

## **Brain Tumor Survivor – *Maureen***



**Last Updated: Thursday, June, 23, 2011**

### ***Maureen's Meningioma Brain Tumor Story***

***It is now 2011 – I am Now a Twenty-Eight (28) Year Brain Tumor Survivor!***

My story may be longer than some and shorter than others. If reading my experiences helps anyone, then it was worth their time and mine in preparing it.

I hope you will read my entire story and find its message one of hope, knowledge and of many realizations about living with or having a Meningioma Brain Tumor. It was initially difficult to write this story, because for so long, I would not sit down and do it.

I finally realized it is all right to write about it and it can and has helped others! Further, I realized as I updated it each time, it is important for others who have brain tumors or whose loved ones have brain tumors to hear from real people, such as myself, who have dealt with all the real life issues of this condition from doctors, tests and hospitalizations to our symptoms and our emotions – all because of a brain disease.

While being diagnosed with a brain tumor often seems like the end of the world, it does not need to be. I am here to tell you it has not been the end of the road for me. How we each respond to what happens to us in the face of any disease – will have an effect on the eventual outcome of our situation.

**Update June, 23, 2011: Rather than place my newest update at the end, I am placing it here.**

My first Meningioma was diagnosed in 1981 after being ill for several years. This past February 4, 2011, marked twenty-eight (28) years since my first Craniotomy to remove a Meningioma Brain Tumor.

In 2008, I wrote a **CNN iReport**. When you read it, you understand why I did an **iReport**. Please see: [www.ireport.com/docs/DOC-24838](http://www.ireport.com/docs/DOC-24838) (it links to Virtual Trials).

My good news is and has been for more than a decade. So far, since 1999, the existing Meningioma Brain Tumor I live with **has not grown!** So each year, I celebrate another year of life, hope, joy and thanks. My 2<sup>nd</sup> Craniotomy for a Meningioma was April 4, 2000. Both stories are included herein.

In the past few years, I have had medical conditions taken care of which has greatly improved the quality of my life. For this time in my life, I feel overall good. I keep busy with my art and writing (Website Links end). This does not mean I do not deal with brain tumor issues. I do, though I deal with it all in a positive manner, knowing what I need to do to take care of myself.

The opening photo was taken Fall 2010 and I am now sixty-four (64). I am reminded of the BEATLES song from about 1964: ***When I'm Sixty-Four!***

I am not on anti-seizure medications and see my Neurologist every four (4) months with an MRI every two (2) years. Some aspects of living with a brain tumor can be annoying, though like other things – life goes on and I just keep living life to its as completely as possible.

I exercise to keep strength, walk and do exercises I can do to keep me mobile and as fit as I can be. I have lost weight and it has made a real difference. I do not have bad headaches, only an occasional one. You will know as you read this why it is significant (that I do not have them).

I strive to display in Art Shows when I can. I keep myself balanced and centered, calm and still get up each day and embrace life! And, I continue to write and seek a publishing company. It is what I do. Art, whether needlepoint and beading, writing or drawing gives me purpose.

Life goes on with much appreciation for the path I have had and I find myself saying many times, as my Celtic ancestors did: ***"Praise be to God!"*** I believe God has more Spiritual endeavors for me to do, thus my writing continues, so generations following mine can learn, know and understand. And, I am still learning.

### **Suggestions for Newly Diagnosed Brain Tumor Patients**

I would suggest if you are newly diagnosed with a brain tumor to rally around you those people who love you. Ask them to read my story and other brain tumor patient's stories.

Ask them to listen to yours, as well. Have courage to face it and then ask, "OK, now what?" Then, move forward. It is amazing to me when people understand more about brain tumors, the kind of brain tumors there are and the treatment options, how more readily they are to help in any way they can.

I hope you will read this to the end and discover that while my road has had many bumps and changes, I have become who I am because of the life altering-changing events, not in spite of them. My brain tumor HerStory begins with having illness for a long time before the final events which resulted in having the 1<sup>st</sup> Meningioma removed. Over the years, I have heard from many hundreds of people. It seems most with brain tumors seem to go through similar series of events:

- 1.) Unexplained illnesses,
- 2.) No medical tests to determine what is wrong (though it seems to be better in the last decade),
- 3.) Weeks, months and even years with no treatment or diagnosis.
- 4.) Finally, some doctor does tests and finds a brain tumor.
- 5.) Then, we receive the treatments needed all along.

**It should not have to be that way.** No one needs to suffer for years before they are diagnosed and treated, not even during the 1980 era.

Since a significant incident seemingly began my decline and illness, I go back to a serious auto accident in 1975. The migraine headaches progressed and worsened as the years clicked away. At the time, I had what doctors called a 3<sup>rd</sup> degree head concussion – a brain injury – multiple bruises on top of more bruises and other injuries. I was twenty-eight (28) years old with two small sons who tried to take care of me after I finally got home from the hospital in two weeks.

On the 2<sup>nd</sup> or 3<sup>rd</sup> day into recovery, I had a Pulmonary Embolism (which is painful, frightening and dangerous). Pulmonary Embolisms can be deadly and require immediate attention and treatment. I am glad I was still in the hospital when it happened. I was immediately placed on Heparin through an IV Shunt. Then, I was on Coumadin (blood thinner) for several months with follow-up X-rays and evaluations with a Pulmonary Specialist.

The contortions of my body during that violent auto accident had sprained just about everything, pulled muscles, tendons and ligament. I was stiff, sore, had muscle spasms and miserable for ages with terrible headaches. I went for intense physical therapy, including swimming – eventually.

