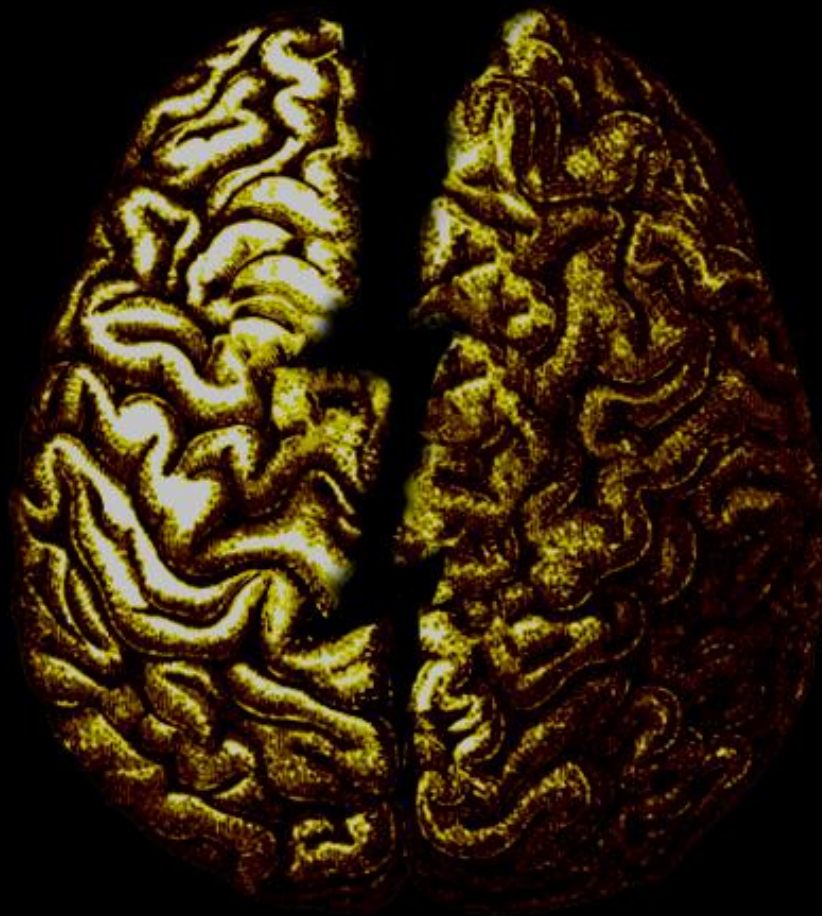


SEIZE THE SEIZURES



a memoir by

MARIANA COLEMAN

ACKNOWLEDGEMENT

To my daughter, Toni,

without whom I would have just had a little book in a strange, impossible-to-read language. She read, edited, and provided advice many, many times through every step of the creative process until "Seize The Seizures" got to its final stages. She was the motivation, the first grade teacher, the alarm clock when I had given up.

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who kept me grounded and always told me that I was given the better option--the option to live. The rest was up to me.

To my newly-found family living outside of America, for being who they are and helping me rediscover who I was with patience and love.

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This book is also dedicated in memoriam to my Mother and Father who made me the way I am but did not live to see me the way I am.

FOREWORD

I have this recurring dream about my Mom--we are in some unknown European city. I rap on the door of a small flat. I hear shuffling sounds as she peers from behind a small opening in the door. She looks startled, like I have just awoken her out of some deep slumber and like the light hurts her eyes...she doesn't say much, but her eyes look impossibly plaintive. "I wish you could be here more." I wake up, crying. It's just a dream, but this is what you feel like when someone you love is hurting. There is a lot of guilt, no matter what you do...and what you do is never enough.

People expect you to wear your grief in plain sight for all to see, as though the only way to express authentic pain is to cover yourself in ashes and wear sack cloth...as though there is something you are supposed to be doing. I am not sure how much doing is going on, but I do know a lot of feeling is. I don't like telling people my Mom is sick because it makes what I feel is a very private thing public. To talk about it feels diminishing and banal. How can pain be banal? I cannot tell you how many times people ask me how she is doing, almost waiting for me to respond "Fine," so they can get on with the conversation. I sometimes don't even bother telling them that she is very far from fine, so I just tell the truth. She is hanging in there.

What a lot of people won't tell you, even though it is such a ubiquitous trope, is how hard it is to talk to someone in a coma. Imagine seeing your Mom lying in a bed, with all manner of tubes sticking out of her like some alien arthropod has nested atop, her body wracked by the spasmic echoes of seizures happening beneath the surface of her heavily sedated brain. I tried to talk to her, but the words were not really coming out. All I could do was look at her and hold her hand. I know you will understand that even coming to the hospital to see her like this was crushing.

This book is the story of a really good woman who had a lot of really bad things happen to her, yet she is sharing her story. It's not a story about epilepsy but something a lot bigger than that. A guy in San Francisco once told me, "See you on the flipside, mama." My Mom's been on the flipside and she wants to tell you about it. To me, it's the ultimate gift of a mother to her daughter and a testament to who my Mother is—a brilliant writer and a firecracker of a woman (even by Bulgarian woman standards!), a spirit of immense strength, and a wicked sense of humor (I like to think I get that from her). I like to think, rather arrogantly, that only I could have edited this book because I get my Mom so well and am connected to her on some subconscious, supra and super-natural level. I feel like the translator of a language of two speakers, one that I hope will not be deemed endangered any time soon. Even the title of the book works on so two levels—I know she can explain it a little better to you...But seizing the seizures is about grasping them, taking a hold of them, hoping to understand them a little better in hopes that will cease to seize over her life.

What I find most authentic about it is that it is so refreshingly pathos-free. My Mom doesn't want you, the reader, to go "Aww," by the time you finish it. There is no overdramatization meant to pluck at your heart strings and appeal to the Oprah set—my Mom really is far too fun and funny for those sort of shenanigans. She keeps it real, I am sure you will see. And yes, there is a lot of sad too. Ultimately, the book is a strange little microcosm of what seizures are—electrical storms—it roils and stirs and moves and severs and connects and fires and rattles...it unsettles and it calms...just like life.

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1. INTRODUCTION



I have been thinking about writing this book for several years. The idea has been simmering in the slow cooker of my brain all this time. I knew I would write something one way or another, but this “one way or another” never arrived. I tried to convince myself that writing a memoir was a piece of cake. I just needed to open up in front of one person (I would be “the one”) and tell out loud the story of my life with epilepsy, the epilepsy that resulted from a massive brain infection. I couldn’t write in the laconic Facebook/Facial Book style (as I like to call it, since it is so superficial and super...facial). It had to be more than “I had a seizure” and “I scared my daughter to death.” It had to draw you in with the good, the bad, and the ugly about a disease not too many folks know about.

If you are a famous person, your memoir flies off the shelves. Sadly enough, I am just one, one of several million who suffer from a serious disease. Epilepsy. It is a medical

condition which I was not born with. It was given to me as a “gift” after surviving viral encephalitis. The disease has made some stories of my life funny, some sad, some just plain baffling. But this is how an epileptic writes...

This book will give you an idea of what epilepsy is in simple terms, not from a doctor’s perspective. You read and watch motivational stories all the time. They affect us differently; some encourage us to try harder, some are discouraging because they do not make us believe we have the strength to be winners in this “game.” This book is not about winning--it is about living and surviving. It is for those of us who give all we can to fight the unceasing seizure monster on a daily basis. Occasionally, we think we are almost at the top of the mountain. But then, unexpectedly, the mountain collapses and we start climbing again.

Memoirs are based on what we remember, what we feel now about the time the events occurred. The storage space in my brain is messy; some shelves are empty, some packed. It is like a teenager’s room.

The memoir will underscore the importance of having a circle of people who care about you. Some of them will become your hospital advocates, following you every step of the way, calling insurance companies and employers, desperately trying to complete the pile of forms given to them. Others will pray....

Maybe, just maybe, you will not be so hard on yourself just because you have epilepsy and there is no article written about you or your heroism in this battle. The mere fact that you are alive and reading this is already inspirational. Everyone around you has something to worry about. At least you know precisely what your disease is. You are one step ahead of them. You *are* a hero.

This memoir gives me the freedom to get nearer to a healing time in my life. After eight years of “hanging out” with the disease, I know her almost as well as she knows me. We agree to disagree on how we see life, people, friends, and family.

If I can reach a larger audience, not only the people suffering from epilepsy, but their families, caregivers, friends, everyone who wants to hear and learn about epilepsy from an adult epileptic and see how funny and sad, how easy and hard it is to “*seize the seizures,*” my job here will be done.

2. EPILEPSY

“Sometimes a cigar is just a cigar,” Sigmund Freud once said. It bothers me when people try to make more of a disease or less of it--epilepsy has taught me this. My mother, whom I lost when I was still in college, was a neurology nurse. One day in my childhood, we were walking down the street. I was squeezing her hand tightly. I did not want to get lost and make her worry about the little devil that I was. Suddenly, in front of us, a woman fell on the sidewalk and her body started shaking, her eyes closed, her teeth were chattering, the legs and arms were jerking. Quickly she lost consciousness. A crowd gathered, everyone was frozen, trying to look and not to look at the horrific picture. There was only one person, my mother, who ran towards the woman, put her handbag under the woman’s head, turning it gently to the side. There was no blood. It looked to me like the woman was not breathing for a very long time. This is what the onlookers saw too. Panic settled in. An ambulance arrived.

When we got home, we did not talk about what happened. I never asked. All I knew was that had it not been for my mother, something terrible could have happened. I was in fourth grade; I had never seen anything like this in my life. Now I know that the woman on the street had a seizure. I remember this episode as though it was yesterday... How can I forget?

My mother did not live long enough to see me with my epilepsy. It would have killed her to see her child suffering.

One day in 2004, I met Ms. Epilepsy again. “Hi, my name is Epilepsy. What’s yours?” Before I opened my mouth to say my name, Epilepsy said, “Oh, well, I have way too many friends. It does not matter what your name is.”

I have to introduce you to epilepsy, just to give you an idea of who she is. My goal, as a person who is not a doctor, is to bring your attention to a disease that is vastly ignored. According to the Epilepsy Foundation of America’s definition, “Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. It is also called a seizure disorder. When a person has two or more unprovoked seizures, they are considered to have epilepsy. Seizures happen when clusters of nerve cells in the brain signal abnormally, which may briefly alter a person's consciousness, movements, or actions.”¹

“Epilepsy affects 65 million people worldwide.”²

Further on, the Foundation site states “Between 48,000 and 469,000 soldiers serving in Iraq and Afghanistan are expected to develop post-traumatic epilepsy (PTE).³ If you are not scared by now, just consider this:

¹ Epilepsy Foundation of America. “About Epilepsy” section. Accessed 2/26/2013. Landover, MD. <http://www.epilepsyfoundation.org>

² Epilepsy Foundation of America. “About Epilepsy” section. Accessed 2/26/2013. Landover, MD. <http://www.epilepsyfoundation.org>

“Epilepsy is the fourth most common neurological disorder in the U.S. after migraine, stroke, and Alzheimer's disease. Its prevalence is greater than the autism spectrum disorder, cerebral palsy, multiple sclerosis, and Parkinson's disease combined. Despite how common it is and major advances in diagnosis and treatment, epilepsy is among the least understood of major chronic medical conditions, even though one in three adults knows someone with the disorder.”⁴

“Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults.”⁵

There are many types of seizures; they display themselves differently, too. Everyone experiences them in their own way. Some may lead to loss of consciousness, convulsions, body twitching, jerking of limbs, lip smacking. These are best known as generalized (grand mal seizures). The partial ones may be simple or complex. They are called partial because they do not “take over” the whole brain; there is no loss of consciousness. However, the complex ones may spread and lead to a grand mal seizure and complete loss of consciousness. All of this is caused by a short circuit, an electrical disturbance in the brain. The cells of the brain do not always carry out their electrical communication in peace and harmony. There is some politics going on there when they send abnormal signals to each other.

