…and then it rained

The personal story of the effects of frontal lobe stroke on patient and caregiver

By Olivia Ferrell

DEDICATED to all those who helped keep me sane during this journey. The Posse whom were there at the beginning, especially Marlene who called me every morning for more than a year to make sure I was okay. To Marti and the Dancing Mule. The Coffee Group whom I still meet for breakfast on Monday, Wednesday, and Friday at Steak & Shake at straight up 8:00 o'clock! All good Christian friends who prayed for me, worried for and with me, made me laugh, took me out of the stress of caregiver. Were/are ready to do whatever I need: Liz (Mel who has left us), Sherry and Don, Bonnie and Bob, Margaret (Jerry who has left us), Valerie and Jim. To Jim Brown who took Tom to the movies, fishing, Bass Pro, etc., every Monday so I had a break. To Peggy, also my neighbor, whom I met at the apartment dumpster (yes, the dumpster), who 'adopted' me, especially when I was diagnosed with cancer, Karma and George who step in when needed. The staff who overlooked much but always made Tom feel special…let us bring in birthday cake. And other customers of Steak whom I also count as God's blessings.

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Forward

I have a framed saying a friend gave me: Life isn't about waiting for the storm to pass; it's about learning to dance in the rain. Nothing was truer than in the days after my husband suffered a significant stroke affecting the frontal lobe. I had no idea how this would impact our lives from that day forward. If I had known, I would have been better prepared to make important decisions. My hope is that our experience might be helpful to someone else finding themselves in the same situation.

Chapter One

And in this moment, like a swift intake of breath,
the rain came.

-Truman Capote

The rain came into our lives in the afternoon of early November. From the moment our youngest daughter found her father on the bedroom floor our life changed. Everything we thought defined our life wouldn't any more. We just didn't know it yet.

"Mom! Dad's having a stroke!"

My breath caught. I could hardly take this in.

I was currently a legal assistant in an attorney's office in Branson, Missouri, thirty-five miles south of Springfield. The attorney heard me say, "I'm coming," and knew something was very wrong.

It was fortunate that Vanessa had the day off and was home. Her father was a freelance graphic artist, working from home. He had been working on the computer but had gone to the bathroom. She became aware he hadn't returned to the studio, something she normally wouldn't have noticed, and went to check on him. She found him lying in the bedroom floor, his glasses askew (He told her they were supposed to be that way) and unable to use his left hand.

Vanessa and her boyfriend, who happened to be at the house, called 911. The ambulance service was right around the corner from our house so they were there in minutes.

While driving toward Springfield I talked to the EMT on my cell, told him Tom had had double by-pass surgery seven years before, what his medications were, and to take him to Cox South

Hospital in Springfield where they had his records. My older daughter, Rachel, called -- "What's going on?"

Rachel was a paralegal in the same law office. She had taken papers to the courthouse in Forsyth, where she and her husband lived, and the attorney had called her. In five minutes, she and her husband, Mac, were right behind me on the way to the hospital. I called the sister-of-my-heart, Marlene, and told her what was happening, knowing she would call The Posse (three other couples with whom we socialized). Two of those couples were in our Sunday school class and calls went out; prayer began immediately.

When I reached the ER at Cox, Vanessa's boyfriend put his arm around my shoulders and led me to the room where Tom was being treated.

If you have no experience with hospitals the Emergency Room can be a daunting place. Our first and only experience was when Tom suffered a heart attack in ER a week after 9/11. He was being treated for a rotator cuff problem and thought that was what was causing him pain. Though Tom had rolling pain through his chest the ER doctor didn't think he was having a heart issue because the EKG wasn't showing anything nor were blood enzyme tests and Tom was in excellent shape. He had played baseball until he was nearly fifty, rode his horse, currently went to the gym three times a week to walk and use weights, etc., then swim for a half hour. So . . . heart was not a suspect -- until he crashed. Then things got serious and in two days he'd had double bypass surgery from which he'd recovered well.

This time was very different.