The headaches became worse and turned into horrific, unrelenting migraines. Pain medicines did nothing for me. Doctors and physical therapists just said, “This is not uncommon for that kind of head trauma.” So, no diagnostic tests of my head, such as a CT Scan, were ever done. Now days, MRI scan would be done.

As time progressed, my overall health declined in measured amounts. I kept having kidney and/or bladder infections, horrible migraine headaches, more aches and pains and other problems – none of which made any sense. I was a mess.

The migraine headaches were the kind where you feel as though someone is stabbing your head. The pain was not just a day or two and then subsided. It began to be weeks on end with varying degrees of intense pain - worse to worst, immobilizing me completely at times. Those migraine headaches were the worst pain I have ever experienced. So, I totally understand about them.

I tried everything to control the migraine headache pain, including eliminating all of those ‘supposed’ foods known to cause migraines. It did not help. Prior to then, I only had occasional headaches. I went from specialist to specialist, doctors of this and that to psychological profiling and was told these kinds of things (and more):

- “It’s all in your head.” (One doctor said I imagined them and brought the headaches on –What? Why would I do that and clearly – I did not cause the headaches.)
- “You are stressed, so do these stress relievers.” (I did stress release practices and I was stressed, all right, because I was sick and no one could figure why or do anything for me.)
- “Head trauma often causes these types of headaches. Deal with it.” (That was just cruel.)
- “Here are some pills.” Then, when I reacted to them, “Here are some other pills.” (This happened over and over. I now have a list a mile long of medications to which I have adversely reacted, including Aspirin.)
- “You’re having a mid-life crisis.” and “Get over it and get on with your life.” (During the time I was age 29 to 34 years old, so doubted seriously I was having ‘a mid-life crisis.’ I generally was quite together, calm and a Spiritual woman. The only ‘crisis’ I had was I was sick and no doctor could figure why or what was going on, much less do any testing to learn why I was sick.)

- “You need to see a Psychiatrist.” (A really good one – I sarcastically say. I did that. One Psychiatrist told me to divorce my husband of almost nine years at the time – which eventually did happen.)
- “You are obviously sensitive to pain. The headaches can’t be *that* bad.” (Another real joke. How can anyone tell you the pain you feel is ‘not that bad?’ I decided the doctor saying it had no clue.)
- “Put up with it.” (Again, that is just cruel.)

Over the years, I have communicated with many brain tumor patients. I can only imagine some folks reading this will now think, “Gosh, this sounds familiar!”

**I was sick of being sick!** Yet, I knew something was quite wrong and it was not my imagination. I did not feel I had to ‘put up with it.’ I had never been so sick in my life! I gave birth to both of my sons by Caesarean and recovered well. I was active and went to exercise all the time to keep trim and fit.

Four (4) months before the auto accident in 1975, I had a hysterectomy (Fibroid Tumors), which I mention because some researchers are now saying those might be related to Meningioma brain tumors. It will be interesting to see what medical research finally finds on this one.

Up to 1975, I had been one of the most active and healthy people I knew, as I danced and exercised a great deal. Modern Dance was in my Soul! I ate a well-balanced diet, took vitamins and was quite Spiritual and it assisted in many aspects of my life. I knew my body well and I knew my mind, my thoughts and how I acted toward and reacted to many aspects of life and its experiences.

**So, I finally, I stopped going to doctors.** Obviously, they were not doing me any good. So, why go? I only went to a medical practitioner if I ended up with an infection I could not cope with and for which I needed antibiotics.

In 1981, before we knew I had a brain tumor, I landed in an Emergency Room. The worst thing happened to me there. I was brought in by ambulance and the attending doctor thought I had suffered a stroke, which some symptoms seemed to indicate. I could not talk correctly and words in the wrong order, nor could I communicate what was happening with me.

My speech was quite slurred. My legs were so weak, I could not walk. My head was splitting and felt as though someone was stabbing my head with a knife - over and over. My eyes had the worst pressure behind them and felt as if they would burst right out of my head. I had a strange event reoccurring they called ‘focal seizure’ activity.

Knowing brain tumor symptoms, my symptoms should have been a clue it was not a stroke. A CT Scan should have been done at the time. They would have most certainly found the brain tumor. No CT Scan was done.

Friends in the area came to see me at the Emergency Room. My then boyfriend was scared and had called them. The ER doctors convinced me they needed a spinal tap to see if there was blood in the spinal fluid. **June 2011:** I recently found letters I wrote to my parents, as my Dad saved them. One letter says there was blood in my spinal fluid about which the doctors did nothing.

Having a spinal tap was the worst that happened while in the ER overnight. I later learned it was absolutely the wrong procedure for what was really wrong with me. Remember, they did not know I had a brain tumor. I later learned a spinal tap is the worst thing to do to someone with a brain tumor. Now, I do not think anyone would do one, since MRIs and other tests are much more effective to diagnosis and certainly not invasive.

When I finally could sort of walk about 24 hours later, the ER released me. My left leg did not cooperate and I had a difficult time walking, as my foot would not work correctly. And, I kept falling down.

There I was, a person who had been a modern dancer, extremely coordinated all of my life and I could not convince doctors I felt spastic (only way to describe it) and something was wrong - very, very wrong. I was naive enough then to think doctors could “fix me” when I was broken. I drove 100 miles home the next day, alone.

The ER doctors said I had not had a stroke. They told me I needed to ask my PCP to send me to a Neurologist when I returned home and to work. I went to my doctor (at the hospital where I worked). He threw away the referral paper to the Neurologist – right in front of me – saying I did not need to see a Neurologist. He said the migraine headaches were “probably causing the symptoms, as some migraines do that.” Then, he gave me some new pills, which did not reduce the pain. I reacted adversely to those pills.