Since 2004, I have had many upon many a seizure; from the generalized ones, followed by my set of questions...”Where am I? Who are you? What happened?” seizures, to the partials-simple and complex seizures. With the partials, there is a safe area of the brain which tells me about everything going on around, inside and out. Most of the time, they will stop just the way they will start—*never ask for permission*. They start in the brain and end in the brain. The visit may be for a minute or two, but I may need hours upon hours to recover fully. I am always angry when the simple partials start. They cannot be stopped. I know quite well what transpires because I do not lose consciousness, but even the strong woman that I am, I can not yell and scream at them to stop. They stop when it is the time to stop.

Doctors say a seizure diary is very important for proper treatment. I did not keep a very detailed diary until the last several years, which is why I cannot give you the exact number of my seizures. It should be in the hundreds. In my life, I kept only one type of diary--a happy diary--the diary about my first love and the diary about my first attempt to speak English, when I had no

³ Epilepsy Foundation of America. “Resources/Veterans. Accessed 2/26/2013. Landover, MD.
<http://www.epilepsyfoundation.org>

⁴ Epilepsy Foundation of America. “About Epilepsy” section. Accessed 2/26/2013. Landover, MD.
<http://www.epilepsyfoundation.org>

⁵ Institute of Medicine (IOM). 2012. *Epilepsy across the spectrum: Promoting health and understanding*. Washington, DC. The National Academies Press. Report Brief.
<http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum/Report-Brief.aspx>

clue about a single English word. I just mimicked the pronunciation of songs by Otis Redding. He was very popular back then.

I continue to have seizures. If they are gone for a week, I begin to worry where they are; when they are back...it is too tough for my little body to handle them. They are like my children. I send them to soccer camp; I worry how they are. When they come back, I worry how to keep them busy so that I can have some peace and quiet.

“Although the symptoms of a seizure may affect any part of the body, the electrical events that produce the symptoms occur in the brain. The location of that event, the extent of its reach within the tissue of the brain, and how long it lasts all have profound effects. These three factors determine the character of the seizure, its impact on the individual, and the social consequences involved.”⁶

Very often seizures in adults are the results of brain injuries, tumors, strokes, brain infections, but “in up to 70% of all cases of epilepsy of adults and children, no cause can ever be discovered.”⁷ This is really scary, to say the least.

I asked many times the few people around me about what exactly happened to my little body during my seizures. The people present during seizures recall this with great difficulty. It pains them to tell you what they have truly seen. My memoir contains some of these recollections but is mostly based on my own.

⁶ Epilepsy Foundation of America. “Seizures” section. Accessed 2/26/2013. Landover, MD.
<http://www.epilepsyfoundation.org>

⁷ WebMD. Epilepsy Health Center. Common Epilepsy Causes and Seizure Triggers. Accessed 3/8/2013
<http://www.webmd.com/epilepsy/guide/epilepsy-causes>

3. THE BEGINNING

My first seizure decided to pay me a visit one regular Monday morning in 2004. It was 6:00 am. My husband Gary and I were going through the usual routine of getting ready for work. Everyone was robotically moving from shower to clothes to breakfast. Every day, Gary and I would commute together in our car to the Metro station's "Kiss and Ride" area. I never saw or got a kiss there, there was no time for intimacy...

After I was dropped off at the Metro, Gary would continue to his job at a local university. Unlike in the morning, when everyone was quiet and the radio was the only one talking, in the evening, it was MY show time! Like a child whose Dad asked her after school "So, how was your day, Mariann?" I did not wait for a question. In fact, there was no question. I would just start my numerous stories, forty-five minutes of non-stop chatting away... I always thought Gary did not hear a word coming out of my mouth.

A day came in our lives when I was proven wrong. Gary was really listening. This Monday morning of 2004 was different than the rest. I was expected to have a strategic planning meeting at work and the level of stress was higher than normal. I had rehearsed and redone my presentation many times.

I was wearing a nice suit and high heels, hair and makeup done. There was time left to sit on the leather couch in the living room and have my coffee.

Gary was still in the kitchen reading his paper. All of a sudden (it was explained to me later) he heard some noise, a 120 lbs. bag of potatoes (me) had fallen on the carpet, unable to talk. My body was on the carpet, jerking; I was OUT.

If you live alone and this happens to you, you may be in trouble. If you do not live alone but you live with someone who loses his mind when he sees a body on the floor, doing weird and scary "stuff," you may be in trouble again. I was really lucky Gary was next to me. He had not seen a seizure in his life; neither had Baxter, our chubby tabby cat. When the ambulance arrived, Baxter exhibited some interesting behavior. Probably the EMTs decided he had been a pitbull in his previous incarnation. Baxterboy was growling and hissing, keeping everyone away from me. He was not skinny and if he wanted to scare a dog or a man (not necessarily in the same order), he could easily do it. He had to be restrained with a blanket and taken to a different room. In his mind, the EMTs were there to kill me, not to save me. In his mind he was "the only one" to protect me. Baxter told me all of that later, when we had our Mama and son time.

I was taken to a nearby hospital and kept there for a week. I was running a 104° F fever. The seizures were coming one after the other. The shots of Ativan did not seem to work. Ativan belongs to the group of benzodiazepines, very powerful drugs, described by WebMD as "minor tranquilizers (sedatives) that prevent or stop seizures by slowing down the central nervous

system. This makes abnormal electrical activity less likely.”⁸ Gary, our best friends, my daughter--everyone was in panic mode already. Tough times for everybody who saw me shaking and shaking and shaking...

At that time, Gary made the life-saving decision to have me moved to a major University hospital. There, the doctors conducted numerous EEGs, CTs, MRIs, and tests I do not even know the name of today. The diagnosis was Viral Encephalitis.

WebMD defines encephalitis as an “inflammation of the brain tissue.”⁹ When caused by a virus, this is Viral Encephalitis. In simple terms, when the body detects the attack of the virus, the immune system collects all its ammunition to fight. This causes the brain to swell. The infection and the immune system response create what we know as Viral Encephalitis. This is how I can best describe it.

After being tested for all viruses that might have potentially caused this, the doctors’ conclusion was that it was a virus belonging to the enterovirus group. The enterovirus was causing the brain infection and putting me in a state of persistent seizure. That was not all. I was not able to regain consciousness between the long, recurrent, seizure activities. Call it “status epilepticus,” call it “status death is near...”

Let’s face it--the brain needed a break. How do you give a brain a break (in a hospital)? A wise choice is to put the patient in an induced coma.

⁸ WebMD Epilepsy Health Center. Benzodiazepines for Epilepsy. Accessed 3/8/2013
<http://www.webmd.com/epilepsy/benzodiazepines-for-epilepsy>

⁹ WebMD, Understanding Encephalitis- The Basics. Accessed 3/8/2013
<http://www.webmd.com/a-to-z-guides>

4. MEDICALLY-INDUCED COMA

I am in an induced coma. It may be more appropriate to keep this page blank? I was OUT, but the medical equipment, the doctors, the nurses, the FAMILY, and two good American friends were in. In the name of all they did for me, I will keep writing. I can't leave a blank page. In situations like these, people behave differently. It is all coming from their hearts. One will hide his fear and try to act strong; another one will cry openly. Those who believed in God and Heaven were praying; I know that those who wanted empirical data for everything around them had already gathered it. After all, I married a scientist. He would not wait for the doctors to tell him what goes on. He knew and the doctors knew... It may or may not work.

He knew something the doctors did not know. He married a Bulgarian woman. Bulgarians are not known for being quiet and pleasant all the time, especially the women. They carry their hearts on their sleeve, but if you cross them, they will fight. The darn virus had entered a Bulgarian woman's body.

Back to the coma(s). I did not know for a long time what the difference between medically-induced coma and coma is. I did not *want* to know. One important component I was aware of was that in a coma, you look the same on the outside (not very attractive), no matter what kind of coma it is. The risk of "coming out" undamaged is "to be determined." From a medical standpoint, the regular coma comes on its own; the latter is supposed to save you when nothing else has worked. It is reversible.

Barbiturate-induced coma is very common when you have a head injury, stroke, tumor, status epilepticus, or infection. It is described in Wikipedia as "a temporary coma (a deep state of unconsciousness)."¹⁰ The skull's job is to keep the brain from expansion. During injury, fluids may gather in the brain, causing it to swell. If the skull is doing its job, the brain feels compressed in the area. If the pressure does not get less intense, some areas of the brain may get deprived of blood carrying oxygen. It is possible for the brain tissue to die, causing permanent brain damage or death. The barbs are supposed to reduce the swelling in the brain. Thus, the pressure decreases and part or all of the brain can be saved. So far, so good.

Doctors argue about the safety and side effects of this procedure. But consider, what options do you have when you are in constant seizures from a swollen brain? I was *in* for about 1-2 weeks, which makes me an expert on it. I claim so.

It is a strange feeling to embrace how you were put very close to the end of life in order to have your life saved. People fall into a coma and never wake up. The brain gives up on them. Others, like me, were put in a coma to save the brain. Some are very assertive about "you are

¹⁰ Wikipedia. Definition of Induced coma. Accessed 3/8/2013.

born alone and you die alone.” You are born with at least one person lifting the heavy load, your mother. As for the dying part, I can’t speak about it; it is complicated. The difference I see and know about is that you cry when you are born, but when you leave the earth, you are *silent*. Finito...

What happens after that is even more complicated. Depending on the time in a coma and the medical condition you were in, you may have had time to dream or experience nightmares. You may talk about “near death experiences” and a glimpse of Heaven. Who knows? Does it matter?

5. WHERE AM I?

The long awaited day when I would return to the world arrived. I do not know exactly what everyone around me was thinking, but it must have been quite intense. Would I be the person I was; would I even know who I was? I am sure it was a concern whether I would recognize anyone. I DID. There was never confusion about one thing: Gary is my husband. I did recognize my daughter, Toni, too. When I became capable of talking normally, not in gibberish, I told them: “You (Gary) were sitting on the left side, while you (Toni) were sitting on the right side.” I remember the big black eyes looking at me with fear, pain, getting ready to cry at any moment. I was still heavy on drugs, but managed to say something like “you have such beautiful eyes, just like my daughter.” Later, Toni would say “that is because you were talking to me, goofball!”

The next several weeks were interesting too. The meds kept me very happy. I was laughing and laughing. There were days when everyone was losing hope; there were days when I would show signs of getting better. I was bed-ridden, but showing signs of being *me*. At least this is what Gary told them. It was time to be moved to a rehabilitation hospital.

This is the way I remember the trip in the ambulance. I was tucked under a blanket and tied onto the gurney, oxygen flowing into my lungs. Since there was a man sitting close by my side, I was not too worried. My conclusion was, “I am going to a better place!” For different people “the better place” may imply something else but for me, it was enough that it was just a “different place.” I opened up a conversation. The boy/man was a medical student or intern; he was not bothered by my slurred speech. He told me that he went to a medical school in this area. I responded in an all-knowing manner that this was one of the best schools in the country. He should be very proud of himself. Poor guy, he did not know at this time that this foreign woman, with a strange accent, who just came out of an induced coma, would not shut up the whole half hour of the trip.

I did not want this road to take me anywhere so fast; I wanted to talk and talk. It did not matter who was listening. I missed my mouth...it was closed for a long time. I missed my English language. I came to USA to live a different life, speak freely, study, work, and meet new people, not to be sick with a locked mouth.

We arrived at “the location.” I did not realize this was a Rehabilitation Hospital. I was very carefully put in a new bed. It was a semi-private room. A white curtain separated me from the other patient. I was relatively alert, curiosity kept my eyes open. Like a child, taken to a theater, everything was interesting to me.

I am missing many medical episodes, but what matters is really not the timeline. I felt *cared for* from the moment I arrived. I FELT ALIVE AGAIN...I did not realize at the time I

was a *big sick baby* with *big baby problems*. What is a baby supposed to know, anyway? Eat, cry, and sleep. I did not realize life was starting a second time around.

6. AT THE REHAB HOSPITAL

In the morning, I awoke in a hospital gown. Not the height of haute couture, let me tell you. The realization that I could not get up, could barely talk because of the tracheostomy in my throat, the need for tubes and bags to be constantly attached to my frail body was disheartening to put it mildly. The strong drugs and the coma time prevented me from deep psychoanalysis. Otherwise, depression could have killed me right then and there.