The room where Tom was being treated was small and full of equipment, most of which was attached to him. He lay on a table, his face turned to his right. I was on his left. He did not respond to my touch or voice. Four to five nurses were working with him, talking to him, but he was unresponsive. They were so kind to him. His clothes were in a heap on the floor on top of his cowboy boots. I was given a large drawstring bag to put them in.

A nurse told me the neurologist on call, Dr. Rodney Quinn, had been notified and had looked at the scans they'd already taken and would be in to talk to me.

I sat on a folding chair, waiting, my purse and Tom's bag of clothes in my lap. The nurses still talked to Tom but there was little

response. Every fifteen minutes they had him attempt to lift both arms, one at a time, and each leg, which he did mechanically and with enough success for them to judge his situation.

For a suspected stroke, I learned later, the physician's exam includes assessing the airway, breathing and circulation, and the vital signs of pulse, respiration, and temperature. Symptoms involving the head, including ears, eyes, nose and throat, and extremities can produce indicators similar to stroke (one is Bell's Palsy).

Blood is drawn and a complete blood count is done, imaging procedures (CT scan, ultrasound, MRI) to help the neurologist determine the type of stroke and rule out other conditions such as infection and brain tumor. When a stroke is suspected a CT scan (computed tomography scan) is performed as soon as possible.

The CT scan produces x-ray images of the brain and is used to determine the location and extent of a hemorrhagic stroke. The CT scan usually cannot produce images showing signs of an ischemic stroke until forty-eight hours after onset, so a repeat scan may be performed.

An ultrasound uses high-frequency sound waves to produce images of blood flow through the arteries in the neck (carotid arteries) that supply blood to the brain and may be used to detect blockage. (Internet search: Stroke)

All these tests had been performed as soon as Tom arrived in ER and were repeated a few hours later to evaluate progress or degradation.

Within thirty minutes Dr. Quinn arrived and said he had looked at the tests and indicators were that Tom had suffered a stroke (he didn't say 'big stroke' but would some years later). He wanted to administer the drug tPA, often called the 'clot buster', and said Tom had agreed. I didn't know how Tom had agreed but I knew administering the drug was imperative and signed the approval for it.

The tPA (the first of many new terms I would learn) is Tissue Plasminogen Activator. A drug that can break up clots and restore blood flow and works best when administered within three hours of the event, if the stroke is one that allows such medication.

The drug was administered and we waited to see how successful it would be. Periodically the nurses told Tom to lift each arm and leg. There seemed some improvement as time passed.

While we waited to see the effect of the tPA, I stepped out to see Vanessa, Michael and her girls, Rachel and Mac to tell them what was happening. I was surprised to see two small waiting rooms already filled with friends. It hadn't even been an hour since I received Vanessa's call. More people had been called and were praying. At a time like this you need family, friends, and a whole lot of prayer.

It was determined that Tom had suffered an ischemic stroke. Ischemia is due to interruption of the blood supply to the brain due to a clot.

We learned, to my surprise, that the left side of Tom's heart was only functioning at about 29% when he entered ER. He saw his cardiologist once a year and always felt well so this decrease in function seemed to come out of nowhere. The decrease had allowed a clot to form and a piece of that clot broke off, traveled and caused a stroke on the right side of his brain. The placement of the blockage caused frontal lobe damage.

We would learn later what this meant.

About four hours after arrival in ER Tom was moved to NICU – Neuro-Intensive Care Unit. Since it was already nearly seven o'clock and it would be an hour or so before I could see Tom, we all went to the cafeteria to wait for him to get settled. Our son, Bill, arrived. He'd been on his way home from work near Kimberling City when Rachel called him.

The reality of what had happened had yet to sink in.

I read once that it takes only one trillionth of one trillionth of a second to change *everything*. Until this day I hadn't realized how true that is. None of us had any idea what Tom's stroke would mean to our lives.

Chapter Two

Change is the only constant.
-Anonymous

Vanessa and her two daughters, Olivia (Livy) who was eleven, and Trinity who was five, were living with us at the time. It was a God-thing that it was Vanessa's day off and she was home and Michael was there when Tom had his stroke. I wouldn't have been home until after six that evening and the delay in discovery could have resulted in even more devastating damage or death.