My gait and balance was clearly off. I literally ran into my doctor in a hallway at work one day. As I apologized for bumping into him and he recognized me, he asked if I was all right. I emphatically said “NO!” I mentioned the reactions to the pills I was having. He told me to cut the pills in half and take half doses. I tried it and still reacted adversely to the medication and it made me even more off balance, why I had run into him.

Here is another good part – post 1<sup>st</sup> brain surgery. Remember I said I kept having kidney and/or bladder infections. After the brain tumor was removed in 1983 – I stopped having them. Interesting! Makes me wonder about the effects the brain tumor may have on the kidneys, on allergies and other things, as my allergies were out of control, until well after my first brain surgery – when they lessened.

All right, the pills were clearly giving me side effects, so I went to my PCP again and insisted on a referral to a Neurologist. I have to admit I was borderline assertive-aggressive. I obtained an appointment to see a Neurologist right away (fortunately). That doctor only gave me more pills – to which I reacted adversely. And, they did not touch the migraine headaches. I was not the least bit amused.

The Neurologist thought my migraines might be allergies, so he ordered allergy tests with an Allergist. Off to yet another doctor. The allergy tests revealed I was allergic to nearly everything or so it seemed: plants, trees, grasses, dogs, cats, cows, hemp {no wonder doing macramé made me sneeze}. You name it – I was allergic to it.

I had a terrible reaction to the allergy tests. **What a mess!** I hear the late actress, Betty Davis saying, “What a Dump!” It is all right to laugh! I do (now). The allergy tests created a massive hives situation on my arms - and, oh, did it ever itch!

Then, sitting in at my work desk with my arms swelling from one end to the other, I began having asthma-type symptoms and was wheezing so bad I called the Allergy Clinic (in the hospital where I worked). One of my co-workers helped me up to the Allergy Clinic, where I saw the doctor, who promptly gave me an Adrenalin injection and then had a racing heart, though it settled the asthma-type symptoms. He said to come back before 5:00 P.M., as he wanted to make sure I was all right to drive home or I would go in the hospital overnight. They gave me Benadryl to take for the hives and itching.

**Back to the Neurologist:** About two weeks later, I went to the Neurologist again and (get this) he said, “If it will make you feel better, we will do a CT Scan.” I was so angry and appalled. I was, quite frankly, beside myself. I am sure at that point I probably did seem like a really stressed-out woman. After what I had been through, was there any wonder I was not bouncing off the walls, totally stressed and all?

Not a single doctor I had gone to seemed to care one rip about what was wrong with me. I think it is what bothered me the most. They still had no idea what was wrong with me and clearly, I was quite ill. Still, no diagnostic tests had been done to look inside my head or anywhere else, for that matter.

I went for a CT Scan and reacted adversely to the *iodine dye contrast*, so it was another really scary time. I began wheezing and choking on fluids my body released in my lungs from an allergic reaction to the **iodine dye** they had injected in my veins.

I found it interesting is medicos at the time had not believed the recent **allergy testing** for a reaction to iodine. This is another real “Duh!” moment in medical history. They gave me a Benadryl injection and steroid to counteract the bad reaction. They said the Neurologist would call me with the results to the CT Scan in a week.

I did not hear from the Neurologist about the CT Scan Report, until I called him, though more on it in a moment. In the meantime, I realized I had another option available for medical care. I had dual insurance and had forgotten about it. Wow! I could go outside of the hospital where I worked. What a concept! As an employee of the hospital, I had elected to have another medical insurance coverage (as I had the other though it was going away following a nasty divorce).

My boss told me of a local Doctor of Osteopathy (D.O.) he liked in the next town. I went to the kind, elderly doctor and he began to run tests, including: 1.) kidney function, 3.) blood panels and 3.) Arthritis and numerous other things. Things he said made me think he was looking for cancer.

He tried different medications for the seeming arthritis symptoms I had: excessive swelling and water-retention. A note here: All of those symptoms disappeared after the brain tumor was removed in 1983. At one point, my ankles swelled so much, my skin felt like it would split open and it hurt to walk. No medication the kind D.O. had me take helped anything.

Nothing made me get better. The migraine headaches began to go from the tail end of one into the next full-fledged and devastating migraine headache. I was a real mess.

**More about the Neurologist:** Only because I needed to take a copy of the CT Scan Report to the D.O. did I go to Medical Records Department and request a copy of it. I wanted to read for myself what the report said and learn what it meant.

After I got the report, I read the CT Scan Report in absolute disbelief! What in the heck is a Meningioma? I gathered from the report it was a brain tumor. Until then, I had never known the word: ‘Meningioma.’

I immediately went down the hall to the Medical Library, across from where I worked. My dear friend (the librarian), Alice, helped me look up MENINGIOMA in the medical books. I was horrified, stunned and angry. You can imagine what else. **It was “ALL IN MY HEAD” darn it, and, “IT” was a BRAIN TUMOR – Gasp!**

I had been so sick for so long – and finally it was almost a relief to know there was something really wrong. Yes, I was sick, all right, because of a brain tumor. Granted, it was not too large – needless to say, it was making me quite ill. Although I knew something was really wrong with me, it had never occurred to me I had a brain tumor.