In the morning during their rounds, the doctors would ask me what my name was, what date it was, who the President of the United States was. I always stumbled on the Vice Presidents. On the white board in the room, I was able to see the date and the treatment plan for each day. The plan involved physical, speech, occupational, and recreational therapies. My mind was never clear of medications, but Gary was there every day, making sure I was not lost in translation. He truly had amazing patience. As an attentive husband, he knew I hear only what I want to hear and ignore the rest. It was evident, in this place, everyone was determined to have me working; little sleep-- action, action, action.

It takes a lot of brain for an *adult baby* to figure out what each part of the body is used for. Even these questions were very difficult for me at first. I eventually learned that tracheostomy was a surgical procedure done on my neck “to create an opening through the neck into the trachea (windpipe).” As it was explained to me a tube is usually placed through this opening to provide a clean and safe airway for the oxygen to get from the mouth to the lungs. Breathing was not easy through a tracheostomy tube, but it was a necessary step. The respiratory specialists, God bless them, were essential throughout this process. You push a button; they run and help clean your throat from the secretions. Gradually, my voice moved from croaky and damaged to somewhat stronger and stronger. The hole in my neck covered with bandages was very worrisome, but you have two choices to make – the risk of not being able to breathe vs. the scar in your neck to remind you of the bad times in your life. Not a difficult decision to make...

I do not recollect having a phone in the room, but there was a TV set. It was not like I knew what I was watching, but it was keeping me company. My room had a window. It was overlooking a garden area, where some days Gary would take me out in my wheelchair. The weather was beautiful that June of 2004, even from inside the hospital.

The therapies started almost right away. My dearest friend, Coleen, assisted Gary in finding sports outfits. In my locker everything was organized for each day of the week. Even my socks had my name on them. Mariann? Like I was going to steal my roommate’s socks! I was ready to be wheeled down the hallway and be taught all over again how to walk, talk, how to grow up fast from a baby to a woman in her late 40s in no time.

The highlight of each day was Gary's visit. At 5:30 pm every work day, he would arrive. When I saw him, I would start doing everything I was capable of. I was like a monkey in a zoo seeing a banana. Gary called me a "jabber box." I would talk unstoppably, incomprehensibly.

The days of the locked mouth were gone. Adios! The throat was completely backed up with words competing to get out of there.

Gary was bringing flowers; I was constantly getting beautiful flower arrangements from my friends... They were placed close to the window and I would spend hours in between activities looking at them. They filled my heart with warmth. I did not associate them with the hospital; they were nature's creations and what beautiful creations!

The brain started healing at amazing speed from the moment I was brought to this place. One thought that preoccupied me was that if I did not learn how to grow up to a 1 year old, 2 year old, then first grader, second grader...until I become an adult, I was doomed. This is IT. I would be sent to a nursing home, mental hospital, or I don't know..., but the prospects did not seem good. The *baby* was seriously worried it **had** to grow up fast.

Everyone who knew I was sick was rooting for me--doctors, nurses, therapists, Gary's whole family, my daughter, our friends. Oops, I was going to forget – even my ex-husband – visited.

When I started throwing in dirty jokes, which I was good at before I got sick [only the jokes were better], people knew I must be on the mend. Every day, Gary was bringing something new to trigger my memory. He brought a boom box with all my favorite music--classical, rock, hip hop, blues. My room was close to the nurses' station. Remember, I [thought] was "the center of attention." In the evening, the nurses would wonder at the selection of music I had. They would not be so shocked with the rock, but my love for Eminem, Usher, and Ludacris was another matter. At that time, they had not met many white female patients my age who would listen to hip hop. I could move only my fingers and toes, since I was stuck in bed, but there was some serious dancing going on in my head. The nurses were happy for me; I was happy to "party" too.

My wedding pictures from Las Vegas got their attention too. At some stage in your life, being "good crazy" is better than being totally normal. Our cat, Baxterboy, was also there in a picture with his Christmas hat on. Regardless of his numerous contributions to my life, Gary had to explain to me who Baxter was. If I could have heard him hissing and growling, I am 100 percent sure I would have recognized my feisty gentle giant. Unfortunately, pets are not allowed to visit their family at the hospital.

One day, I asked Gary to go to Victoria's Secret and get me some decent pajamas. "I can no longer wear these rags." He came back with several sets of silk pajamas in purple, red, and

pink. A week ago, I was in a coma, looking like a “little Eskimo with a big round face”; a week later, I was in Victoria Secret’s pjs. This was some major beautification!

I also asked for some cash to have on me. Gary was curious where I was going and how much I needed. I can’t deny he always gave a Hollywood performance, always pretended he barely questioned my decisions. “I need to have \$20 with me, just in case,” I said. “OK,” he answered, “I will hide them in the boom box.” I am not sure how this hiding place was discovered--there was no one around, but the next day, my money was gone. So was my Ludacris CD. This was really ludicrous...

I had many visitors. Sometimes I would be so medicated, I would not know who they were, but I liked to be visited. One time, a colleague of Gary’s asked, “What food are they feeding you, Mariann?” I said with confidence, “Oh, very nice food. Kangaroo.” The man looked at Gary with deep compassion. “Excuse me, look up and read!” I pointed at the bag; it said “Kangaroo Ready-Feeding Pump.” I was right! There you have it, professors!

Another time, I really thought there was no wall separating the rooms with the patients. I heard noise at night sounding like sexual activity. Hello, drugs! I did not get a peace of mind until the next day when Gary explained to me how wild my imagination had been. The rooms were separated and judging from the patients’ diseases, this was the last thing on their mind, if we all had any mind at all.

7. DREAMS

The dreams I share with you are exactly the way I remember them. Since I told them to so many people around me soon after they occurred, I am absolutely sure of the authenticity of this story.

There are three stages of dreams and nightmares I went through. The first type is at the Rehabilitation Hospital. My health had improved and the dreams were more “heavenly.”

I was always looking forward to sleeping after so many hours of therapies. After the night nurse woke me up to take my vitals and give me my medication, I went straight back to the dream and would continue right where I left it off. Every night, one and the same beautiful dream was coming to me. My thoughts were very lucid. I would enter a magical world. Sheer lace and satin curtains, billowing in a wind and wrapping around me, caressing my skin, as though communicating with me through touch; all sorts of colors--red, gold, blue, purple curtains with tiny glass beads at their ends. As their beads tinkled in the wind, their melody soothed me and I kept opening one curtain after another. I was walking forever and ever through this magical landscape. I was fascinated by them and always wanted to stay there. To walk and to weave my way through them and to always have them with me--to have that time with me always.

In the morning, it would be really hard to forget what I have seen, to accept the world at night does not exist. I was completely relaxed and ready to start the recovery again. There were no people in this world; it was just a world full of colors and relaxing music.

The second group of dreams and nightmares are from the coma state. As I was getting better, I started describing in great detail the events which had occurred during the induced coma. Some were dreams, taking me back to my childhood to times I never understood and always wanted to find an adult answer for. I did not have a sense of time; it seemed like one story was going after the other in some strange chaotic order. It was an endless series of good and sinister, all of it extremely clear and vivid. I was never touched by a human being or an animal. But I talked and was talked to in this different world, I saw and was seen in a way I never thought possible.

I am really grateful for this unconscious coma time. I will share some of my dreams from that time with you. It did not take long after I was taken out of coma for me to be able to start describing this rich imagery to my husband and my daughter. They were both fascinated. I

was not reading any books and could not read books at the time. The stories appeared as an attempt to dwell deeper into myself and my family, my lost and newly found “reality.” There was no deviation in the descriptions whatsoever. Throughout the years, I kept telling more and more people about them. Gradually, everyone knew the stories and got used to them. My mind identified as dreams some of the memories; there were also new dreams.

My mother appeared in my dreams as a flying angel, with a big smile, red hair flowing in all directions. All I remember is a huge, huge smile. I have to give you a little background of who she was.

Her name was Anastasia. She passed away at the age of 58 from liver cancer. I was still in college. Prior to her retirement, she was a nurse practitioner; before that, in a different town, she worked as a nurse in a psychiatric clinic. Her career started in the late 40s in the Northern part of Bulgaria, my native country. Back in those days, in a backward communist country with poor healthcare, there was one midwife serving a couple of villages. My mother was that midwife. She might have delivered hundreds and hundreds of babies. It was in this environment that she met my father who was a doctor in the same region. This was the time when penicillin was just beginning to be used. When they got married and my mother got pregnant, it was also a time when my father was away, saving other children. She was alone. By the time he got back, their baby had developed pneumonia and died. I can only imagine how they survived the death of their first-born. In addition to losing a first born child, my father had to live with the thought that he could not come on time to save him with the same medicines he used to save other children.

My mother was a red-haired beauty. She knew how to dress well on a limited income; she knew how to be the best house decorator, the best chef, the best mother, and the best wife. She put a very high value on education. “You need to do it *all* to be complete.” That was her life philosophy.

I was quite a rebellious child. Mom did not have much hope that something good is going to come out of this child. My sister went to piano lessons for 8 years and Mozart’s and Beethoven’s music were heard from our little room daily. Mom sent me to piano lessons too. It seemed like my progress was not anywhere close to what was expected. I did not go beyond the simple exercise named “The Donkey” from a famous Bulgarian composer. I can play “The Donkey” with closed eyes even now.

Mom did not give up. She thought I could learn German. There was nothing I hated more. Back in those days, athletics were not an option, nor did I have a natural predisposition to any sports. What was Mom supposed to do with me?

It was early 70s--a time when language schools were gaining popularity. My mother was scared to death to send her 13 year old girl to study in a town 70 miles from where the family

lived. This was the *only thing* I wanted. Going to an English Language School was a big deal. As worried as Mom was for my life and virginity, she was very proud and happy for my decision. My sister's success as a student in Germany had a lot to do with it. Finally, I was moving in the right direction.

In my coma, my mother was not crying--she was smiling at me. I needed her strength. I believe I got it in this stage of unconsciousness.

My father came to see me in my coma state, too. His name was Anastas. He was an orthopedic and trauma surgeon and a very good one. He was one of those people born to be a doctor, born to save lives. He would have his little suitcase with everything for emergency medical care next to his bed. No matter what time it was, if someone was at the door asking for help, he would run with him. Remember, these were not the days of 9-1-1 as in the USA. This was a small communist country, where you may or may not get medical help, you may or may not make it to a hospital. Most people do not own a vehicle. Families live in one room, small apartments.

Being a doctor does not make you rich, but it gives you the gratitude of all the people whose lives you have saved.

My father was extremely intelligent. He was not someone you would like to have a beer with--he would rather focus his time on saving lives. Though he was an introvert, he enjoyed playing in a chess club. At the hospital, he would play volleyball. Even back then, he knew how important it was to clear his head for next day surgeries. He had a strong sense of justice. I have inherited this from him. He was not good at hiding what he thought—he was always outspoken.

Dad was very proud of the doctor he was. We moved often from city to city. To me, he always kept his “celebrity status.” As far as his children were concerned, he was not the talking type. It was difficult to determine how he felt about me. He delegated (conveniently) the role of the “speaker of the house” to my mother. What you are NOT supposed to do always came from her. I wish we talked more. I would have known how proud he was of my going to the English Language School. He never reprimanded me for my antics. He would know immediately when I lied about being sick so I could stay home from school but would not question me to the point of embarrassing both of us. He asked enough questions to make sure I deserved a break from school, but nothing more... I would get his precious note to give to the teacher. Then I would go back to school and get only As.

My father loved soccer. Our daughter-father time was the soccer games. There were not so many girls going to every soccer game like me. Who knows--maybe my love for soccer made my Dad proud. I had forgotten this bonding experience until my friends from high school told me how excited I looked on the days after games.

One day, during their retirement days, my father admitted to having an affair 10-15 years ago with the mother of a boy whose life he saved. My sister and I knew my mother was emotionally distressed. He could have easily kept this sin until his final days, but he might have been seeking redemption. He might have felt, "I love my wife too much to die carrying this infidelity with me."

