

January 21, 2013

Hi - my name is Alice.

I was a talker, a salesperson, a recruiter. I was driven. My career was a major reason I got up in the morning. No matter what I did, it was not enough. I worked for Microsoft. I tried and tried and tried. Owned a business. I followed the American Dream. I have a great marriage. I was and always will be a "C" student. Resourceful, but never passes the ultimate test.

Until I had a rare stroke.

The anniversary of my stroke is February 25, 2008. Five years ago. I almost died.

But I didn't. I'm here to tell you if you make it through those first days and hours in the ICU, you are on a path to a new life. One that many of my fellow stroke survivors tell me is richer - and happier - than their first life. But this ain't pollyanna talking, I'm here to tell you.

My stroke was rare because it was a hemoragic bleed. (Most stroke are ischemic, caused by blockages or clots and are related to high blood pressure or heart issue.) But not just any bleed. It was a bleed in the part of the brain that usually is not affected by strokes. I happened DEAD CENTER (most strokes happen either on the left or right hand side, causing paralysis on the opposite side of the body), at the intersection of the Brain Stem (which controls breathing, and all you involuntary functions) and the Cerebellum (which controls balance, works with your vestibular system/inner ear/eye movement, and orchestrates muscle movements in line with what your thoughts/brain is thinking.

Essentially, my stroke shot the operating system in my body. Many with strokes have aphasia or lapses of thought. My thinking is just fine. My mind races 100 miles an hour, but my darn mouth and tongue don't know how to obey. It's like having a Cray super computer attached to a crappy dot matrix printer.

So when I woke up from my stroke that morning in ICU, I could not walk. My vision was blurry. Worst of all, I couldn't talk coherently. I talked fast and slurred like a drunk. My mind raced but my mouth would not create sounds that people would understand. I swear it was like my first days when I lived in Paris. I knew what I wanted to say, but couldn't be understood. I think it helped to relate my current experience to one I had known before. I had learned to speak French. I was going to learn to speak English again. And I had the hospital to give me resources to learn how.

I will never forget what my wise doctor told me that night in ICU. By some wonderful coincidence, I had been brought into NW Hospitals emergency room the same night that an experienced cerebellum brain doctor, Dr. Rasis, was on duty. Dr. Rasis told me this: One in ten stroke survivors come out of this completely like they were. Your stroke is the kind that could be that one in ten. The first 90 days of any stroke are hell. Your brain has been attacked. But your brain has amazing regenerative powers. It will rewire if you tell it what is needed. So you need to do your therapy RELIGIOUSLY and follow what your therapists tell you TO THE LETTER to "Retrain your brain." Alice, you are in a situation of "use it or lose it." You have always been someone who has been goal oriented. Well, you have the opportunity to create the biggest win in your life."

90 days later I saw huge changes. My sight returned to clarity. I got so I could sit up, then use a walker. My PT and recreation therapist at NW told me it was OK to be clumsy - that was part of having a stroke. What was not OK was being clumsy AND weak - the latter of which could be solved if I did my

exercises. So I did them.

I took speech therapy and got clear about what a journey this was going to be. Learning French was a bitch. This was going to be the same drill, but having done it once, I knew I could do it again. I just had to calm my thoughts so my tongue could catch up.

The worst part of my stroke was invisible. My vestibular system (did you know you had one?) got whapped. And why do they call these things awful names - "ST" words were the hardest for me to say, and yet I had to tell people about my STroke. About how my veSTibular system being shot made me sea sick, made me fall down and made me dizzy. Anyway, my therapist gave me exercises to do FIVE TIMES a day. I did them and six months later, the dizzies are gone.

There is a rhythm to stroke recovery.

The first 90 days when you get lots of support, therapy and results

After 90 days - two years - when, if you do what the doctor tells you, they will continue to prescribe therapy. Your insurance will keep funding therapy IF you should you are doing what they told you in the last appointment (why give you more appointments if you are not doing the work)

After Six months: apply for Social Security. Call a lawyer to get your finances aided.

After two years - something happens in that you get used to living with a stroke. Your brain settles out and rewires, things stabilize, but keeps improving slowly. Your life gets a new rhythm and you have a second life.

After Five years - I have "graduated" from a number of speech and physical therapist, having exhausted what they recommended me to do. I swim. I do weights. I garden in the P-Patch. I worked with DVR and Neurological Vocational Services to do a "internship" to see how much I could work (yes, getting tired never leaves you from a stroke, but you will get so you don't need two hours of naps every day - but I still need 10 hours sleep as a MUST). I have a part time job doing career coaching (I was a recruiter and coach in my first life) and I have a better marriage than before. Not being able to talk - well I had to learn to listen. And I had to depend on my dear husband. The bitch on wheels had to learn to bend.

I am grateful for my stroke. It was a game changer, and you know, I was born to be disabled. I am not angry. I never got depressed or cried. My stroke was caused by an Arterio Venous Malformation (bad plumbing in my brain that I was born with.) I am grateful it waited to happen until I was 55. I am grateful it happened when I was not self employed and we had health insurance. I am grateful it happened at my house, just blocks away from NW Hospital (a week before I was on an island in Mexico - I shudder to think of a stroke there).

So people are not supposed to be happy about a stroke and that is why I am often the weird one in support groups. Beating my stroke is the most affirming thing I have done in my life. It has also helped me listen to others and to know that the true path is to give to others. Your problems are never as bad as someone else's, so get off your damn pity pot and move forward. (yes, you guessed it - I have no bedside manner and would qualify for Nurse Ratchet, but truly, moping in your muck won't get you there)

It is all about attitude. Accept and move forward. You can do this. You are stronger than you know. My second life is actually happier than my first life. As a disabled person, I do the smallest darn thing and people go "WOW" - whatever. It is so easy to outdo people's expectations. I find that affirming that I can meet the expectations of friends around me.

My friends expected me to get better. I wanted to get better. Do you?

If you think you can't, you're right. But if you think you can, there is hope. You need hope - that, and NOT GOING IT ALONE! Stay involved with others. Get a buddy to take you to the gym. Join Toastmaster or YASS. Think of a hobby and do it. Tell people what you can do and ask for them to join you. When I was first sick, people wanted to help but didn't know how. Your job is to get out and get people to help you with what you need, or want to do.

My hope is a "One in ten chance of going back to normal"- Dr. Rasis, five years later I am 90% there!