I shuddered and I shook. Then, I tried to calm down. Alice was equally shocked. I went to my office and told the ladies I worked with about my CT Scan Report. They were stunned. I called the Neurologist (as this was more than a week after the CT Scan). I asked him ‘when was he going to call me with this bad news?’ He did not say anything at first. Then, he made some lame excuse. I let him have it on the phone, as I was so angry.

Darn it, when a medical test report comes back saying a person has a brain tumor, the doctor needs to let you know as soon as possible and then begin planning what to do about it. I was not amused at all.

The Neurologist acted like he could have cared less. He finally referred me to a Neurosurgeon. That ended up being another bad experience. The Neurosurgeon said, “At your age and with such a tumor, you should get used to having migraine headaches as part of life and get on with life and do nothing.” WHAT? I was age thirty-four (34). **June 2011:** I have been so glad so many times I did not listen to or take that doctor’s advice!

I could have sued the Neurosurgeon and hospital, once all was said and done. I was too busy trying to get through each day. I was on my own and barely functioning. I did not have the energy to do sue – and, I needed my job.

I did not even make it into my bed most nights, falling asleep on the couch. I was constantly exhausted. I did not make it to work a whole lot, either. I did not hear the alarm clock many times.

Later, I learned from close friends how much my personality had changed over the last few months and years leading up to having the 1<sup>st</sup> brain surgery. Good friends will tell you these things. Life was slipping away and I could not seem to do anything about it. Life was sinking and I felt quite helpless and hopeless.

All right, now I knew I had another medical option, the D.O. sent me to a world-renowned Neurosurgeon/Brain Surgeon at University of California at San Francisco (UCSF), Charles Wilson, M.D. Dr. Wilson explained he felt we should watch the brain tumor progress for a year before doing anything. He said I was not in immediate danger. He said this way he would have a baseline of it and could measure the growth rate. He said they just do not rush in and do brain surgery.

UCSF did another (much clearer) CT Scan which showed the tumor clearly at the top of my head in the Falx (between the two halves of my brain), pressing into the right convexity - presumably which caused all the left-sided symptoms, weakness and focal seizures. Their equipment was state-of-the-art. MRIs were not in use much, yet and CT Scans were the diagnostic tool used for brain scans. Now, nearly everyone in America uses MRIs.

During the next 12 months, I steadily declined. I felt so drained (sort of like in the movie Dark Crystal when they sucked the life out of the little folks). The tumor grew in a year's time.

On February 3, 1983, I checked into the University of California San Francisco Hospital for pre-op procedures. On February 4, 1983, a Benign Falx Meningioma was removed by a craniotomy. Surgery lasted 5.5 hours. They opened a huge hole at the top of my head with five (5) entry holes in the skull, which remain as indents. The Meningioma was **benign** and part of the Falx was removed with it, the pathology report says.

When I came to following surgery, it was the first time in ages I did not have a migraine headache. I was on oxygen and it helped. I was 35 years old. I recovered relatively easily, even though about three (3) days after surgery I got a cold in the hospital. They said no sniffing, no blowing my nose and what a mess it was. My nose and under it got really chapped. I used up a lot of tissues dapping at my nose.

I was in intensive care unit (ICU) for a day. Then, moved to another ward with about eight (8) patients, like an ICU with a Registered Nurse on the floor at all times. Then, I had a private room for which I was glad. I was in the hospital for a week. I began walking all over the Neurosurgery floor, to the solarium and looked at the San Francisco Bay.

I visited with other patients and their families, which everyone seemed to do and people were nice. I was not allowed to leave the Neurosurgery floor. They did not want brain surgery patients walking all over the hospital and scaring everyone with their gauze 'helmet' heads.

I was fortunate enough to have my Daddy with me at the hospital for about six (6) days. I was glad for a familiar face following surgery. We had a chance to visit a whole lot. I am so thankful he was able to be there. My Mother was still not well enough from a stroke, so was not able to make the trip. At least my Father was there.

I recommend everyone have someone you know there for you after surgery. If my Daddy had not been able to be there, I do not think I would have had anyone else, as none of my family or friends could be there on a constant basis, day in and day out while I was hospitalized.

I was on Decadron (steroid) for two weeks after surgery and told it reduces brain swelling. It made me so hungry I ate everything in sight. I was still thin in those days and put on about 10 pounds during my recovery. Had to walk and exercise like mad to reduce those inches and pounds, once I was recovered and back to work. I was on Dilantin for five (5) weeks, as protocol then to make sure there were no seizures. I got the worst hives from them.

Being bald is a real trip. It is just simply weird, especially for me, who had always had lots of hair. (**June 2011:** The last couple of years, I finally have long hair for the first time since 1983.) I had long hair to my waist before I had it cut short and then shaved for brain surgery. I never wore a wig. I wore hats I made to match outfits I made. My hats served me well. I gave them to the next employee at the hospital where I worked who had brain surgery.

I recovered fairly well and rather quickly. I returned to most normal activities soon. I was motivated to do so. I missed my sons and wanted to see them. I had to wait until June, as they lived in Texas. I felt so great afterwards with some side effects, which did not last. Gradually, the symptoms got to a tolerable level and I stopped falling down, running into walls and doorjambs and bruising my arms.

I managed to return to work within two (2) months following surgery. For about three (3) months, I felt like I needed a nap by 3:00 P.M. every day. It took some time to begin to feel like myself again. I began going back to the gym/spa and exercised with a dear friend, Alta.

About seven (7) years after the surgery, some of my memories returned about certain events during the brain tumor years. I realized I had lost some memories and once I began remembering, it was like a whole chapter of my life had been restored. I could then close some doors to those chapters and opened new doors to my new life.