My mother died from cancer, BUT, in my head, I always blamed my dad for what happened to her. It may not make sense to anyone, but to me, it did.

When my mother died, a part of me died with her. She was the nucleus of the family. My father came to live with me, but it was so not the same. The family spirit had already died with her. Half of everything and everyone was taken away.

In the coma experience, my mother showed up alone. My father was not there. I saw him later. He looked sad and pitiful. He was asking me for money. I was hateful, very hateful. I said "I do not have money", which was true, but we did not have anything else to say to each other. Perhaps, if I knew how much he loved my mother, how much he loved us, his kids, if he had confessed all his feelings, I would have forgiven him. He would not have needed money to live in the world of the evil. A doctor, who saved so many lives, should not live with the evil.

Now comes my turn, for I am not perfect. I did not remember how, but I ended up in the middle of a big Roman coliseum, similar to those where the gladiators were thrown to fight with the lions. The stadium was filled with people. All of them were alive; I had met them at some point in my life, with some I was in contact at the time I got sick. They were asking questions about one thing or another I had done to them. "Do you remember when...?" They were not thanking me for doing something good. Just the opposite, I was given a chance to explain what I did and why I did it. I suppose it sounded credible because they all forgave me and gave me a second chance. There was one particular person whom I value very much. I am very careful every time I interact with her since I am not sure she will give me a "third chance." Boy, she was mad.

There is a third kind of stories, which undoubtedly are only nightmares. They occurred at the time I was taken out of coma, but my future was quite questionable. There was a whole group of neurologists who would come to see me and discuss my case. I was paying close attention to their faces; the words were not clear to me. I remember their group in white coats

looking concentrated...Then, they left. This was happening several times. What came out as a nightmare was this:

The doctors had left. I decided to look at the patients lying quietly in their beds to the left of me. They were all completely covered in white sheets. **THEY WERE DEAD.** I wondered why I would be left in one and the same room with dead people. The lights were on in the room and the door was barely ajar, or should I say “the door was almost closed.” Shortly after, someone decided to turn the lights off. I wanted to scream, to scream as loudly as I could “Hey, wait, not everybody is dead in here, I am NOT! Don’t turn off the lights. Please, please, don’t turn off the lights!” There was no voice coming out of my mouth.

This was the scariest and most heart-wrenching nightmare. After I told it to Gary a few days later, he said, to make me feel happy, “The opening in the door was size 10.5 to allow my foot to hold it open.” He confirmed that there were days where **NO ONE** thought I was going “to make it,” which made me see the “I see dead people” room in a grimmer context.

Another story is from the same period and had to do with cockroaches. We all hate that nasty creature. They had infested the area between the ceiling and the wall and were crawling in several lines slowly and methodically. I was appalled. What kind of hospital would have so many cockroaches in the patients’ rooms? The next day, they were gone.

My life had taken a turn to better and “cleaner” pastures.

I did not know what was ahead of me. I only knew that I have been through a lot; imaginary or real, it was somewhere in my Universe, our Universe.

8. THERAPIES

Very often when we hear the word therapy, we assume it is referring to psychotherapy or physical therapy. In rehabilitation hospitals, there are a variety of therapists who work as hard as the doctors and nurses to make sure you recover as much as your body and brain allows it and wants it... There are physical, speech, and occupational therapies. You can excel in one, but you can be horrible at another. They do not always go together.

You may envision in your head how fantastic it would be if you could play football again with your son. Or imagine you love to go to movies and parties--how will you party if you can't move your body? How will you party if you can't speak clearly to anyone around you? My way of explaining what therapy does is "compartmentalize your recovery one area at a time."

As long as you understand that your brain is in charge, you will be okay. Different parts control different organs, skills, functions, and behaviors. The left side of the brain controls the right side of the body. The right side of the brain controls your emotions, motivation, and happiness.

I trusted the therapists and knew this *was* the *only* road I could take. In this beautiful facility, surrounded by gardens and trees, I did not have much time to turn my head and enjoy nature. I had a number of problems: some from the seizures, some from the virus, some from the induced coma. Also, women always have "women's problems," i.e. "There is not a single thing about me that is attractive."

Day after day, step after step... I knew I could get worse, but I also knew I could get better. That is what the brain whispered in my ear. I BELIEVED IT. Hope has to be the last to leave the room. Hope will turn the lights off. The injured brain with "the electrical storms" suppressed by medications – that was what I was intent to lean on. We were going to do it together. We made a good couple.

My physical therapy was meant to make me strong enough to move and sit in bed, safely get out of bed and into a wheelchair, then walk with a walker. Walking a straight line, climbing stairs...were not a joke. Muscles, joints, bones had to recover from doing nothing in a coma. Some were severely overworked during the seizures' shaking and jerking. So was my brain.

Later, among the papers at home, I found a "family conference report" from the hospital, explaining my progress in this area as "tremendous." After 10 days, I was able to walk more than "200 feet with contact guard assistance." The report continues, "She demonstrates a loss of balance occasionally when she starts laughing, requiring minimum assistance to recover." That was absolutely true. My pulse would start racing and I would need to sit and calm down. My constant showing off was in evidence even back then, to my embarrassment: "She is occasionally impulsive with decreased safety awareness." My parent/husband had to address those issues with me. "OK, I will get better," I promised him. Hmm.

The speech therapy was meant to ensure I was not left with a speech disorder resulting from my brain infection, the seizures, and the frozen vocal cords. I was able to express myself decently and I could understand what others were saying. My simple sentences were comprehensible. Having another native language was a major impediment. Outside of therapy, when visited by friends, I did not know in what language the words were coming to me. Some words I did not know in either language. Interestingly enough, I recovered first the foreign language (English), not my native language (Bulgarian). A plausible explanation (not the neurological one) was that after I “survived,” I wanted to make sure everyone around heard what I saw and what I went through. The silent days were gone.

I was a bad patient. One day, the therapist stepped out of her office for a minute, leaving me sitting in a chair. I spotted a phone and pounced on it like a lion on a gazelle. Of course, Gary’s number was in my pocket. I wanted to have it, just to feel safer. I can only imagine he did a double-take when he heard a little croaky but sweet voice with “Hi, Gaaaa-ry! I am just calling to say hi...I am in therapy. Bye!” That was how much time I had; the therapist was back in the office. I hung up the phone and looked guiltless. I did not have much more to say anyway.

The “family conference worksheet” stated “moderate to minimum cognitive linguistic deficits characterized by decreased problem solving, decreased short term memory, impulsivity, and decreased safety awareness.”

I admit to all of the above!

The occupational therapy had three main goals: teaching me self-care, such as eating, grooming, toileting, and dressing; functioning in a working environment; and leisure. Thinking back, many people need to be taught leisure even if they consider themselves healthy.

All of these three therapies were to give me maximum independence. To some extent, this order of therapies makes sense. You have to learn to bathe yourself and put your pants on first, and then you can think about the other activities, like work, or going to a restaurant.

I was very good at grooming and dressing. I was just born with these skills. Gary would prepare my clothes in advance and leave them for me, ready for the next day. I even asked for lipstick to be put in my special “beauty purse.” In the morning, even without the “occupational skills,” I would be dressed and waiting in bed. Then I got the occupational training and all was in order.

One time, I had a male medical assistant washing my hair. Instead of simply thanking him, I told him “You are the first man who has ever washed my hair. You may be the last one too.” I thought I was hilarious.

The “therapeutic use of work” or “playing work” to help me adapt to the adult world was not fun (for me). It required attention, coordination, and memory. I was lacking *all* of them.

I was getting angry and really frustrated with my failures in occupational therapy. One day, I was given a task to balance a checkbook. I had never done this in my entire life. After all, I did not go to high school in USA; I came from a communist country. The only currency was the old reliable cash. First, I refused to do it and gave the therapist a lecture on how useless this was. She had to nicely ask me to take this homework to my room and get it done by the next day. I felt so scared. “If Gary does not come, what is going to happen to me?” “What if I am locked up in this hospital until I agree and learn to balance checkbooks?” “What if?” It never crossed my mind that I can actually do this like many Americans do all the time. I was resolved *not to* deal with this sh... When Gary came to see me, he told me 100 times how to do it. He gave up on the 101 time. Some fights are not worth fighting, especially with your sick wife.

Another time, I was building a small wooden plant box. There was a model in front of me. Piece by piece had to be put together, then painted different colors, and glued. *A coffin and a ladder to climb out of it* (is how I saw it). Though not good at arts, my imagination was wild, no? I did not finish “the coffin with the ladder” during the class session. I started crying because of my failure. An hour later, I saw the therapist in my room with the finished project. We hugged. I knew, even then, I would always keep “the coffin” with my name on it and “the ladder” to climb OUT of it.



It was easy to be taught to have leisure. We all have hobbies; all children know what leisure is. It is a little twisted with adults. The TV set in the room and the medications were the leisure to fill up the time between therapies.

The pills were helping me stay out of seizure trouble, but my brain was not an adult one. It was his fault I was constantly in trouble. I was as mischievous as a little kitty cat. Why? Because, I reminisce now, something had to show a SIGN of life. I HAD to live, I HAD to get out of bed, I HAD to work, and I HAD to look like everyone else.

I was plotting how to cheat the safety system all the time. It got to the point that one day my hands had to be put in white gloves (similar to boxing gloves) and strapped down to the bed at night. I was lying in bed not being able to move in any direction. The sticky tapes on the gloves made sure I did not slip out of the gloves in the middle of the night and try to walk on my own. I was biting the gloves so hard, there was blood on them. In my sick mind, I was also afraid a sick(er) patient might kill me. The soft gloves would not allow me to protect myself.

What was this, the World Wrestling Entertainment? After that episode and my loud complaints, I was not “chained,” but new gloves arrived to remind me that I was not as smart as I thought I was.

Step by step, I was getting stronger. I was hearing the doctors being pleased with my progress; Gary describing it as a “straight line pointing up.” I had a smile from ear to ear. It was a few days before the 4th of July. This was not just Independence Day; it was also the day of our wedding anniversary. I made July 4th our wedding day to make it easier on Gary. Scientists have a lot to think about.

Gary was pushing my wheelchair through the beautiful garden when I told him “the doctors think I am doing so well, I can go home for the 4th of July.” I proceeded with conviction: “You will put me with the chair in the car; we will have nice dinner, and you will bring me back.” Gary did not look too convinced. “Oh, really? Let me double-check with the doctor.”

This was a bogus plan. I was truly disappointed. My dream for an anniversary dinner did not come true.

I admit, I was a bad patient, but I was also called a “jazzy” one. I will remember this word as the first class compliment a nurse has given me.

If there is a lesson to be learned from this experience, it would be what Bill Clinton wrote in his memoir *My Life*: “Laughter is the only response to pain.” In my memoir, I am adding: “Crying has not cured anyone.”

9. MY DAUGHTER-TONI



I came to the USA with my daughter on January 6, 1992. Toni's father/my ex-husband had arrived before us and had started his Master's in law studies. The day when you arrive from one world to another always stays in your memory. In order to understand her, you have to know where she and I come from – a beautiful ancient country on the Black Sea, the size of Tennessee. Bulgaria, our Bulgaria.

It was “immigration time” in Eastern Europe after the communist dictatorship had fallen. Most educated young people found it as the best opportunity to see the world and the world to see them. Some, already highly-educated, would end up raising their children in US, get even more advanced degrees, establish their position in society, and create a life abroad.

Others would stay for awhile trying to find the “American dream” they had heard about. They would try studying, working, doing all that it takes but would fail in the fight with the immigration rules. Finally, they would go back home. They would not go back empty-handed; they would carry big bags of presents, bought for a few dollars from K Mart. Since fashion

appeared first on the black market in Bulgaria, everything brought from USA in the early nineties appeared fantastic in the early Bulgarian market economy. No one made “the present givers” feel like losers.

There is always the group of “in between,” who managed to succeed, educate their children, made a living *by being THERE* for one another. These are the Bulgarian immigrants who may live close to each other. If geography does not help, emotional connection does. When the phone calls to Bulgaria were so expensive, you couldn’t call home. They would call each other to exchange “holistic” advice about any disease.