Our home was in a small bedroom community six miles south of Springfield. Tom had recently retired and I had retired but was working at the law firm with Rachel. The girls were in school all day and Vanessa worked three to eleven for T-Mobile in Springfield. Our ranch style home was three bedrooms, two baths, large living room, dining room and fair-sized kitchen, a bit crowded with five of us but we enjoyed having Vanessa and girls there. Our house and hearts were full. Tom especially enjoyed them, took the girls to get ice cream after school, teased them. But the stroke changed everything.

On Wednesday after I knew Tom was stabilized, I called his family. He is the oldest of six children. His mother had passed but his father, in his eighties, was still living. Tom's family is from the Bootheel section of southeast Missouri, in a small town very close to the Mississippi River. Tom's oldest sister Sheila is my other sister-of-my-heart.

I called her husband, knowing Danny would tell Sheila, their father, and siblings calmly. I would keep them updated on Tom's condition.

Tom had recently retired from Silver Dollar City, at Branson, Missouri, where he was Senior Designer for eight years. He was known in the area as a very talented graphic designer and fine artist – he worked in watercolor and acrylic and had shown his work for years. At Silver Dollar City he designed all the printed material: brochures, billboards, and art directed photography as well for all other Herschend Entertainment properties which included Whitewater and The Branson Bell in Branson, and Stone Mountain in Georgia. We had a studio at home for years, so after Tom retired, he did freelance work (computer design) for a variety of clients.

Knowing he had a project going, I called the broker who was Tom's major contact for work, and told him what had happened to Tom. Rob Presley is a fine Christian man and immediately began to pray for Tom, for us all. We were still processing what had happened, with no idea of what was next in store.

On Thursday following more tests Tom was definitely diagnosed with an embolic ischemic stroke with damage on the right side of the brain and frontal lobe. With that I expected physical damage to the left side of his body and that after time and physical therapy there would be improvement, perhaps full recovery. I was wrong.

At the time, Tom showed some left side weakness and the left side of his face and mouth were slightly drawn. He continued to look only to the right and did not respond to conversation.

In NICU Tom was already receiving therapy: conversation – making him tell where he was (he knew he was in the hospital) but he said nothing else. He had drawn inside himself. His body had suffered a shock and illness of this level makes us withdraw when we feel our body has betrayed us.

Motor skills had improved slightly from Tuesday night but reached a plateau on Thursday. The NICU staff had him get out of bed and sit in a chair, made him feed himself, chew slowly. A therapist sat with him so he wouldn't choke on food. Eating was a long process. By the time he finished breakfast it was almost time for lunch.

Another therapist made Tom use his left hand. The drawing down of the left side of his mouth seemed less significant than on Wednesday. His speech was slow but he principally said only Yes and

No. There was a vacant look in his eyes, just an *empty* look. He did not look at me or respond to my voice.

He continued to keep his head turned to the right. A therapist worked with getting him to turn his head forward and to the left. A therapist told me that Tom's vision was affected to the point that he saw only half a page and worked with him to read, to make him use his vision.

Though I was there, there was nothing I could do. I spent most of my time in the waiting room.

New medications were being administered – Coumadin and Heperin – blood thinners because the clot that caused Tom's stroke seemed to have originated in the left ventricle of his heart. The Heperin was administered by injection in the stomach and would be until the Coumadin by mouth began to work. His stomach was already bruised and tender. He was already on antidepressants that had been prescribed after his by-pass surgery. More medications would be added once his condition leveled out. I had yet to fully understand the words Traumatic Brain Damage. But that's what we were dealing with.

Almost on autopilot, I got Livy on the bus for school at seven then got Trini on a later bus at the front door before going to the hospital and spending the day in the NICU waiting room while therapists worked with Tom all day, periodically going in to see him (who seemed to not really recognize me) until going home at 3:00 to greet the girls after school.