Since 1983, I have had not had headaches I would classify as migraines, except for three (3) bad ones during the first year after surgery. It took me a while to equilibrate to being able to go above 2,000 feet in altitude without having altitude sickness.

I have had very few bladder infections since 1983. My allergies are not as severe and I have not had further testing done, nor have I tried any of the medications to which I adversely reacted. I am just not comfortable with trying any of them to find out if I would still react and why would I?

During the time before I had the first Meningioma removed, I remembered saying to the D.O. at one appointment, "It was as though my left side of my body was not mine and there was no connection between my left and right side of my body." I just did not feel like myself during those years. I often felt stupid, as though my brain did not function correctly and my thought processes were not right.

I could not help it. Nothing I did made any change with what was going on with me, even my Spiritual meditation and prayers really did not seem to help, though now, I believe meditation and prayers kept me sane during those awful years.

During the time when I was the sickest, I remember having destructive thoughts and those really scared me. I know my Spiritual side suffered. I got mad at God and asked, "Why This?" – "Why Me?" – "How could You do this to me?"

Eventually, I realized it was not anything which could be changed. Perhaps the experience was something I had to go through to understand other peoples' grief and medical situations. I concluded: **a person who has had brain surgery can understand another person who has had brain surgery.**

I asked God to help me. Finally, I lost the anger and became calmed by knowing I had not brought having a brain tumor upon myself. It was not my fault. I was no longer stressed and I realized God did not do this to me on purpose or to be mean.

Life goes on and once I got better, I had to move back to the Bay Area where I worked. I had moved about a week before surgery to stay with friends, as I had no idea (nor did anyone) what I would be like following surgery. They helped me and it was nice for them, as I paid rent on the room in which I stayed.



My dear sister, Janet, came to visit me a lot. She cleaned my friend's home, as part of her help for me. That was nice and we had great visits. She helped me become me again. I will never forget it. She is a dear sister, very loving and supportive.

The medical staff at UCSF and Dr. Wilson had been straightforward in their approach. A friend of mine was a Neuro Nurse on the Neurosurgery floor. It was an unusual experience, having a friend care for you and be your Nurse in such a setting. My overall experience was a good one at UCSF.

As far as I know now (2011), Dr. Wilson and Mitchel Burger, MD, my Neurosurgeons from UCSF are on the American Brain Tumor Association Advisory Board.

### **My Story is Not Over! There are Other Chapters**

I had a follow-up MRI at one year (1984), at five years (1988) and at eleven years (1994). As I do this update, **November 1, 2004**, marks 21+ years since that first Meningioma brain tumor was removed.

The UCSF Neurosurgeons had said if I got beyond ten (10) years without showing any more Meningioma brain tumors I probably would never \* have any more of them, ever! Unfortunately, the doctors were wrong about that.

They recommended MRIs every five years. I felt like I did not have to worry about them and tried not to even think about the tumor years or surgery. I was, after all, taking good care of myself, mentally, spiritually, health-wise and all and with what the doctor's had said (\* above), I felt quite secure I would never have to face going through brain surgery again.

From about 1993 on, I had not felt good or right. I did not think for a minute I had another brain tumor. I have had two to three bladder infections, more colds and bad allergic symptoms. I fell down a total of four times during 1999, had extreme dizziness and other symptoms which just did not make sense – A BIG RED FLAG went up and waved, sort of saying, “Listen and look at what is going on here! Something must be wrong!”

Concerns really hit us when I took a nasty fall while in California in late November 1999. My left leg just gave way and did not function. Down I went – really hard onto a cement sidewalk. My two sisters, who I was walking with at the time, were as shocked as I was.

We thought at first I had broken my left tibia. Thank heavens I had not. I sure had some mighty bone bruises, though. My sisters insisted I look into this falling down business, the dizziness and other weird symptoms which made no sense. They insisted I see my PCP right away when I returned home to Ohio {where I live}.

So, I did and talked with my PCP about checking for a brain tumor with an MRI. My doctor ordered the MRI, saying to me three times that day, “I do not think you have a brain tumor, but we will do the MRI because you have had one in the past.”

When my December 16, 1999 MRI report showed three masses, two of which were identified as Meningioma brain tumors, I was devastated all over again. I could not believe it. How could this be happening? I went into denial, sadness and was quite angry.

Then, as I went to three different Neurosurgeon appointments (to get opinions), my spouse and I were told about these three masses, two Meningioma brain tumors and one CT Scan report later claimed that the mass behind my ear was a hemorrhage that resolved itself, which we learned in 2002 at the Mayfield Clinic in Cincinnati it is nothing of the kind and of no consequence.

After going to get these three Neurosurgeon opinions, I got the approval of my company's Insurance Company for the Neurosurgery (Brain Surgery) to remove the Right Parietal Meningioma. We settled on the Cleveland Clinic. So, I went into the hospital on April 3, 2000 for pre-surgical testing and preparation. In the end, that insurance company did not pay one single dime toward my medical expenses.

**On April 4, 2000**, 17 years and 2 months to the day after having the first Meningioma removed and I was then age fifty-two (52), I had a Right Parietal Benign Meningioma removed. My recovery was more difficult. The surgery was only 2.5 hours long and I spent 2.5 days in the hospital.

### **Update: June 27, 2000 - What I Wrote Family & Friends**

Life is like a roller coaster with ups and downs and it often takes us for a loop-de-loop we are not expecting! On Monday, June 26, I went for Neurological Evaluation at Cleveland Clinic, since I have been experiencing symptoms which have increased over the past month or so. Instead of feeling better following the first few weeks of this brain surgery recovery, I have begun to feel worse. It has been 11 weeks since my brain surgery.