Who did they call if they felt like crying for Grandma, dying back home? They had no money to go to the funeral, but they had the “in-between Bulgarians.” This group would do all they could to scrounge up some money for an airplane ticket. Maybe it would not be enough, but they would try. The “in-betweeners” would not remind you of any favor; you would not feel obligated to do something in return. They just know (and you know)... ”You may have many countries to live in, but you have one native country. Never forget those you have left behind!”

Toni was 12 years and 8 months old when she stepped on American land. She did not have enough time to go through the tough but fun years of puberty in Bulgaria. Regardless, she entered the “new world” extremely mature for her age. I will not even venture to compare her with the children her age today, nor will I venture to compare myself with the mothers of the present. I will just drop in a few tidbits.

Toni was home-schooled English from the moment I realized she was smart and she was not interested in her father’s hobbies. She was quite self-sufficient in keeping herself entertained. And, mind you, these were not times of video games, iPads, movies, and numerous toys. I suggested one day “How about I teach you English?” and she got very excited. Probably she knew this task might come in handy later.

I was very excited about teaching her; I had the curriculum, homework, grading system, I had it all down. It did look like a game, just like studying is supposed to be. She would always be prepared, sitting in her little chair, ready for the class to begin. She never got a B- it is 5 in the Bulgarian system. The best grade is 6. Toni had only 6s.

The second day after we had arrived in Washington, D.C., Toni started school. SHE WAS READY. Her father and I had to worry about the big picture, the food and shelter. Somehow, she fell off from “the big picture problems” because she was not a problem. She was a little trained soldier who did all the Army General told her to do. Only there was no Army General.

She would sleep on a broken couch, her clothes would be the ugliest and cheapest possible (from some garage sale), but she would always be clean and with homework in hand that no one had helped her with and yet was perfect. No mistakes.

Toni was a stranger to these strange new kids at school too. SHE WAS READY. They were not ready for her. All she had were her parents, who had to work on the future world for her, forgetting that the future was today... The future had already started. There were no tours of museums, no walks on the Mall.

She would move with parents from place to place; she would graduate from high school at the age of 16, when I was graduating from my MBA. She would get accepted into Georgetown University. She would study and study and work, never fitting in with the prep Catholic girls.

Instead of having joyful college years, her parents would go through a divorce with all the ugliness, nastiness, and hatred a divorce in a foreign country can bring. There was no time to feel or to talk about what happened. One had to keep going. I had to move out of the house where Toni stayed with her father. I LOST her. What I was afraid of the most had happened. All of a sudden, I was alone and she was alone.

Going back to the groups of immigrants, there is a category where parents divorce selfishly and little kids are left in between. No money can replace the time spent surrounded by parents' love. If the love is gone, I sure hope the child is a grown-up and remembers what should be remembered and what not.

Toni and I grew up together; I grew up faster than her. We are very much alike in fighting to death to defend our stance... As far as I am concerned, Toni would never forgive Ms. Epilepsy for what she did to me. Never, ever!



10. MY HUSBAND-GARY



I married Gary on July 4, 2000. I decided on the date. It was special and significant--Independence Day. Impossible to be forgotten, ever. On the wedding day, it was just the two of us (you can establish whatever tradition you want when it is not your first marriage). We had some style, I thought, getting married at the Little White Wedding Chapel. An Elvis impersonator gave me away, singing "Love me tender, love me sweet, never let me go. You have made my life complete, and I love you so..." It may look tacky to you, but to me, it is the best wedding ceremony I can think of. The Venetian hotel was new at that time. The wedding suite did not disappoint (nor did Gary).

Gary and I found each other on the Internet. It was the time when internet dating was not popular, so "Love at AOL" helped those like me who did not frequent bars to look for new love. My daughter came up with this e-husband searching idea. I suppose she has to take credit for the uniqueness of the outcome.

I will not describe my whole love story; all you need to know is that some men are born to be men you can lean on. Others will not have the strength to help, only the desire. The third group will simply run the heck out of there when times get tough. There is a fourth group which

developed recently. They ask themselves too many questions: why, what, when, where, who.... By the time they get the answers, you may be dead.

I have lived a life long enough to know a few things about men. If he can't find a Starbucks in downtown Washington, D.C. and we keep walking for four hours in the cold winter weather, it is not because there is no Starbucks downtown. He is interested in the conversation. If you tell him, "I may have cancer. You should move on with your life" and he answers "I will sit in front of your door until you let me in," this man cares about you. If he invites you to his house and cooks a nice meal for you with a nice bottle of wine on the table, this man is terrific. If you laugh the whole time being around him and his humor is better and catchier than yours, you have to start thinking about him day and night. It is just a matter of days before you realize you are meant for each other...

Gary is my life saver. He does not like to be told that because it undermines what I have done by myself to get better. But the truth is *he was there* when I got the viral encephalitis; *he was there* when my seizures refused to stop; *he was there* to sign papers to put me in a coma, to *look* at my ugly face in a coma, *to see* every baby problem, baby progress; *he was there* during therapies, doctors' appointments, any important communication with the doctors, nurses, medical staff, insurance companies, employers; *he was there* for our Baxterboy cat, too. The cat needed his explanation for why the house was so quiet. I can go on and on and on...

Family, friends, my daughter came and had to go back to work. My hospital stay lasted a long time. My only caregiver was Gary and his only care-receiver was me. I always knew on which side of the bed he was sitting--on the left side. I wished I could stretch my hand and hold on to him all the time, but I couldn't.

I was very good at voice recognition. I would always hear his voice talking with the doctors out of the room, somewhere. Gary is not a medical doctor--he is a PhD and a professor. It was very difficult for these doctors to leave a matter not fully explained to him. Gary always had his own research about my disease. He was reading every night; he knew how to ask his questions of the doctors. You can't help but like him. You can't help but return the respect he gives you.

Naturally, sometimes, he had to demand something to be done; this was his wife fighting for her life. There were days the doctors would lose hope. One of the doctors was given the name "Dr. Doom" by Gary's brother. This poor doctor really did not have any hope that he would ever see me walking and talking again. There were days all the doctors would lose hope. They tried to prepare Gary for the worst, but he was confident. "This cannot be true. She is from Bulgaria." The doctors did not know what this meant. To Gary, at this time, I exemplified Bulgaria – something little but strong and stubborn. Fighting till death. Death by fight.

I have talked too much about Gary's good traits. I have not explained the origin of it all. Gary loves the FOREST and the TREES. He is a nature boy. "The trees are big, interesting plants, and they live a year around," he said. An explanation well-worded for a child. Then followed the philosophical side...*"They do not think; they evolve and adapt. They are nature. Evolution acts on DNA. We all evolve through genetics."*

"We evolve and adapt." It took me awhile to understand the importance of this simple sentence for my existence and my disease. I will get back to it later.

Poplar trees are Gary's favorites. They grow fast to become 10-15 feet tall and are used mostly for paper. They pollinate by wind, not by insects. We have poplar trees growing in Bulgaria. This was not an unknown tree to me. We even have a song about them. Let's just say poplar trees are very prominent in the Bulgarian psyche. Who would have thought my husband would "play" with poplar trees?

When he first showed some of them to me in the green house of the University, the trees looked like they were one-month-old babies--so tiny, living in pots. How would I know they were to become the tall trees I knew from Bulgaria?

At that time, which was also during our dating phase, I would pretend I was interested, but the little green plants looked like nothing spectacular. Gary was their mother and father, "giving" them water, making sure everything was right for them--the light, temperature, humidity. I went to see them a month later and they were almost my size!!!

"Being able to work with nature--understanding how nature works; how energy moves; how nutrition moves through it. Isn't that cool?" Gary was getting more and more excited telling me this. "The poplar trees could eventually replace some of the billions of gallons of petroleum-based fuel. Experiments can take months and years, but working with it, with the people who love it... being a part of it all, feels great!" I have heard and felt this passion so many times.

I have to thank Nature first, then his family, and friends for giving Gary the strength during the time I was at the hospital and after that, in rehabilitation. I have to thank his big farm boy heart for being *there*, for beating there with me all the 8 months of various treatments.

Gary is the one who has to be praised for the *most important change* in my life after the hospital part. I *rediscovered* my long lost SISTER. Her Bulgarian name is Zdravka, which translates as Health in English. I had not spoken to her or knew where she lived for 15 years. She, her husband, and my niece are the family I have from Bulgaria.

As I was recovering, thoughts about her were coming more and more into my head. I used the last address I had somewhere and wrote her a letter. Gary encouraged me--"What could

happen than she not responding to the letter?" I could have died and she would have never known about it. She responded; we reunited. She thought I was angry at her; I thought she was angry at me. This is all in the past. She visited USA. We visited Vienna. Gary and I went to Bulgaria. The world is bigger with more relatives, with the house I was born in, the school I went to, the life I had forgotten but I lived in. Then I rediscovered friends from my English Language High School in Bulgaria.



11. OUT OF HOSPITAL

The dream date of leaving the hospital arrived. I was released under the primary care of my husband Gary. He was driving to our house, trying to prepare me as much as possible for what I was going to see and find there. I did not remember much (if anything at all) about what I left behind, how the house looked, how I had decorated it room by room, leaving a piece of me behind. As we arrived, I entered the house through the garage and walked in like a cat into a place he has not seen before. The first “person” I saw was our big boycat Baxter. He was the one who witnessed seizures, ambulances, falls, late nights with sad people in the house.

Baxterboy did not know what to expect this time. He and I looked at each other awkwardly. Neither one knew what to say. There was no “meow” and there were no loud outbursts. From a practical standpoint, he perhaps thought that the days of late feedings are over. I thought, “He knows more than me at this point,” so the conclusion was, “I will wait for him to lead the way.”

The house seemed very huge to me. All I knew was the hospital room; I had forgotten how high a ceiling in an American house could be. It really helped holding Gary’s hand while he was taking me from room to room, like a realtor (only they do not hold your hand). I had to touch every piece of fabric, every object in there. After several hours, I finally knew this was our house. I adored everything in it.

The master bedroom and bathroom were on the second floor. Right before the bedroom door, I had my own “shrine” with three beautiful, originally painted Eastern Christian Orthodox icons. Flowers and candles were scattered around (from the time I left the house). This was the place for my connection with God. This was the place for my “personal” praying. If there was any power left in me after climbing the stairs, it was used to thank God for allowing me to see my “shrine” again and ask him to mobilize all the saints to help me go to bed.

Gary was so well-prepared. He was, as Maya Angelou says (in “I Know Why The Caged Bird Sings”) “hoping for the best, prepared for the worst, and unsurprised by anything in between.” I managed to get in the bathtub and Gary gave me a bath. He said, “This is a very dirty puppy I have to clean.” I was enjoying the water and soap. I really missed them. The puppy was so happy, wagging an imaginary tail. Getting out of the tub was just as huge of a workout as getting in, minus the dirt.

A memorable moment of my “coming home” experiences was going to bed. We have a huge king size bed to accommodate my territorial tendencies. I need the queen area and Gary would squeeze into the single end. The mattress was new and beautiful. That was good, but how do you climb so high? It seemed to me that the bed was 3 feet above the carpet. I had to use a little stool to get into it. This is how physically rehabilitated I was at the time.

I spent 6 months in physical therapy to further improve my coordination, balance, and endurance. During this time, I also discovered there wasn't much of a right shoulder left. This was the result of lying in a coma. The rotator cuff was screaming with pain. There was no muscle left; it was looking ugly, very ugly. The basement was equipped with top-of-the-line gym equipment. My weight was good. The bags of food had done a decent job to keep some strength in my body. Besides, I was already eating everything.

There was a long road ahead of me to adjust to the world and the world to adjust to me.

12. BACK TO WORK

After the 2005 New Year's celebration, 8 months after I got sick, I returned to work. The work place was on its last leg before being sold to another company. Many employees had already left; the rest were looking for jobs. I felt unwanted and unneeded. One co-worker (I did not think very highly of her) almost wanted to say "Wow, we thought you would not come back; you would die!" She loved to use the statement "*Don't you remember you did this plan?*"...Don't you remember this...? How about that? No, I DID NOT remember. Do you remember what you worked on 8 months ago before you went into a coma? I was getting very frustrated day after day.

