

So here it is July 2011 and I am still here fighting the Beast. Original surgery was in 2002. The only way to describe the next few years is the word horrific. I was diagnosed because of continuing sinus problems and was then sent to an ENT specialist who ordered a MRI. I thought he was going to scare me with the words "surgery for nasal polyps." When he said "brain tumor" it didn't scare me as much as nasal polyps would have. Since the Beast was mostly frontal my emotional responses were a little impaired and there was no response at all. I also was noted to have no facial expression responses. After surgery I couldn't get used to all the things I couldn't do anymore. I suffered with double vision, severe memory problems, head noise and loss of balance, etc., etc., etc. I cannot smell or taste any longer, which is most interesting to say the least. One of the more annoying things was I was not making rational decisions and it was constantly being pointed out to me. Example of this: one day when I had a headache I got in the car (with double vision) and drove to the primary doctor's office a couple of towns west, about 20 miles from where I lived. Once there I did the waiting thing in the waiting room. My husband was at home and when he realized I was gone, with the car, he was frantic. He and one of my brothers started calling around to find out where I went and one of the places they called was the hospital and then the doctor's office. I had never thought to leave a note which I had always done before. Luckily the PA knew I was alone and kept me there until they arrived to take me back home. I don't think I ever saw dear hubby or brother so angry. To prove to me I shouldn't be driving he handed me the Rx and told me to read it.....I couldn't see it well enough to take from his hand. The thought that I could have had an accident had not occurred at all. There was no fear or thought that I could have killed someone or myself. One of the feelings I did have after the car keys were all hidden was of total despair and loathing where I was now. Having always been the independent one who was able to do everything and even to helping others I did not like the position I was in. I was determined to get back to my old self as much as possible. Over the ensuing years my vision with glasses corrected and now I drive. I was absolutely lost without this privilege.

Due to the poor vision I have fallen, have reached for something on a top shelf in the basement only to have a pipe come down, striking me across the nose and across incision line and pins inserted at surgery. Nose was broken but not displaced, two pins were knocked loose but not floating around in there. Thank heavens this doesn't cause any more electrical circuit problems in my brain. I have missed a step on the stairs and gone down a way other than how one is supposed to go down, skinned up a leg but it healed without incident. Turned too fast and fell in the snow, breaking my wrist. How does one break a bone falling in that white, fluffy stuff!

When Social Security sent me to their and psychologist for testing I failed the test with flying colors and was granted disability. About two years later a friend told me I could apply to SS for a copy of their findings. I did and I was upset when I read the results of the testing and diagnosis. It read as if I was mentally retarded. It was suggested that I not be left by myself, not to trust me handling household finances or the bank accounts and that we should consider moving to an area where the way of life was much slower. All my family and friends were here; I did not want to go somewhere else. I was enraged and my feelings were, "who are these people to say things like that about me." This was just more fuel to the fire that pushed me to do everything I could to get back to my old self.

First off, the seizure meds that I was given were causing severe side effects and after complaining multiple times about it, the doctors finally changed it. It took a few years but now I have no seizures at all. The worse ones were when I woke at night seizing. This was scary and my only thought was if I did not wake up during the seizure I was going to die. Once this problem was solved I was to be weaned off steroids. I have heard bad things about steroids but my metabolism must of been just right for them. I lost weight (Yea), had the energy of ten people and was so hyperactive that it was driving others crazy. I would have gone out and been a famous baseball player if only I could see the ball. Touch of humor there. I could not sit still and have a cup of coffee without jumping up to check the coffee pot, wipe the counter top, run out to check for mail, etc. and all the while trying to have a conversation with company. This was a joke because most of the time I could not keep track of what was being discussed anyway. I still have this to some degree even off steroids. I was never hyperactive and always could stay focused on the project at hand, even when multi-tasking. Now I can jump from one thing to another and have to work very hard to start, do and complete a project before moving on to another or nothing would ever get done. I can no longer multi-task. I get confused if too many things come at me at the same time. I have to walk away, regroup and then tackle one thing at a time.

My language skills were messed up. My comprehension was messed up. My speaking language was messed up. Sometime I could think of what I wanted to say but couldn't find the words to say it. My ability to learn new things was messed up and I found myself asking others to show me how to do something that I knew or to help me with instructions that I could read but had no clue of what the words meant. My language skills went from college level to grade school level. My neurologist suggested that I start taking Vit. B complex pills and doing word and math puzzles to gain back some of what I lost. In other words, I was to push myself to be mentally active. I took his advice and also went to the library and started reading large print books. In the beginning it was difficult and many times I just got frustrated and stopped. Major frustration and anger with myself made me keep pushing.

I still have memory problems but not like I did after surgery. The cliché, “out of sight, out of mind” definitely applies to me. I still do the note thing and think I am keeping 3M in business. Everything has to be put on a large calendar or appointments, etc. will be missed. With glasses the double vision was cleared up, except when I am really tired. Since I was an avid reader before the Beast invaded my life I am now able to read large print books from the library. Thank heavens, something from my old life was coming back! Now comes the good part, remember “out of sight, out of mind?” Well, I now put my initials in pencil in each book I read because if I don’t I could read the same book a dozen times and never have a clue that I read it before.....the old memory problem. Strange that I am afflicted with this annoying and frustrating problem but am confused that I can remember how to cook dishes that I always made or to crochet/knit patterns that I have always done over the years. Not that I am complaining but it would be nice to understand it and work on correcting this.

