

aren't quite as dramatic. Adding *aardvark* to your vocabulary isn't as big as the first time a survivor walks to Starbucks by himself, orders hot chocolate, hands over the right money, and leaves his wife at home. I admit to cheating the first time, calling ahead to tell them what he would order, but then I learned to let go.

Michael is back. Not my prestroke Michael who could do it all, but our huge connection survived after all. We laugh, we learn, we love. And when all else fails, we hug. You haven't been serenaded until someone with aphasia sings "Happy Trails" to you as you fall off to sleep.

I will never ever stop missing the Michael before the stroke; I will never stop missing being in the passenger seat of the best driven car; I will never stop missing his computer assist, his great mind at work, his take on politics, on life, on people. But there's one thing I'll never have to miss. The enormous power of true love. He promises me he'll come all the way back. I'm not sure about that, but it's an honor to have his back.

APPENDIX

There's no one way to survive a stroke. But here's an A to Z guide from the most reliable source – someone who's been there.

Aardvark – A large burrowing nocturnal animal of sub-Saharan Africa. See also: the (life) lesson at the top of this story: People with aphasia still get a say.

Boner – A milestone for a male survivor. Caretakers and docs may be focusing on more pressing matters – like breathing, walking, and talking, but the return of the boner is a very big deal and well worth the wait. Results may vary.

Caretaker – advocate, bill payer, chief of technology, cheerleader, coach, communicator, chef, chauffeur, financial planner, food shopper, friend, guide dog, guard dog, interpreter, maid, mechanic, nurturer, paper pusher, plumber, personal trainer, teacher, therapist, turkey carver, vacuum bag changer, but wait there's more! You're a mother, father, daughter, sister, brother, employee, too? All your old jobs + all the survivor's old jobs + all your new jobs + all the survivor's new jobs = Caretaker, Primary. See you at the Gates of Heaven.

DVD – Any spouse with so much as high blood pressure should leave DFD (directions for dummies) for the DVD (and the programmable thermostat). Michael's brother tried to get me on the 12-step program: Turn the DVD on, turn the Integra box to DVD, turn the Comcast remote to Auxiliary, toggle thru 6 switches to Video 4, have the Sony TV on the cable channel, hit Play. It's been a year and half since my last movie, so I must have missed a step. When Michael tried to help, he lost our regular TV too. I cried. He hugged me and said, "Let's just think and pray." I said, "Do you pray now?" "No, it's just an expression [sic]."

Eyeglasses – aka "meat" in the early days of recovery. Perhaps that's why he was so often without them in the hospital – maybe they were giving him a burger when he just wanted to see (see also: Yes and No). A sight for sore eyes? Take a scratched or dated pair of eyeglasses to the optometrist and they can copy the prescription. The survivor may not be ready for an exam, but they still would like to see.

Facebook – Educational fun for survivors. Michael isn't ready to write, but he makes friends with reckless abandon, happily clicking anyone Facebook suggests. "Mike Ward is now a fan of Gene Wilder." I used to be a "ghostwriter" for Michael, typing what he wanted to say, until I read about the woman who lost her disability checks when they saw her happy pics on Facebook. She was out of work because of depression. To Michael's friends on Facebook: No comment.

Google Images – a remarkably good tool for people with aphasia. When the survivor asks for a new car, he may just want a new comb. Start your (search) engine before you leave for the dealership.

Help!!!!!! – Don't say, "If there's anything I can do..." Just do it! We'd love anything off our to-do list. Drive us to rehab. Grab us some groceries. Take our car in for service. Pick up a prescription. Mail us a can of tuna and you made us lunch. Hang banana bread and coffee beans on our door and you make our day. You can't do our heavy lifting (that's for us), but surely you can lighten the load. Do something little. It's big.

Independence – You can teach dependence as well as independence. Let a survivor do more than (you think) they can handle. Success is worth the occasional stumble.

Jill Bolte Taylor – Author of *My Stroke of Insight*, a must-read for caretakers and survivors.