I knew it would not take long before I would get sick from all the energy wasted. There would be nothing left. After a week, I did get sick; I was also talking in my sleep all night in some self-invented new language. Gary was beginning to worry whether I would ever catch up with what I wanted and needed to tell him. Would he ever get some sleep might have been another reasonable question. He was never able to rest.

An episode on the Metro line confirmed "I have to get out of here as soon as possible." I loved to take a little nap while riding the train. There was at least half an hour until I reached the final destination. One second I was looking outside the window, the next, I must have had a seizure because the eyes of the EMT were staring at me and telling me what happened.

The Metro train was already emptied and everyone was probably wondering when this drama would end and they would go home for the evening. I suspected there were "nice" words said in my general direction... At the same time, at my pick-up location, my husband was sitting in the car and listening to "Attention: delays on the orange line. Sick passenger on train." He knew right away who that sick passenger was. He arrived shortly. I had already signed all the release papers refusing to go to a hospital. I was very confused and dizzy, babbling something.

I remembered Gary's words "No sleeping on the Metro!" Since then, I never sleep on the Metro; I hate the Metro.

I got a new position almost in a month at a location very far from where we lived. Since I was not allowed to drive, Gary would drive me to work, then go on to his job. He spent 3 hours a day driving. I spent 10 hours a day at the desk.

During this time, I had many seizures, increased or changed medication. Ambulances came several times to "pick me up" after a seizure; other times I would refuse to be taken to a hospital. I was beginning to notice some memory changes, different behavioral signs, communication and social patterns. BUT, I never thought I would not overcome this. I never

thought of my condition as something more than a temporary impediment, which hard work and concentration would cure. To me, it was a temporary setback.

I realized though that my work priorities shifted. I did not enjoy management or following established rules and procedures. I wanted freedom. I wanted first-hand information, data. I was dying to research what no one else was interested in. Changing what was not changed for years, reassessing one thing or another. I was never happy with the answers I was getting. There was this constant disbelief and dissatisfaction with what was done instead of what should be done. I would find myself beaming in the evening over something very minor but important to me which I had accomplished. I would be sad when we would have the usual weekly meetings and no one would say something meaningful. I called them “meetings about nothing.” I stole this from George Costanza on *Seinfeld*. It was almost mandatory in my head to break the ice with a stupid joke. At least I would laugh...

On days when I was not feeling well, I would close the door of my office and hope the phone would not ring for a few hours. The seizures and the meds do this to you; you need some “after coffee time” to start feeling capable of thinking. I would have difficulty starting a casual conversation when nothing in my head was running casually.

I am very proud of the work I did in an environment where I was not comfortable with myself and others. Every little action, every small talk I perceived as derogatory, against me, offensive to me. It may have been true; it may have been an attempt to just push me over the edge. It may have been lack of any awareness of my medical condition, but no hard feelings.

13. THE NEW WAY OF LIFE

After Ms. Epilepsy arrived, she established several new house rules. First, we needed a new house. We bought a smaller house. It was clear climbing to the second floor of a house would remain a challenge for the rest of my life. The housing market had just begun to tumble. The area we got into was only a couple of miles away from the old house. It is called a “55 and better community.” The houses have the fancy name of “villas.” The “better” is the marketing word for making 55+ aged people believe Maryland is a good place “to crash” at the time of retirement. You can hear children’s voices only during the summer when they swarm the adjacent pool while visiting Grandma and Grandpa.

I knew I was going to live in an area where I could give myself a physical break. If I have difficulty getting to the second floor, I have everything available on the first floor. The pool is across the street, trails in the woods, a gym close by; everything a disabled person may need is in close proximity.

Many of the owners have dogs. Dogs seem to like this way of life. There is plenty of space on the sidewalks to make them dogwalks. I like dogs, but I cannot take the risk of having an early morning mandatory walk with one eye open. Losing balance is not what I wish for. Even tripping over a pebble triggers my seizures easily. So, I am dogless. Baxter, my first cat, was not a dog lover, so I settled for bragging about him being bi-lingual and having advanced cognitive skills. Our second cat, Tiger, is a muscular tabby who likes people but likes his parents more. He has very good public relations skills.

The houses in the area are attached to one another, noise-isolated well enough to eliminate any chance of hearing the blasting of U2, Led Zeppelin, Uriah Heep, some hip hop and more loud music from our house. We received only one complaint, but it was probably because it felt like there was an earthquake in the area. Even Gary was scared. I have this habit from when I was a teenager. If I do not blast the music loud, there is no satisfaction.

I managed to squeeze all pieces of furniture from the old house into the new one. It looks like I have a mini “villa.” Our Asian room, my Bulgarian room with its folk art and symbolism, our contemporary room, and our Native American area--everything is right where it is supposed to be. All our favorite art pieces found their rooms too.

There are also some differences between the two houses (not just in the price). There is no big yard, decks, big trees, bushes, and plants of all colors. Gary used to play in the old yard every weekend. He had turned it into a place every wife would dream of. I did not even offer to help since non-qualified labor was only going to slow down the landscaping. At the sale of the

house, some nature beauties stayed with the new owners, some were given away after a long conversation with the “new mothers.” Gary wanted to make sure the children would be well taken care of. When I was getting emotional about the pots, Gary was saying “Let them go. I will *make* you new ones.” He did.

The basement in the new place is completely finished. It is the area to relax. We do not have basements in Bulgaria. I thought whoever came up with this idea was brilliant. You can practically live without leaving the basement. The best part is screaming at the top of your lungs watching sports. The screaming increased after the Washington hockey team (Capitals) recruited #8, Alex Ovechkin. He is my favorite player. Gary watches the games like he is the General Manager. Concentratedly, expressing emotions when someone scores, thinking of possible trading of players. I watch like a child from the stands. I am angry; I am happy. I cry for every loss and every win; I am so passionate about this game.

Watching sports, going to movies and hockey is what makes me feel totally healthy. I do not remember *ever* having a seizure when watching a hockey game.

The house feels like and smells like Mariann’s and Gary’s *sanctuary*.



In 2010, we decided to go and visit my sister and family in Vienna. An event occurred which changed my perspective on life. We--my sister, my niece and my little nephew, Gary, and I, were getting ready to get on the giant, world famous Ferris Wheel. I got a grand mal seizure and lost consciousness. No one from the group but Gary knew how scary this can look for the hundreds of children trying to get on the Giant Ferris Wheel. They were lucky; the “doctor” was able to cover me and pull me aside, almost carrying me to the side and having me sit down. He covered me like a child with his body, with my sister helping him. When my nephew came close, his eyes ready to pop out, he did not see anything. Everyone was scared, but I insisted after recovery (somewhat knowing what was going on) that we get on the wheel. I put my head on my niece’s shoulder. She and I wanted to cry, but she is a mother and I am the aunt. We had no right to scare anyone.

I did not catch the magnificent view of Vienna from 200 feet up in the air, but I was there. It took 200 feet up to realize after 6 years of hopes that I am *disabled*.



14. HOBBIES

Hobbies developed during an illness are nothing short of life-saving in their way. After a life trauma, you start measuring your time more carefully.

I get very despondent reading the success stories of people who have overcome epilepsy. I have deep empathy for those who have many seizures every day. I am somewhere in the middle. Ms. Epilepsy told me one day “*You are here, with me. Don’t you get it?*” I started digging deeper and deeper. This is what I found – two new hobbies I cannot live without.

Baking

Before Ms. Epilepsy came, I never baked much. Primarily “Whole Foods” did the heavy lifting for every American holiday.

I was fully aware my memory was affected by the disease. One thing I would never forget though were the fantastic sweets I was baking and eating way back in the past, before I came to America 20 years ago. Homemade breads, cakes, cookies, quiches...

I knew my current deficiencies. I knew I did not remember where the vegetables in the house should stay. I would lose them and I would find tomatoes a day later in the cabinets where the spices stay. One thing I would never forget is where to put the bread. Why? Because there wasn’t time for the bread to make it into the house. I would devour it in the car, while my husband would watch in disbelief. “Is it really possible to eat a whole baguette in 15 minutes? No butter, no oil, no cheese on it?” This is how much I like bread.

After a seizure, there is never enough food you can stuff your belly with (this is how I feel). “There is something you can do about it. Start baking yourself,” Ms. Epilepsy recommended. She was *right*.

I got all the needed books, did all the research, the recipes were put in folders--Bulgarian, Italian, French, famous chefs, internet recipes, you name it. Since the baking was for me, family, and people close to me, the highest quality ingredients were selected.

Making one dessert was taking me 4 hours, a day, or 2 days, depending on the complexity. I was not able to move my body after the dessert was out of the oven. The hardest part was following a recipe. I would go 50 times back and forth to “the right folder” to make sure I used the correct amounts of each ingredient, convert some amounts from the metric system, and use all in right order. I questioned myself a hundred times until I tasted what I had made.

There was no relaxation. I was walking miles in the kitchen with the hair net and an apron on, constantly washing my hands and cleaning the working area. Chef Ramsey would have declared me “the most obsessively clean baker of all time.”

Perhaps, the biggest accomplishment is being able to bake the pies President Obama’s pastry chef Bill Yosses bakes for the President’s family and the White House guests. It was a real challenge. This is an apple pie that takes your breath away.

I guess now I have some confidence. After all, this is not my first time. I am a *yummy-yummy baker*.

The second sign making me feel more confident about this new skill was making my own recipes. Ms. Epilepsy did not suck everything out of me. She left some juice in me and my desserts.

Good food can bring only love. I don’t think anyone remembers *me* from the places I worked (maybe a few friends), but everyone around remembers my sweets. This IS sweet!

“I have died and gone to Heaven,” was how one lady described eating my baklava. I am glad she is back. There will be more from where that came from!

Baking is a very risky hobby for an epileptic. If you fail in baking, you get very stressed out and disappointed with yourself. On top of it, you are hungry. If you succeed, you are on cloud nine. Your belly is celebrating; you forget the disease. In our busy world, cooking and baking from scratch can make you a celebrity amongst your loved ones. I can’t play basketball; I can’t swim; I am not allowed to do sports for my safety, but I CAN BAKE.



Writing

Everyone has a story to tell. Everyone is convinced her life is more difficult than others. Writing about one's medical condition is not an easy thing for the writer or for the reader. Why the reader? Because she is convinced this will not happen to her. Still, the information of a disease she does not know about scares her. I insisted on having everyone "taste what was on my plate." I shared just a little teaspoon so that I still had enough for myself. Even so, I realize that people are different. We may all have the same disease but we cope with it differently.

Writing is an amazing therapy for *me*. It easily refocuses my mind from being sick to being capable. In fact, my grandchildren may be able to remember me not as the sick grandma, but like the unique one. My writing is not a seizure diary. It is a discovery of what it was to be me, before I met Ms. Epilepsy. I spoke and wrote to high school friends, relatives, everyone I found. Now that I met Ms. Epilepsy, I am wondering what it is like to be me with Ms. Epilepsy attached to my hip. I wonder where the two of us are going, who is the bigger sister. Who has more power? Who is the walk-behinder? I would wake up in the middle of the night remembering something from the past or yesterday which I would like to share with everyone. By the morning, it would be gone... I keep hoping it will come back one day. With all the

childish naiveté in my writing, you may find something in my stories to make your life more invigorating; you may find yourself more present in your life. You may become more *you*, who knows?

In the meantime, I will just keep writing...

15. THE FENCE WITH THE TREES

I am dedicating a separate chapter to the fence and the trees. They turned out to be more important than initially thought. There is no yard in the back of the new house, but some owners have built patios or decks. I did not like either. Between the rows of houses, there is a small “common area,” covered with grass and randomly-situated trees. I have this cat’s ability to just stare at things. So, one day I noticed a couple of trees in the common area looking very sickly. I asked Gary “to diagnose” them. He told me in simple, funny English, “That tree dead.”