Rachel and Mac sat with me every day. Mac was with the Taney County Sheriff's Department and the Sheriff told him to take what time he needed to be with us. Chuck and Marlene came every day after they'd fed horses and finished other chores (they lived south of Springfield). Friends came by. Knowing they were there should I need them was comforting and I knew many prayers were being lifted for us. We definitely would need them though none of us yet knew how badly.

Each night I went on Google to read what little there was, and went to the library for books that might give me some insight to what lay ahead. I learned that when a specific part of the brain is deprived of blood flow, that brain area no longer functions and it dies. The body function regulated by that particular brain area is damaged. In other

words, Tom would not be the same person and we didn't know what might remain of the person we had always known.

The initial shock of the episode had worn off somewhat but each new piece of information brought a new kind of shock. The seriousness of what had happened began to sink in. How could this have happened? What would it mean?

Chapter Three

Do not dwell in the past, do not dream of the future, concentrate the mind on the present moment.
-Buddha

I am definitely *not* a follower of Buddha but the adage fit in those days as well as in the years following. The 'present moment' was more than enough to deal with. My Christian faith told me that someone was in control at that moment and it certainly wasn't me. I began to not look toward tomorrow, just today – just what must be done *today*.

When we thought of stroke, which we really didn't since we didn't know anyone who had suffered one, we thought only of the physical affect: halting walk, difficulty using one hand or the other, perhaps slow of speech. I never thought about anything else. Ignorance is not bliss in the case of serious illness but at this point I was overloaded with what I was seeing and hearing from Dr. Quinn and the therapists working with Tom. And while this is a negative aspect, you need to know all this information so you're an informed decision maker.

Tom didn't exhibit much of the physical damage we anticipated, but he *looked* different. That vacant look in his eyes continued, a lights-on-but-nobody-home look, and he still didn't acknowledge who I was. He didn't talk. If he responded at all it was very tentative, laboriously, as if the wheels were turning slowly before even a single word response could be formed. One therapist commented that he never initiated anything and was mostly non-responsive. That was definitely concerning to me.

For five days I stayed at the hospital all day, going in to see Tom periodically as allowed, not interrupting his therapy sessions, meals, etc. He didn't miss me as he normally would because he didn't acknowledge me at all.

Strangely enough, though Tom was mostly unresponsive, one morning the nurse asked the usual questions: What is your name? Do you know where you are? And Tom said, "I'm in sick bay on the starship Enterprise and we're circling--". He loved Star Wars.

The nurse was not amused. He then relented and told her he was in the hospital. Odd that that little bit of humor had come through for just that moment. It didn't return for years afterward.

On Thursday I talked to Dr. Quinn and afterward had a bit of a meltdown. He said Tom could have another stroke and "it would be devastating". The options to hopefully prevent that happening were not great. Tom had inherited "significantly small vessels in the brain". That, along with his unanticipated heart issue set the scene for his stroke. Tom having 'small vessels' ruled out any balloon surgery to clear a clot. There could be a rupture and he would "die on the table". There was a by-pass option, Dr. Quinn said, and a medicine (pill) option to hopefully prevent another clot forming. He would confer with others and devise a treatment/prevention plan.

I appreciated Dr. Quinn's directness. I am pragmatic, a person who wants to know worst case. Then I can cope with what could happen in between or comes after.

I was told that after Tom was transferred from NICU to a room he would be there a few days then go to a rehabilitation center where therapists would work on his motor skills and balance, for perhaps two weeks. Then he would be released to go home. I didn't know what that would mean. Already he was not the Tom we all knew and that was scary. All I could do was keep things as normal as possible at home for Livy and Trinity.

There were already so many questions, so many decisions to make. I didn't know if I could continue working, whether Tom could be left alone, whether the possibility of another stroke meant I would need to be home all the time. The term Caregiver had not yet entered my vocabulary. Meanwhile, there was no determination yet of the extent of stroke damage and how much recovery time would accomplish.

In the evenings at home, after the girls had their bath and were in bed, I went on the Internet to find any information I could about stroke and frontal lobe damage from stroke (I do caution here. You can't accept as total truth what you might read on the Internet. In any event there was very little there). I went to the library to check for any books that had been written about this kind of stroke. There weren't any. Most were about brain damage from car accident, falls, etc., and one by a younger man who'd suffered physical damage and recovered very well after therapy. Physical limitations, we would learn, were the lesser of Tom's issues.