Kindness (of strangers) – Family and friends are supposed to come through, and they do, they really do! But sometimes it's the people you know the least who touch you the most. From the 24th & M Starbucks baristas treating Michael like a VIP to the cabbie who waved the fare when I couldn't fold the wheelchair to Cliff who found us defeated on the side of the road when Michael input the wrong radio code enough times to throw our car into anti-theft lockdown. These gentle gems get us through our darkest days.

Listen with your heart. Try to learn our new language as we try to learn yours (again). Survivors need to be heard, and you'll hear a lot more if you listen with your heart than if you just listen with your ears.

Mid-life crisis – My husband's mid-life crisis was a stroke. I'd have preferred a red sports car.

Networking, social – An educational tool for survivors, and their doctors too! Note to neurologists trying to determine the timeline before administering tPA – have the family check sites like Facebook and Twitter for clues. Michael tweeted at 4:59 pm on that fateful day ("Waiting for a Phillies win"), and within 2 hours, he had a catastrophic stroke.

OMG – Oh. My. God.

Paperwork, passwords, power of attorney and privacy? Please! – Everyone has the right to privacy, but the password-protected panic is huge. Many stroke survivors (like mine!) forget or can't communicate computer passwords, ATM card codes, etc, and it's a project to pick up the pieces. Place a power-of-attorney and your passwords in a safe deposit box (share the code!) or better yet in a top drawer sealed with a kiss. By the time you get your hospital bills (piecemeal over 6 months so you never know what the whole stay costs), you're ready to just mail your life savings and declare bankruptcy. Don't. Contrary to popular opinion, hospital billing departments have a heart. Make them an offer they can't refuse. Give yourself a *healthy* discount. You earned it.

Questions – Don't pepper us with questions. Even well-meaning ones are too much of a workout for someone with a communication disorder. Follow our lead. Hi. How are YOU? Make

yourselves comfortable when the conversation falls silent. We rather enjoy the quiet.

Rx – Get to know your drug dealer. Pharmacists are a great source for a second opinion. They studied medicines and their side effects longer than the docs who prescribe them, so voice your concerns and see what they say. They help you more when you value their time, so come back if they have a long line. I heart my CVS pharmacists.

Speech-language pathologists (SLPs) – Ours at NRH (Patty and Paul) are the reason we made it to the other side. Do not rest until you find the best.

Toileting – A stroke euphemism if ever there was one. Most of our meltdowns – public and private – revolve around “toileting.” It takes a man stronger than mine to wear Depends, and timing can be a problem. *Low flush* (environmentally friendly) plus high stress can complicate matters so buy a \$20 “snake” from the hardware store. I felt like Wonder Woman when I unclogged my first toilet.

Unscramble this sentence: Brush Hair Your. Michael had about 50 of these to do for speech homework, and he was getting them all wrong. I messed up my hair like Cousin Itt from the *Addams Family* and said, “If my hair looked like this, what would you say to help me?” “I like it,” Michael replied. Survivors feel “scrambled up.” Help them unscramble to show the love.

Vagrant – Mistaken for one 18 months after the stroke. The halting, faltering communication is often mistaken for a low IQ (cue condescension and high-pitched HIYA BUDDY) and Michael has also been mistaken for a vagrant. We may have to rethink the beard. Sit on the wrong step to catch your breath or enter a chichi condo at your own risk (“get out”/ “go home”). Please people, get a clue. One day it might be you.

Ward, Michael – approved my telling his story – the good, the bad, and the ugly. He’s enormously private (prefers updates like “he’s great” for colleagues and cousins), but we’re hoping this fuller disclosure will make it a little easier for fellow and future survivors.

X – Michael’s signature until he learned to write his name again.

Yes and No – People with aphasia will often say yes when they actually mean no, so don’t just take no for an answer (or yes). Give them a chance to explain.

Zzzzz – SLEEP!!!!!!!!!!!!!! I cannot overestimate the power of napping those neurons. These power naps are a must after most workouts, and as survivors know, just brushing your teeth is a workout. Naps are restorative for the caretaker, too, whether we join along for the snooze or indulge in the “off duty” silence. So all of you who wish us well, don’t call us, we’ll call you.