Unfortunately, there was not a single “common tree” planted close to my house. All the trees were bunched up close to the neighbor’s patio. It looked really ugly. I need to see a piece of nature, life going on right in front of me. I have to make sure I am alive. I need trees, plants, birds talking to each other. The direct recipient of my whining was (who else but) the Master of the Forest, Dr. Gary, my husband. There was not a day in his life, when he was not reminded of the importance of a landscaping plan for the community and me personally.

For many reasons, mostly human-related (Who else? The trees don’t fight), the plan was not approved. Not everyone shared our vision.

I was really hurting. I was saddened, taking it rather personally. After several months of Gary’s working on it, I was familiar with every tree which was going to come, every plant, and every flower. I was going to introduce myself and every neighbor to all of them. Love was mulching the air where they were going to grow...

I am not a quitter; no, no, no. I just jumped into the next project--to have (what is called) a privacy fence. In the little 6 feet tall fenced-in area, I have the sun, the sky, the BBQ, and a table with an umbrella – all the essentials. This was the beginning. Tiger, the cat, can hang out; I can sit under the umbrella and have coffee. What happens behind the fence, stays behind the fence; whether it is a dance, yoga for oldies, or a conversation in a foreign language... This is how the privacy fence started, but there was something still missing.

What appeared soon behind the fence were herbs, flowers, and two *trees*. Close to the door is a Colorado Blue Spruce. I call him Colorado Blue Bruce. He does not grow fast. He takes his time, but he never loses his leaves. We put some little purple plants around him so he is not so blue in the pot... He needs company (I believe). Bruce is prickly. I have to be careful when watering him. He does not need much water either; I just like to flirt with him. Bruce can survive under any weather. One has to be careful going back into the house after a few glasses of wine. Several needles can plant in your derriere and teach you a lesson. This is his way of flirting...

The other tree is a Japanese White spire birch. When he grows up, he will be around 30 feet tall. He will be reaching for the sky... This is my praying tree. It has a “marteniza” on it. This is the Bulgarian symbol for luck and health; the constant battle of life vs. death, good vs. evil.

Building this fence became an event of “historic” proportions for me; it was started and completed by a small Bulgarian-American union of two. It may be a metaphor, but it is a real new world for someone who was already stamped as not of “this world.” I was happier to have the fence and the trees than to have the house.

When the trees first arrived, I was checking on them like they were my babies. I made sure they were no pesky Japanese beetles trying to destroy them. Tiger already owned the grass. He was helping with the beetles, too. Don’t get the impression he was eating the beetles; he was working for a minimum wage of 6 delicious organic cat treats instead.

There was a day when he jumped over to the other side of the fence to see the world “behind the fence,” but his interest waned rather quickly. There is nothing like home. The problem was he could not jump back home. You can’t have both worlds...

The fence became the area of the house which is solely mine; this is my space of peace. Under the birch, you can talk and discuss everything you want. With the Tree. After the tornado, the first thing I went to see was the trees. Gary and Tiger were in my sight. I did not worry about them.

When I asked “Aren’t the trees cold in the winter?” Gary said “Are you planning to put a sweater on them? Oh Lord, trees are not like dogs...They generate their own heat. They form their ice outside of the cells. This way, inside the cell, there is dehydration.” At least, this word was familiar. “So inside the cell, there is less water to freeze. Trees don’t just stay warm. Understand?” “Understood,” I responded proudly. Every good scientist should be able to simplify his science so that even a child can understand it.

Let’s revisit what we talked about previously: “*Trees evolve and adapt.*” Yes, trees are like people. They grow, they get sick, and eventually, they die. It takes millions and millions of years for the evolution to work and give us, or those trees, more advantages, compared to another tree or population group.

Through millions of years, our DNA and genetic structure will adapt to survive the virus which attacked me. My immune system could not fight it off that easily. So, when you read my story, be moderately happy... Life is full of surprises.

The birch and the Colorado Blues Spruce made me think how unfair I have been in the past towards trees. It has always been the fruit ones that were getting the attention. If you do not feed me, you have no meaning. I never realized that it really does not matter. If I have to talk to someone, who is not tired of complaints, it is my tree; someone who will never be tired of me, is my tree.



Humans are worried the trees will get very tall and overshadow the skyline and their “picture.” They keep forgetting the picture is not **theirs**; **the trees make the picture** and will remain long **after** we are gone.

16. AURAS AND SEIZURES

Auras are interesting phenomena. At first, I was not sure they were significant enough to talk to my doctor about. They really kept bothering me, however. I was never able to figure out their meaning. Most of the time I would see female faces, very familiar faces. I felt they were associated with some form of art--movie, painting, show... They never spoke to me and I never spoke to them. I kept racking my brain over and over to recognize who they were. I was furious for not remembering them. It was like in a movie you have seen at some point in your life, but you cannot remember how it ended and who the actors were.

One time I thought about asking the auras who they were and telling them to leave me alone. But then I worried about what if they decided to play this sick game with my head and never get out of it. So I left them alone.

Very little is known about the auras. People may not even know what this word means. As described on epilepsy.com site, it is “a distinctive feeling or some other warning sign when a seizure is coming...they can be helpful because they can give you time to prepare for the seizure and keep yourself from being injured, or if there is not enough time to react to it.”¹¹

My auras never came just “to visit.” It would be a minute or two before a seizure--enough time to find a bed or tell someone “I am going to have a seizure.” Occasionally, one or two aura faces would show up during the day. This way I would know “by the end of the day I will have a seizure. I better skip this event. I have to be careful and not be alone.”

Some people with seizure disorder really hate these auras because they may include visual hallucinations, hearing voices, unpleasant smells, weird faces and bodies. As far as auras go, I am lucky. I am dizzy and nauseous; I see these strange ladies. They make me nervous, irritable and also very scared. Still, I am not planning to fight with them.

The worst place and time to get the auras was at the viewing of a friend's brother. He had died from cancer. I was looking at all the people, looking at the pictures of the man who died, but the noise and the crowded setting was too much for me to go through.

I heard the women from the aura talking too. They were not invited; what were they doing at an event, honoring the life of a good man? “Hey, Aura women, please do not tell me I am going to have a seizure in front of all these people! They are NOT here for me!” I felt very lost, almost falling down, completely not present in the conversation going on around me. My legs got so soft, I could barely move. I felt “absence of presence.” This is how I can best

¹¹Epilepsy Therapy Project. Initiative of the Epilepsy Foundation. “Auras” section. Accessed 3/10/2013
<http://www.epilepsy.com>

describe it. I touched Gary's hand and told him "We have to go!" Gary, as many other times (but not at a viewing), tried to cover up what was happening. In one second, he had to prevent a seizure. He had *exactly* one second. Gary did what he had done the hundreds of other seizures he has been through. He just said, "Look at me!" staring at me. He kept repeating "Breathe, breathe!" Easier said than done...

If there was a God at the viewing, it was Gary. The seizure went away. She could not defeat Gary, nor spoil the final celebration of the life of a good man.

17. IN THE STIGMA WORLD

My first office seizure is deeply ingrained in my psyche. I was on the carpet; the whole office had gathered around me. I was already “back.” One woman asked if I had a grand mal seizure. Someone, who had seen seizures, answered affirmatively. Up until that point I had merely talked about my disease -- now my undercover work with seizures was revealed.

I was not scared. The people present *were*. If I was able to talk, I would have sounded very apologetic. I did not mean to scare anyone. I would have reassured them “I will be fine. I just need to go home and take a long nap.”

At this company, I chose the path of saying “I have seizures.” It did not mean much to me, so I chose the road of saying it openly. If you have cancer, you go through chemotherapy and radiation; if you have epilepsy, you go through brain tests, plenty of seizures, medications, changes in medications, more tests, and more seizures. Normal stuff... Everyone gets sick.

It is normal to me; it became normal to my husband to get a call about a seizure and drive to pick me up. It is still not normal to the outside world. Unfortunately, the disease still carries stigma, misconception, discrimination, even disgust, if it appears right in front of your eyes. It is a condition that drives people away from you. I could not get my mind off how I looked when the paramedics arrived one time. I felt small, I knew no matter what I do from that day on, everyone would remember this scene; no one would accept me for who I am.

One day, I fell on the stairs going from one office building to the other. The sidewalk was next to a major street. The vehicles had stopped waiting for the light to turn green. This was a three lane street. NOT a SINGLE person came to check on me. ALL of them witnessed the seizure. It was clear even to someone who had never seen a seizure that at the very least I needed help. I was not able to get up. Then slowly, with bruised knees, all pale, I made it to the next office building. I had a meeting scheduled. The world was not going to end if I did not show up on time for a meeting, yet I plodded along to it, dutifully. Sad.

Julius Caesar, Alfred Nobel, Neil Young, Charles Dickens, and Lev Tolstoy also had seizures. Since ancient times in Mesopotamia, the seizure disorder was known and studied. The list of celebrities and artists with epilepsy is really long. I still do not know if their talent stemmed from epilepsy or if they simply happened to have epilepsy. History books talk about people with epilepsy “being possessed,” “being chosen,” men being burnt at the stake, women deprived of their ability to bear children. “The epileptics are strange, dangerous, crazy, they should be avoided,” I hear around me.

I believe I am hurt more **BY THE PEOPLE**, not by the disease. Remember this very well next time you meet a woman without hair because she goes to chemotherapy. She has the

guts to not wear a wig; she also has a **chance** of beating cancer. When someone tells you “I have seizures,” think before you respond. She has the guts to, perhaps, **face having no such chances**.

I may not have a chance of beating the seizures and having them controlled fully by medication. Besides, medications have serious psychological side effects. The disease created some idiosyncrasies in my behavior, but they are now a part of me. I am either accepted **with them** or not accepted **with them**. This is a **package deal**.

I have heard sometimes conversations about me, such as “She is really nice but after a seizure...I can’t stay around her,” or “You never know what she will say. I may not even understand what she is saying.”

There are situations in which your own family will say “I told you 100 times about this” or “What is it she does not understand?” I try to force a smile like it really is not a big deal and it is funny to me, but it is not. When I write something on Facebook in response to someone’s “funny,” I find it really funny, while the youngsters (related to my daughter, the Millennials) consider it confrontational or irritable. The ability to distinguish “funny” from “not funny” has suffered as a result of my condition.

A very sad part of the epileptic life is when *friends* depart from me because of my disease. One group I consider a “*filling the gap*” friends. I provide good company, worry about them, share their problems in life, and consider them real friends. I never see their friends though. I do wonder but never ask openly why this is happening. Are they ashamed of me?

There is also the group who pretend to be friends when you get sick. They are named “*I miss you*” friends. They just disappear into thin air only to post “I miss you. We should get together for lunch soon!” on Facebook. When is soon?

The third group, the “*direct offenders*” is the group who know it all. They tell me intentionally how “mean” all disabled people are and that “we never explain what we want.”

BUT, in this big world, there **IS** a group of **REAL FRIENDS**. You may not see them for months. They may be busy with grandkids, work... I do not need to discuss how I feel every day with them. **THEY KNOW**. There will be days when I will make them laugh like a comedian would. There will be days I am quiet; you can only hear me breathing on the other end of the phone. These real buddies will come in the middle of the night (if I need them), not worried how “**CONTAGIOUS**” epilepsy is and help me. These are people I call my friends. **THEY TAKE ME AS I AM**.

And last but not least come the dogs and the cats, our ever-present, ever-faithful pet friends. We have seen and heard many stories about dogs trained to discover roadside bombs, and save the lives of soldiers or dogs who make the lives of old people or kids dying from cancer

more cheerful. We know about seizure service dogs. Many of them are just born this way; they do not go through special training.

So, let's give what is due to Baxter and Tiger--my house buddies. I already mentioned Baxterboy, my first cat, who died 4 years ago. He saw me with my first seizure and we looked in each other's eyes when the end came and he was put to sleep. He had a kidney disease. I was his nurse during his last months. Baxter hated cars and the drive to the vet always sounded like the end of his life to him. The time when it was really going to be the end of his life, he was quiet. Gary and I wept; Baxter wanted to be remembered as the big man he really was.