I did learn that stroke is the third leading cause of death in America and Number One cause of adult disability. It was difficult to think in terms of 'brain damage' and 'disability'. While I am a total realist, I guess part of me still thought Tom would somehow 'get over' this like he had his heart surgery though intellectually I knew that wasn't true. Maybe it was just hopeful thinking, wishing things would go back to normal. But they wouldn't.

Plus, there were the at-home issues. Previous to Tom's retirement I had always paid our bills. But since retirement he had taken over that duty and as a result I didn't know exactly where we stood on that. He paid bills on the computer but I didn't know his passwords. I went through files he kept to see what needed to be paid immediately and found some credit cards bills that hadn't been paid off as was the plan – Tom was to pay them with freelance money he made designing web sites, brochures, a magazine, etc. but he had not. I was not happy about that discovery.

But I wrote checks and made my own schedule for paying bills again and felt a little more in control, at least with this part of my life.

I read an article by unknown author: *There are moments in your life that make you and set the course of who you're going to be. Sometimes they're little, subtle moments. Sometimes they're big moments you never saw coming. No one asks for his or her life to change, but it does. It's what you do afterwards that counts. That's when you find out who you are*.

In the years that followed I definitely found a new side of myself that was defined by Tom's needs and my reaction to the changes in him and in our life.

On Friday, after an early morning visit with Tom, Dr. Quinn told me that Tom's official diagnosis as a result of the stroke included depression, neurotic with paranoia, with psychosexual disorder. Words. I had no concept what that diagnosis meant. I would within a few weeks.

The neurologist also said he was scheduling an important test for Tom. Said it was a dangerous procedure. Tom could have another stroke during the test but he felt it was necessary in order to determine what course of treatment to take. I took a deep breath.

In preparation for the test Tom couldn't have breakfast. The morning passed, noon came and went. Late afternoon and Tom still had not been taken for the test. Tom, of course, had no recognition of time passing or that he had missed two meals. I spoke with the NICU nurse just coming on schedule but she didn't know what had happened. She began checking with the neurology office and the radiation office. That took some time because on Friday afternoon few people are available who can provide information. But she finally learned that Dr. Quinn had asked another neurologist to review Tom's most recent scans and it had been decided the ordered test would not be necessary. But communication had broken down somewhere and no one told NICU that the test had been cancelled so they didn't feed him. But there was no follow-up as to why Radiation hadn't called for him..

I was livid. I told the nurse that I wanted to talk to the doctor at the earliest opportunity and made it clear how upset I was about the situation.

It was difficult to maintain calm, to hold my temper when things fell apart like the test schedule. But for me it was imperative to make my position clear, while maintaining patience. Anger would get me nowhere; it would only make me a difficult person to deal with in the view of the healthcare professionals and I wanted them on my side. Their focus was to be on the patient, not dealing with an angry spouse.

On Saturday I arrived at the hospital to find Tom had been moved into a semi-private room late the night before (no roommate). He was eating breakfast, slowly -- the nurse left me to monitor that. After he finished eating, she got him up to sit in a chair by the window

so she could change the bed. He turned right to look out the window, rocking back and forth.

Friends came and brought donuts. He ate two. Though he continued to look out the window, not at visitors or respond to conversation, he did say, “I like donut therapy” but then closed down again. Strange. He didn’t look at me or speak to me at all.

Tom’s family – sister Sheila and Danny, brother Dennis and Ann, sister Sharon and David as well as brother Randy and Connie, and their father came Saturday morning. I had spoken to Sheila daily so information could be passed on to others but they wanted to *see* their brother. I had warned them how he looked and acted so they wouldn’t be too shocked.

The family lives two-hundred-fifty miles away so it was a trip. Other visitors as well as our son and grandson came to see him but Tom just sat staring out the window, rocking back and forth. At least they saw him, saw the condition he was in so they had some frame of reference when I phoned or wrote with updates.