The problem was I still have another Meningioma. Best guesses with symptoms are it is this tumor causing the problems. One of the symptoms is an ammonia smell from time to time (I smell ammonia – it really is not there). The others are fatigue, uncoordinated gait, waking up every day with a headache, blurry vision and several others.

So, after trying to deal with these, praying they would just go away, keeping daily notes on my calendar, not feeling like I am progressing, though moving backwards, we felt my condition needs to be addressed.

After having talked with my Neurosurgeon's RN recently (I sent her a Fax-Memo), she set-up an appointment for me to see Neurologist as soon as possible. She felt that we could not wait another six weeks. Thus, the appointment this Monday.

The Neurologist asked me a bunch of questions (based on my Fax-Memo list of Symptoms, Concerns and Questions). He did a mini-Neurological Exam. He had seen me two weeks after my surgery. He said brain tumor patients all have a “long laundry lists of complaints” and they realize for the patients it is unnerving, unsettling and frustrating.

He said he was concerned about the ammonia smell, as it is a form of seizure activity. My notes on my calendar reflected the ammonia smell had occurred at least four (4) to six (6) times per week, sometimes two (2) to three (3) times per day.

The doctor was concerned about my bad headaches. He asked how much caffeine I consumed. Two (2), eight (8) ounce cups of coffee per day. I do not drink sodas or other things with caffeine. So, he determined caffeine was not the offender.

My allergies are calm now, especially for this time of year. I am not outside to breathe in the pollens and we have a good filter on our HVAC system. I am not waking up with stuffed head and nose, so they clearly are not sinus headaches.

Gee, what could be causing headaches when I wake up every day? My best guess is the pressure the darn tumors put inside the head, as the headaches subside a whole lot after I have been up for a while!

The doctor had me walk and as I stumbled across the room, catching my balance on the wall, he asked if I use a cane. I said “no” (I do not like to walk with a cane, because I think it is hard on the wrists and back). He did not tell me to use one, though indicated if I felt I needed to, to do that. Forget walking one foot in front of the other. I would be hard-pressed in a sober situation to pass a sobriety test! (Laugh! It is OK!)

Needless to say, it is frustrating when you have been coordinated all your life to feel like an absolute klutz when you walk. One of my dear friends said I should just use the cane and get the best out of it - besides she said, "You would be elegant with a cane!" Nice to hear, though part of me says using a cane admits I am disabled and I may not be ready for that step.

The doctor asked about my mental state, stress, frustrations, etc. I told him about our insurance situation on top of everything else. That was when I said I could not handle the stress of how I feel, physically with my symptoms. I frankly did not need the insurance mess on top of the stress of having brain surgery and still having a brain tumor to deal with. He said I should not have to deal with the insurance companies. I said I needed my spouse to do it for me now, as it just makes me so darn angry.

Then, the doctor asked what else was there. I began to cry (I try to be so tough and not do that); so told him I feel "sort of stupid" (lack of better word at the moment), as I feel this increasing mental decline is really pushing my anger and frustration buttons. He handed me the Kleenex box.

The doctor explained since I have had two brain surgeries over the past 17 years, still have a Meningioma that it is not uncommon to feel the way that I do. He said every time a person has brain surgery and brain tumors, they lose certain brain functions. I told him I just "do not feel smart enough to go to work" because I have such a hard time concentrating and remembering things.

It takes me a long time to do anything. I fish for words when I talk or write (and I have not had to do that before). He said I would not have to go to work now and is keeping me on disability with an Undetermined Release Date - wait and see how things go. The reality is if this other tumor is inoperable and continues to cause me to decline, I may never be going to work. Time will tell.

He asked me if I wanted to go on an anti-seizure prescription and he explained all the pros and cons. I said if I really did not have to, I would rather not, unless I absolutely needed to (too many medication sensitivities) and I had reacted to Dilantin the first time around.

He said we needed to call them immediately if I have other things which seemed more like seizures, besides the ammonia smell, i.e., full shaking, or obvious shaking. He did not think the tremors we tried to explain were seizures (who knows?).

Then, we talked about the mental stress and frustrations while I was really upset some more. I had told him I just do not feel like myself anymore (or normal). The doctor seemed to think I am normal for my situation and with the existing tumor, the unbelievable stress I am under and it was a nice validation. I have a right to feel what I am feeling, given my current situation.

The Neurologist suggested I try to get more activities in my life. I walk some, though walking is a problem because of my gait and I get really tired, really quickly.

I did tell the doctor I have been doing some art and craft projects for fun (dècoupage, shadow boxes and such), focus and to relieve stress, plus meditate twice a day. He wrote it down and seemed to think it was really good (at least I am doing things).

I told him I e-mail, write and it helps me a lot and have a supportive family and friends. So, even though I face this inevitable dragon - the brain tumor monster - I can feel comfort in the fact I have so many supportive friends and family.

We go forward from here. My next MRI is August 7, 2000. I see the Neurosurgeon to discuss options and see the Neurologist again. My job right now is taking care of myself and working at trying to adjust to the new me.

## Thoughts, Hope, Information & Helping Others

My thoughts continue on brain tumors, recovering from brain surgery, living every day with a brain tumor, pondering the things I believe in, seeking connections to the whys, genetics, reasons and cures for hope. So I write more, so perhaps my experiences can help others cope and find hope.