After Baxter, we got Tiger from a shelter. I lasted only two weeks without having a faithful friend sleeping next to me (plus a faithful husband). You know how they say you get the pet that captures your heart. Entering the cat room of the shelter, we heard one continuous "meow," so loud that it would have been heard 50 miles away. It did not stop for the whole time we were there. A decision was made right away. Tiger is my kitty. He is a buff tabby, long boy kitty. He knows that when there is a seizure, this is some kind of a distress in the house so he never climbs the bed at that time. He does it when I fall asleep after a seizure and things are back to normal (in his mind). He curls up next to my stomach. Probably he thinks, "The stomach seems to be the safest area I can crash on." Before that, he faithfully stays in the corner of the room, making himself as invisible as possible.

Tiger insists on sleeping alone but he learned how to open the door of his room and let himself out. There is no window in "his" room. The only clock is his belly telling him that breakfast is served. In fact, there is no door which cannot be opened, as far as he is concerned. Without curiosity, there will be no science. Living with a scientist, he is encouraged to do what other cats will not be allowed.

The tiny problem I have with him is that he writes this book with me, stomping on all the pages, sitting very close to the computer, staring at me, talking, in case he has not been noticed, waiting for 2:30pm, which has become his dinner time. I am not sure where he reads about this type of diet, but he sticks to it.

After that, everyone minds his own business.



18. HOW DO I SEE MYSELF NOW?

Living with Ms. Epilepsy makes the world a busy place for me. I have to live for two for the rest of my life. It took a very long time to internalize that I was sick, but once I “got it,” I really “got it”... Earlier I told you I always felt I was special. There is no better confirmation from the outside world than my seizures. With them, comes my inability to perform some major life functions; psychological and social changes; the dependence on family and friends; the struggle to overcome what may seem simple to everyone surrounding me. BUT, with the seizures comes a new ability to be a new ME.

I told one time one of my bosses “I don’t want to be you!” I could not have said this if I did not have my new ME. I just meant his life was difficult too, but he did not take it this way. Internally, his ego was bleeding. The disease made me stronger and more objective on what was surrounding me. At the same time, seizures made me more vulnerable when someone attacked me on the grounds of not doing something right BECAUSE I have a seizure disorder. Of course, no one would say it openly.

Occasionally, I would blame the American environment for giving me the disease. Such nasty viruses cannot get to small countries and destroy my brain. If I was told in advance this (and broccoli) was what I would get for coming to America, I would have thought harder.

The bottom line is that the virus found me. Physically, I do not look too bad. I am no spring chicken, but looking around me, in my age group, I cannot say I look bad; we are all the same. We hate to admit we are not young. We read books and spend money on beauty secrets, hide birthdays, but we all have mirrors at home (this is a famous Bulgarian saying) and we all have lonely moments in front of the mirrors. After a seizure, there are dark circles under my eyes. I need about four hours to recover and walk a straight line. No makeup can cover a seizure. Watching where you walk is a must. That reminded me of the days when I was walking close to a boy I liked. I could not look him in the eyes. I was so shy. I would look straight at the ground (sweet, isn’t it?).

The seizure medications are so strong; you are tired from the moment you wake up. However, if you forget to take them, it is very likely you will forget that you want to be alive. I am very good about regularly taking them. I take four types of anti-seizure pills now, the most faithful of which are KEPPRA and Zonisamide. When I first left the hospital in 2004, both Gary and I had some rather silly ideas about how long I would be taking medications for the seizures. The doctor’s answer was “Probably for the rest of her life.” Of course, I was in denial. That is me. If you say “yes,” I will say “no.” “That is not possible.” I continued. “I just got sick...how can I be taking pills for the rest of my life? I am still young.” Now I sadly have to agree with his prognosis. “Epilepsy is usually controlled, but not cured, with medication. However, more than

30% of people with epilepsy do not have seizure control even with the best available medications.”¹²

Then a new pill came on the market, VIMPAT. Since it was invented in Europe, I thought “It is for European genes and I am European, I will be cured! Yeaahhh!” I was wrong again... There is no miracle drug. With the many years of taking anti-seizure pills, I have become very good at swallowing them at once though they literally fill my entire palm.

When I was growing up, I always dreamed of being an actress. Ms. Epilepsy made this dream come true. When I was feeling dizzy after a seizure and “out,” she would give me a smile, pick me up, fix my face, put the words in my mouth... I would get up and I would be in my other role.

How do I see myself now?

I see Mariann *and* Ms. Epilepsy. We are always together. Do I miss my old self? Ms. Epilepsy was sent to me *not* as a well-deserved punishment from the powers above. I realize now I never had the guts to do what I like to do. I never enjoyed what I studied, yet I never had the courage to study what I enjoyed.

This trend continued all my life until I met Ms. Epilepsy. She puts me through the challenges of failure on a daily basis. The medications I am taking are still not able to control my seizures and my memory loss. It is very difficult to concentrate for a prolonged period of time. Even reading the paper presents a challenge because I get some “inside calls” to do several other chores. How do you prioritize, organize, structure? Who should be on hold?

It is really tragic for anyone to try to teach me anything. I cannot follow directions, yet I argue that there is a better way of doing what I am supposed to be doing.

I did not inherit many traits from my father, but there is one which is definitely his. When I decide to talk and have my voice heard, even if this is in the most inappropriate setting, saying the most inappropriate things, I will do it. No hesitation...I would not be able to verbalize what I want to say and I would get overly emotional, but I would speak. The person on the other end may not get a word, but do I care?

As far as my written communication, what I see going back into my work e-mails is that they are somewhat abrasive. I was creatively rude. I did not ask for answers; I demanded answers. Some of the e-mails were so long that the major points were lost. My vocabulary shrank so much; I did not know where to look for it. It was somewhere in the “skinny closet”

¹² Wikipedia. Epilepsy. Accessed 3/10/2013

every woman has, but I could not find it. Forget about my grammar. That applied to my native language too. I was so ashamed I could not speak my native language...

Stress is everywhere around us. It is the main cause behind my seizures. Small stressors become big; big get bigger in my mind. Losing control over my brain and body is related to losing control over everything around me, too. I am no longer in charge. My whole personality is born to be *in charge*.

The doctors say I am too hard on myself. I have to be because this is the only way to get better. You either climb half way to the top of the mountain (that is what I aim for) or you stop at the bottom. I know I will not climb to the top; I know my limitations well.

How do I see myself now?

Better than before I started writing. I AM A SURVIVOR. All survivors, their families, their real friends know what that means. I am not a deeply religious person; I was raised in communist times. You lose your job if you are seen going to church. My mother was taking me and my sister secretly to church. I never really became a believer, but I was given the privilege to see more than the believers and come back to tell you. What I believe in now is that we all have something in common. We cannot be separated into evil and good ones. We all make mistakes and we all do good things on Earth. The rest is not for us to decide.

19. PAST, PRESENT AND FUTURE

We all have those blue moments when we do not see the good things around us and in us. Some of these moments are from the past, some belong to the present, and some we predict for our future.

When the disease came, it shook me really hard. I was sent to an unknown world and then kicked out back to a world I knew even less. By asking questions, day by day, I got to know my personality, my parents, friends, all my values and beliefs; I found Mariann. I am not sure who said that “the worst thing is to get old but not gain any experience from that.” I have to give credit to Ms. Epilepsy for getting me to the point of having experience and wisdom, yet keeping the innocent child-like me.

All I can say about the Past is “Mariann, I love you just the way you were!” I hear often from relatives and friends how much fun I was to be around. I was smart and had a wry, infectious sense of humor. Even when I did something bad, I had to be forgiven because there was no malice; there was an innocent childish sense of irresponsibility--never risking my life though, only breaking the traditional boundaries of right and wrong. Stubborn and determined to do things my way was the game of my childhood. Nothing was taken seriously. “Life is like theater.”

Theater, art, and music were the world my babysitter, Elena, introduced me to. She also introduced me (unintentionally) to how life takes a turn when love is in your heart. I was too young for that, but I realized if you are not loved in return, it hurts very badly. My babysitter’s daughter spent all her life loving a man who never loved her. She was a real tragic character. I was very, very sad for the way she lived her life. Although a child, I figured out “Something is wrong here...either in her or in him. There should be comedies in life too.”

The happy love story came when my sister fell in love. I had never met a man more in love than her husband. Since my sister is eight years older than me, she was not discussing her life with me, but I was better than the KGB at snooping (dates, phone conversations). I never told on her to our parents; I just “studied life.” Whether they were together or distance separated them, I learned what love was/is. They are still married, in the way love should be--forever.

I had completely wrong ideas about my parents’ love towards each other, as well as their love towards their children. I was measuring in quantity and quality love and attention, tangible and intangible things, values, and beliefs. When sickness struck, I had to get out of my cave and *understand* some simple truths about parents’ love. It can take different shapes and forms, but it does not mean it is not there. There is no 5 lbs. love for the good child and 4.5 lbs. for the “other” loved one.

The Present I was dealt is the present of love and seizures. The more the seizures, the stronger the love. I am fully aware how the seizures make me act ridiculous many times. I am “at my best” when I make fun of myself. I have the seizures; the aftermath is where I am barely aware what goes on for the next several hours. I am fatigued, confused, my muscles hurt. People around me should not see any of it; this is “the rule.” They should not worry; they should not know (not all of them) what had happened. The *show* must go on.

I am extremely stupid about one thing or another, but, hey, there is no contest in stupidity. Look around yourself. Sometimes I am so bright, I shine like a star. I look at Ms. Epilepsy all cocky and I ask her “How about that? Look at Mariann now...”

It is very hard for me to beat the anxiety, irritability, the panic attacks... Defeating these sides of my epilepsy is the biggest war I fight. Solving the problems of the world is not a task for me; I got that. Gary likes to say “You are like my mother, worrying about worrying!” The more you get used to the disease, the more you worry about those around you, especially the family and those who take care of you. Gary’s way of coping is creating his own “seizure protocol.” I wish Tiger learns it and gives Gary a break, but so far, the boycat refuses to sleep in our bedroom where he may be woken up and scared. I rely only on Gary when seizures strike. As ashamed as I am for my dependency, I am humbled for being sent such an angel (he will laugh if he reads it). He can find a way to make me laugh when I feel low. He can make me mad too when during a partial seizure he wakes up startled and starts asking questions: “What is going on? What is happening?” Gary knows I cannot answer at that time, but he cannot be blamed for being startled.

I have built my “seizure protocol” too. Being alone in the house, I know I have to be brave, command my lungs to breathe. I have to be the best soldier in the one man army. Then, it looks like I start breathing just when I think I may not be able to. Making fun of the situation and my behavior seems to be the best therapy to get me out of pointing the finger at myself for being sick. I know my body and know the games it plays with me.

I do not know what our Future will look like.

Some epileptics will continue to be on medications and have their seizures under control. They may live their lives like they have never had seizures in the past. Others will continue to be on medications and not have their seizures under control. The term “under control” may have different meaning for different people. Another group may be able to use Vagus Nerve Stimulation (VNS), similar to a pace maker, as therapy. Surgery is also an option for the right candidates.

New scientific research and studies may bring new medications and therapies on the market. Maybe if epilepsy had its Magic Johnson or Michael J. Fox, it would have been more visible to the general public and demanded more government resources.

Organizations such as the Epilepsy Foundation (with its 48 affiliated foundations around the country) and the award-winning patient care <http://www.epilepsy.com> web site lead in our knowledge about the disease and our hopes for a cure.

My future will depend on my ability to become a Manager of Ms. Epilepsy and show her how we can work together. I will be her Manager, not the opposite. She is still not known enough. Society does not know how widespread she is, how many children and adults live with her and hide her “in the closet,” how she affects quality of life, how the individual’s psyche suffers and fights back...

I promised her to introduce her and fight her stigma. Next time she shows up, I will explain to as many people as I can that she is just a brain disorder. She occurs because of a sudden electrical discharge in the brain. When too many neurons get excited, a brain storm starts. Ms. Epilepsy may show up in all her beauty and glory. In my case, she was precipitated by viral encephalitis.

She did *not* turn me into a witch, but she sure changed me. My life is *much harder*.

No matter what, Ms. Epilepsy will always be my friend. **She made me who I am. She taught me who I was. She will tell my story like no one else can.**