Chapter Four

Feed your faith and your fears will starve to death.
-Unknown

Sunday morning, on the way to church at eight, I called the hospital, the nurse's station on the fifth floor, to ask when the doctor planned to do rounds. The nurse told me the neurologist on weekend call had already been in to see Tom but she would see if he was still in the hospital and call me back. I was almost at the hospital when she called to say the doctor would return to Tom's room if I could come immediately.

I was waiting when the neurologist came into Tom's room with the RN who had a file folder of paperwork. I told the doctor what had happened Friday, how upset I was about the miscommunication. I needed to know what had happened and why there was a change of plan when I was told the scheduled test was important and necessary.

My upset was not that the test hadn't happened, if it wasn't necessary, but that no change had been communicated and no one had followed up so Tom had not been fed or had his therapy.

The doctor insisted the test had been cancelled, yadda, yadda, suggesting apparently that the problem lay in NICU. But the RN with him looked at the paperwork and quietly told him that while the test may have been cancelled verbally, according to the paperwork the order was still standing. The doctor looked at the paperwork, realized that was true, and his attitude changed immediately.

Then he scheduled a new brain scan to be taken immediately. On a Sunday! Within an hour! Apologies all around. I thanked the RN for her help. After the scan was completed the doctor took me to the computer in the nurses' station and showed me the scan of Tom's

brain, indicating exactly where the clot was situated and what that meant (what he said about the clot location would sink in later). I had made my point, no sense in belaboring it, and with concise information I felt a little easier about things.

I did a lot of praying in those early days . . . and in the days following. 1 Thessalonians 5:17 says to *Pray without ceasing*, and I did. Not a formal prayer, just a breath most times, but I clung to the faith that God knew what needed to be done.

Still not knowing exactly what frontal lobe damage meant I researched more. I started with Google then searched out books in the library that had *anything* about stroke, brain damage, or frontal lobe function.

Through initial on-line research I knew that an embolic infarction occurs when emboli formed elsewhere in the circulatory system, typically in the heart as a consequence of atrial fibrillation, or in the carotid arteries in the neck. These clots could break off, enter the cerebral circulation then lodge in and occlude brain blood vessels – block a vessel. When blood flow to any part of the brain is stopped the part that doesn't get blood flow dies.

Ischemia – not enough blood

Infarction – cells dying due to lack of blood flow by an ischemic stroke

Due to collateral circulation, within the region of brain tissue affected by ischemia (lack of blood flow) there is a spectrum of severity. Thus, part of the tissue may immediately die while other parts may only be injured and could potentially recover. Only time would reveal which.

The human brain is not only one of the most important organs in the human body; it is also the most complex. The cerebral cortex is the part of the brain that makes human beings unique. Distinctly human traits including higher thought, language, human consciousness, as well as the ability to think, reason, and imagine all originate in the cerebral cortex.

In the case of stroke, the challenge for doctors is to determine which blood vessels are causing the stroke. Dozens of blood vessels are associated with the right leg, for instance. Neurologists can guess but CT scans, MRI, ultrasound, etc., help define which vessels are causing the symptoms.

Every forty-five seconds someone in the United States experiences a stroke and four million Americans live with the effects of stroke.

Recovery can take months or years. Many people who have had a stroke never fully recover. Stroke can cause death or significant disability such as paralysis, speech difficulties, and emotional problems. Those who have had a stroke are at increased risk of having medical complications from other sources like flu. It's important to keep in touch with ALL the treating doctors, including family physician, for flu and pneumonia shots, etc.

The brain weighs just a couple of pounds yet it uses about a fifth of your body's energy – even when it seems to be idle. Solving problems and other stress, significantly increase the brain's energy consumption.

The brain gets all this energy from blood. The basics of blood energy are glucose (sugar) and oxygen. Unlike muscle tissue and other organs, brain cells don't store energy to be used if the blood doesn't provide enough. The brain can't adjust to lack of oxygen. It burns sugar so fast that without blood flow it begins to fail within thirty to sixty seconds. You can hold your breath for a minute or so without injuring your brain because your heart is still beating and there is enough oxygen and glucose to keep your brain going. When all available oxygen is pulled out of the blood you either have to take a breath or lose consciousness.