The doctors said at the time of my 1<sup>st</sup> Meningioma it could have been triggered to grow when I was in the auto accident in 1975 and had the 3<sup>rd</sup> degree concussion. Who knows? They just do not know about these things. Here we are in this advanced techno age and medical science still has so little information on why we have brain tumors – or so it seems.

Needless to say, I have seen a plethora of medical doctors over the years. I have even gone to some doctors who just act as if you are ‘crazy’ when you give your medical history and say you have had two (2) brain tumors removed. Then, they blow you off and never listen. Time to get another doctor. I think some of them just do not know how to act or treat brain tumor patients.

I learned one of my great uncles on my Mother’s side ultimately died at age 79 from a Meningioma brain tumor which had become so large, the Neurosurgeons could not get it all when he had surgery two years before he died. He went blind. So far as we know, there is no one else in the family who has ever had or has Meningioma brain tumors and we all hope and pray it stays that way. So, we do not know if it is genetic.

I do not look forward to check-ups or doctor appointments. I know if I want to live the rest of my life in a quality situation, I must have them, so I go. I may have to make decisions for treatment options for the other Meningioma in the future. It is something I do not look forward to; however necessary it will be for my health (maybe). **June 2011 comment:** Since it is not growing – we leave it alone.

I live each day and enjoy being here, surrounding myself with family photos and things I like, making my own little ‘Peace of Heaven on Earth.’ If I cannot, no one else can do so for me. I know God’s plan for me is for a long life, so I must find the best medical care I can get and insist on proper care and cures.

All of this is part of my HerStory and experience with Meningioma brain tumors, doctors, hospitals, medications and the devastating illnesses which seem to go with what brain tumors do to the body. I often wonder how many other people suffered as I did?!?!? How many have similar situations with doctors just not doing appropriate testing to locate the problem(s) and find proper treatment?

I have learned we have to be our own advocate or appoint someone in your family to do it. With all the technological advances in medicine, I do not believe anyone should have to suffer in these modern times. Get doctors to do the tests to find what course of treatment is best for each individual's situation.

Get insurance companies to pay for the diagnostics, necessary treatments, hospitalization and surgery to give quality of life back to the living and not approve and then deny payment. Is it not why we have medical insurance? And, one size certainly does not fit all. Each brain tumor case is different.

**I Advocate This:** I believe no clerk behind any insurance desk has the authority (or right) to tell any patient or doctor what treatment to give or to deny treatment. To deny any patient treatment goes against the **Hippocratic Oath** doctors take when they become a doctor. In my opinion, the insurance companies need to follow it.

I will step off my soapbox now! I try not to be angry or upset, because it is not good for me. I strive every day toward adjusting to changes in this physical body and within my mind. I now need to work toward accepting this new and different me. I am glad to be alive! I have loving family and wonderful friends.

## **Update: August 8, 2000 - We actually have some GOOD NEWS!**

I went for my 4-month MRI and evaluation after April at the brain surgery at Cleveland Clinic on August 7, 2000. In talking with my doctors, we have found we had been misinformed about the Meningioma brain tumor which still exists. We had been told by a doctor in Columbus it was near the Circle of Willis. The Meningioma is not near the Circle of Willis.

The good news is the brain tumor has not grown since December 1999 or April 3, 2000 MRIs (**as I said June 2011, it still has not grown**). The rest is, the existing tumor is another Falx Meningioma, though deep brain (about 2 inches lower than the original one removed in 1983). I asked the doctor if this was a re-growth from the 1983 tumor and he very emphatically said "no!" without hesitation, so it is good news!

However, because access to the brain would be difficult in the area, a high-risk surgery and the fact it has not grown, the NS's recommendation is to "Watch, Wait & See" (some more). Sort of the idea, "Let Sleeping Babies Lie" - applies here. Let sleeping tumors lie and do not disturb them. He said next follow-up MRI in another six months (around February 2001).

Unfortunately, I am still experiencing symptoms which are unpleasant. I am just not coming back to feeling well again and it has been a long haul. I manage all these symptoms the only way I can, deal with them and adjust to changes. It is a challenge. I am glad I still have a sense of humor. So far, I have not broken anything expensive. The doctors are still keeping me on disability with an undetermined release.

If it can be funny, here is one of the funny things. Brain surgery/tumors have deleted some of my brain's memory chips. Now, for some things it can be helpful. However, I questioned: recipes and cooking? Well, it is actually quite hilarious (sometimes). At other times, it is disappointing and frustrating.

Having been able to cook for most of my life with all those recipes in my head, I now find my recipe files have been erased. It is, well, just a tad weird. I have always loved to cook good food (and consume it). We have had some strange meals. It is just strange to be a stranger in my own kitchen. In searching my brain for some other files, I find I am missing some other things, so I adjust my sails and go on with life.

The MRI shows the Right Parietal area of my brain, where my April 2000 tumor was removed, looks clean and clear. That is good news! The doctor's recommendation was if the Falx Meningioma requires treatment I consider the Gamma Knife. Read further and you will learn why I would not ever consider it. To read about the Gamma Knife: <http://www.elekta.com>

### **Internet Brain Tumor Resources (USA)**

I appreciate being able to tell my HerStory through Virtual Trials. I can only relate my personal experiences. I cannot and would not give anyone any medical advice. For any medical questions, each patient and their families need to direct those questions to their doctors.

I have heard hundreds of brain tumor stories and about many whose experiences have been much the same as mine with doctors, hospitals and insurance companies.

It is comforting to know I can refer those needing more information to the **American Brain Tumor Association:** [www.abta.org](http://www.abta.org) or **National Brain Tumor Society:** <http://braintumor.org> where people can receive lots of help and advice. It is nice to be of service in this way.