I am determined to beat this learning problem also. I am taking quilting lessons an hour each twice a month. I have to admit I am very slow at this and often forget an important lesson but there is another woman in the class who also had brain surgery but for an aneurism and she is just as slow. She just does not forget what she was taught as much as I do tho. I know it is not nice to point the finger but with her in the class I feel almost normal - finally. We have become good friends and can laugh at some of the things we both have gone thru that most others do not understand.....we both get it. The space were my BT was is now mostly just space so I guess it is safe to say I am now an air head! She has to worry about another aneurysm, stroke or clot on a daily basis and I worry about the Beast's baby starting to kick. Yes, I have a baby Beast but so far it is happy to stay a baby. I will not let this effect the progress that it has taken me nine years to make. I am determined to stay optimistic. I figure if it took thirty years for the Beast to grow to grapefruit size before starting cell changes that with my age plus thirty years more, I am not going to worry about it. It’s possible I won’t be around when the odds are no longer in my favor.

Because of auditory nerve damage from the Beast, not the surgery, I have head noise all the time. It is worse at night when lying down. This damage also effected my balance. I carry a cane in the car at all time because I never know when the balance problem is going to strike. I cannot look up or I will fall over so I have learned not to look up unless I am holding onto something sturdy or sitting down. I also cannot dance, I cannot turn my head quickly or bend down to get something out of the lower kitchen cabinets or I will lose my balance and fall. I use a shower chair, especially when washing my hair just in case. Instead of bending or reaching to get things I get down on my knees or use a small step stool - which my family doesn’t like but I cannot just ask others all the time to stop what they are doing to come do something for me.

One can learn how to live without doing some things that were once done. The brain can help us compensate in areas that we are now lacking. The important thing is not to give up, not to lose focus on trying to become what we were before the Beast if this is indeed what you want. Don’t sit back and let life go by without doing anything to help yourself. I am grateful that I had the drive to accomplish all that I have and am able to change or learn to live with what I have to. I consider myself lucky to be here today to share with others. My sister-in-law tells me I am a blessed one. I guess everyone has their own way of looking at it. I see it as my job is not done (whatever that is) and I am a nine year survivor of a grapefruit sized Beast with atypical cells, who has left me with a baby to care for. No one has told the Beast that I am retired!

As it turns out after taking care of the “new me” my Dear Hubby’s heart has decided to take a turn for the worse. It is slowly declining and he is not a candidate for a transplant. Now it is my turn to take care of him as best I can. To me, this is worse than all the problems that the Beast has caused. My illness is a drop in the bucket compared with what I see him now facing and my pain is totally emotional. Here it now is, nine years later, and I am able to feel emotion again. I don’t want to feel this!

We sold our home of 38-years and had a modular home built in PA and delivered to Son #2’s property. Most retirees downsize but we up sized. In my irrational, illogical, crazed moments in trying to heal myself I designed the retirement home that I thought would be nice. Once it was actually built, it turned out really nice - don’t ask me to explain this for I cannot. I should have put a patent on it. LOL Suggestion: Don’t doodle on paper and let someone else see it - you could be in trouble. A friend saw my doodling and sent it off to a modular building company and they liked it - thus my new home. No, they didn’t give it to us - they liked the design, built it but we had to pay for it. I sometimes wonder if they use my design, shouldn’t I get royalties or something. Fat chance.....

We have temporary custody of our three year old Great Granddaughter until the parents get their act together. She is a joy in the house. When we got her in April 2011 she didn’t talk at all. Now we can’t keep her quiet. LOL It is a good thing I never threw out all the children’s videos and toys that we had. It was a consideration when we built and moved into our retirement home but I kept them. I always knew they would come in handy some day. LOL My home decor has slipped back into early childhood and my language skills are easy to handle - potty, peepee, poopy and yucky. We also have our 16-year old

Granddaughter who we have had since she was one. She is my right hand. She helps me do some of the things that I no longer can (when she is not texting that is). She scolds me when she sees me up on a step stool and both girls head for the kitchen when they see Grandpa heading there because they know he will share good things with them. I am truly blessed in that we have a close knit family and the offers of help are always there.

It has taken me a long time and a lot of editing to write this update and apologize for it's length but nine years really is a long time even though it seemed to fly by. I still have many doctor visits to make sure things are continuing on the right path and still have to have annual MRIs. I hate MRIs. The first postop one after discharge was a horror which sent me into hysterics. Major seizure hit while in the tube but the tech was not sitting outside the window like he was supposed to. Of course, while seizing one cannot hit the emergency button. When he finally returned I was half off the table and couldn't get the basket thing off my head and all he could say was, "Mrs. Jones are we having a problem." Murder was going through my mind and ever since I have major anxieties about having this test done. Logically I have tried to psych myself into being calm but for some reason I cannot. I have told myself this is a stupid reaction, it is a noninvasive procedure, I am an adult and this is childish behavior but so far nothing works and I have to admit that the anxieties make me a person not fit to be around. I can only hope that some of my experiences can help the reader and give them insight as to "there really is light at the end of the tunnel." Best wishes to all who get it.

Joyce J in NY

Frontal olfactory groove extending into anterior skull base, parietal and sphenoid wing & temporal areas, completely resected 3/2002 but left with neurological deficits.

12/04: Hyperintense Enhancement

9/05: 2mm Enhancement.

9/06-present: W&W