Two million brain cells die every minute during a stroke, increasing the risk of permanent brain damage or death – not that I was thinking about that at the time.

Having never been a biology or physiology student I read all I could about the human brain. I learned it is divided into four sections known as lobes. The occipital lobe, at the back portion of the brain, is associated with interpreting visual stimuli and information, including the visual cortex that receives and interprets information from the retinas of the eyes. The temporal lobe is at the bottom of the brain. This is the location of the primary auditory cortex which is important for interpreting sounds and the language we hear, associated with the formation of memories. The parietal lobe is in the middle section of the brain and is associated with processing tactile sensory information

such as pressure, touch, and pain, essential to the processing of the body's senses.

Damage to any one of these areas results in specific changes in the body and mind.

In Tom's case, the frontal lobe was affected. Frontal lobes are considered the emotional control center and home to our personality. This area is the executive center and involves motor function, problem solving, spontaneity, memory, language, initiation, judgment, impulse control, and social and sexual behavior.

Damage to the part of the brain responsible for memory, learning, and awareness results in dramatically shortened attention span, deficit in short-term memory, ability to make plans, comprehend meaning, learn new tasks or engage in complex mental activities.

Stroke survivors who develop APRAXIA (caused by a disruption of the subtle connections between thought and action) lose their ability to plan the steps involved in a complex task and to carry out the steps in proper sequence, have problems following a set of instructions.

In addition to these problems is an inability to acknowledge the reality of impairment – ANOSOGNOSIA. Stroke survivors feel fear, anxiety, frustration, anger, sadness, grief, clinical depression (that Tom had already), and a sense of hopelessness. Sleep disturbance, change in eating habits that bring sudden weight loss or gain, lethargy, social withdrawal, irritability, fatigue, self-loathing and suicidal thoughts – "If this is what my life is, I don't want it", is what I heard Tom say later on in the process of recovery.

Those with frontal lobe damage have cognitive/linguistic problems. Comments can be 'off color' and humor can be 'inappropriate'. Stroke victims can focus on insignificant details in conversations, make tangential remarks (change direction to follow another unrelated train of thought), and display a reduced range of intonation – speak in monotone with no inflection in their voice. Speech may not necessarily reflect their mood. Flat monotonous speech does not mean they're depressed. It is simply the way they speak post stroke.

Patients with frontal lobe damage exhibit little spontaneous facial expression, speak fewer words, speak slowly, and have difficulty interpreting feedback from the environment around them.

These patients have a problem integrating and organizing information that they are presented with – no multi-tasking here. Stroke patients with frontal lobe damage tend to interpret language figuratively, cannot discriminate between direct and indirect speech. Instead they interpret the indirect speech directly, without taking context into account. Humor or sarcasm is taken literally. They can have problems grasping intended or implied meaning embedded in what is said.

So, Tom had significant frontal lobe damage and all that entailed: a diagnosis of depression, neurotic with paranoia, with psychosexual disorder, with Apraxia. Plus, there was no connection between what was on his left side and what he saw or didn't see and how his brain interpreted it.

At the time I had no idea what that meant, but in later months all those issues became a significant trigger to problems and a real test of faith.

One of the most common effects of frontal lobe damage is a dramatic change in social behavior. Sexual behavior can also be affected, introducing abnormal sexual behavior.

Though I had no idea yet how much damage Tom had suffered, the depth of it, nor the length of recovery time (if there would be 'recovery'), this information made me realize a little of the enormity of this medical issue. But I still had no way to imagine how it would affect all our lives, especially mine as a new caregiver, and our lifestyle.

Perhaps I was expecting his recovery from stroke to be somewhat like his recovery from double bypass surgery. He had come home four days after surgery and returned to work six weeks later. That wouldn't happen this time. Every piece of information I could ferret out told me this was going to be a much longer, much rougher road. I just didn't realize how long and how rough.