We all need information and should utilize all we can get. To be armed with information is to be forewarned.

## **Update: February 4, 2003 – I Changed Neurologist**

I have changed to another Neuro doctor. Summer of 2001, the Neurologist at CCF told me there was nothing he could do for me and did not bother to see if any other specialist could see me and help. I left there feeling as though no one at CCF cared.

So, I sought out a new doctor and clinic. I strongly feel we each need to go to the doctors who offer hope and help, kind words and will not hesitate to send you on to someone else who can offer help, if they cannot. I did not get a warm fuzzy feeling when the doctor told me, "I cannot help you," so why would I want to continue to see such a doctor?

We learned much from this new Neurologist. The existing Posterior Falx Meningioma brain tumor (deep brain) has not grown since my December 1999 MRI. The doctor said in July 2002 I do not need to have another MRI for a year. So, this is good news.

I am convinced prayers, healing energies and good thoughts of family, friends, healers and my own positive outlook and thoughts have kept the tumor at bay. There is an NBTF remote healing experiment in progress (I am not a part of that study).

I am determined my support group and I have already done our own experiment and it is a success. I am and the MRIs are proof of healing energy, prayers and all do work. It is the only explanation I have for the lack of growth. I am confident God has more work for me to do.

## **Update: November 1, 2004 – Networking & Outreach Programs**

I continue to have an MRI every July. So far, there has been no growth in the deep brain Meningioma tumor. I still maintain it is how I live my life, my Spiritual beliefs, the healing energies and prayers of friends and family have kept it from growing. I believe my personal attitude toward life has kept me feeling better – overall.

I have health conditions for which I see a Neurologist locally. She has had testing done which have identified certain things. In a perfect world, there would be a cure for what ails me. Since there is not, I wake up each day and as said by Tom Hanks' character in *Sleepless in Seattle*, "**I breathe in and out**" – life goes on and we do the best we can each day, nothing more and nothing less. When I am tired, I rest or sleep. I have good days and bad days, though I get up every day, thankful that I am alive.

I have a new primary care doctor. I advocate to everyone if any doctor is not providing you with the best health care – find someone else. It is really not difficult to do. We are the ones who hire our doctors and we can fire them if they are not doing anything to help us. I am glad I found a new PCP, as it has made all the difference in the world. We all need the best doctor.

I am happy to have been a part of the *Faces Of Brain Tumors* book that goes to U.S. Congress in Washington D.C. each May. Yes, all brain tumor patients have faces, names, lives and his and her stories. When people see us, to look at us, people cannot expect we are anything other than doing all right. There is no particular look to cause anyone to say or think: 'that person has a brain tumor.'

I am happy to have donated one of my 2000 post brain tumor surgery hats for the *Hidden Under Our Hats* project. I think it is an important aspect of and makes a statement about those who have had brain surgery. The project was displayed for U.S. Congress in May 2004. I understand it is being taken to various locations for display.

I am thankful to Al Musella of Virtual Trials for the opportunity to post my BT HerStory.

I do not write updates to many family and friends anymore about what is going on with me. Some people I do let know about my MRI results. I figure if people who know me are interested in knowing my status, they will ask. It is a matter of choice what we tell others and when.

I decided updating on e-mail was not benefitting me and I did not want a pity-party attitude. I cope and get on with my life as best as I can. I do what I do.

All any brain tumor patient can do ask for is hope. We can realize that life is a precious gift and live our lives, as through each day could be our last day and show others we care about them. Sometimes it says more than anything and it is returned in kind.

### **Updated: June 2006 – Final Thoughts – for now**

My deep brain Meningioma still sleeps and it is fine with me. It has not grown since 1999. In fact, the latest MRI of April 2006 shows it smaller than ever before.

I have to wonder if my Spiritual endeavors, certainty of faith and belief in God has caused the brain tumor to actually recede. I was asked last year to share my Brain Tumor Survival Story in a book published by a lady in Greece! I had many wonderful correspondences with Maria.

I offer to each person who unfortunately ends up with a brain tumor to begin saying to them 'self' in the mirror this, **“I am not my brain tumor!”** That is not who we are! It just happens to be something which for whatever reason, we are to experience.

Below are my LINKS. I create *Intuitive Fine Art* and it is posted on Yessy, as is my some of my *Medieval Art*. I have books posted on *AuthorsDen*. My time prevents me from corresponding with brain tumor patients these days. Creating art and my writing keep me occupied and are my focus. I still communicate with some brain tumor friends and have for years. The camaraderie continues. **“Keep on, keeping on!”**

Respectfully with Best Regards,

**~Maureen**

**“Say Nothing & Nothing Changes. Say Something & the Whole World Can Change!” ~Maureen, 2009**

### **Places where ‘What I do’ can be Found!**

**Maureen’s Books at AuthorsDen**

[www.AuthorsDen.com/MaureenWClifton](http://www.AuthorsDen.com/MaureenWClifton)

**YESSY Art Gallery # 1, *Intuitive Fine Art***

[www.yessy.com/Maureen1947](http://www.yessy.com/Maureen1947)

**YESSY Art Gallery # 2, *Medieval Art Misty Isles***

[www.yessy.com/Maureen1947/Medieval.html](http://www.yessy.com/Maureen1947/Medieval.html)

**iReport CNN: 25 Year Brain Tumor Survivor  
February 4, 2011 was 28 years – *Happy to be Alive!***

[www.ireport.com/docs/DOC-24838](http://www.ireport.com/docs/DOC-24838)

***Emeritas et Liberatas***