WHAT HAPPENED?

I went bike riding on June 30, 1992 and I wasn’t wearing a helmet. I had been looking at helmets at a bike shop in my local mall, approximately 2 miles round trip on my bike. I had just gotten back in to cycling and the helmet I purchased with my red Schwinn road bike got misplaced in my move.

The helmet I was looking at was around $100.00. It was red, white and blue. No matter the cost of a helmet, they must meet specific standards. For current information about helmets visit the Bicycle Helmet Safety Institute. My brain injury cost me much more than a helmet. I regret not purchasing a cheaper helmet until I could afford the helmet I wanted.

According to a witness, I got off my bike in the middle of an intersection, took one step and fell like I was shot. It's unclear why I lost consciousness; I may have had a seizure, although I did not have a known seizure disorder. I was under a lot of stress dealing with a difficult situation at my place of employment and I strongly believe I passed out from stress.

I had a Glasgow Coma Score of 4 at the scene (eyes opened to pain only). A CT Scan and Spinal Tap revealed a subdural hematoma and subarachnoid hemorrhage.

I learned the hard way – literally – the importance of wearing a bike helmet. The asphalt didn't give, but my head did resulting in two bleeds. It changed me and my life.

NOTE: My loss of consciousness could have happened while I was driving a vehicle, from the seat of my bike, or while standing over carpeting or my bed. I would have preferred the latter. Since, I have been thrown from my former bike (a Schwinn road bike) twice while wearing a helmet. The first time my bike tires got caught in a dilapidated railroad track while crossing them at a 90 degree angle and flipping me off to the side of my bike. My helmet hit the metal track cracking the right side of my helmet. A few months later, I went over the top of the handlebars cracking the top of my helmet. Was it a problem with my bike's fork after the railroad track incident or did my wheels get caught in something? I'll never know. I don't recall a period of time after I hit the ground.

LESSON LEARNED: *If your bike is involved in an accident, have a bicycle technician check your bicycle for damage.*

MY HOSPITALIZATION

I was in the hospital for ten days of which I have a few sporadic memories. I understand coworkers and fellow reservists came to visit and I have no recollection. I stayed with my neighbor for a few days after I was discharged from the hospital and I don’t have memories of that either. I was told I slept most of the day. I understand that period of time to be considered post-traumatic amnesia (PTA) and PTA is a major factor in determining the severity of a brain injury.

BACK TO WORK AFTER A TBI

I went back to work about 30 days after my hospitalization. I complained to my primary care physician that I was unusually tired all the time and he suggested I start back to work for four (4) hours a day initially and move up to the regular eight (8) hour day over a few weeks. For a long time, I thought the reason I was having difficulties with my memory, concentration, emotions, etc., was lack of sleep. I have since learned that fatigue is a major issue for people who've had a brain injury.

One of the first things my supervisor noticed was my inability to keep my desk organized. She asked me one day: “What happened to your desk?” Pre-injury, I was fastidious about cleaning my desk daily in preparation for the next day's work.

I was abnormally forgetful when I returned to work. I couldn't remember names of people I knew and I often forgot what I was supposed to be doing.   There were occasions when I would walk across the large building where I worked and then forget why I went there. I forgot the retirement party for my internship mentor and that stressed me greatly; I know I never would have missed that pre-injury.

My director asked if he could talk to my doctors because he was concerned about me. He told me I appeared to have many of the problems his wife had when she was first diagnosed with multiple sclerosis. I let him talk to my psychologist and she wrote in my medical records: “Colonel ‘W’ said Ms. Palmer hasn't been the same since she hit her head.” Shortly after that I was diagnosed with major depression.

Many of the people I worked with noted changes in my personality. I was told by my employer that I had to go on two weeks leave "to find the sweet, smiling Debi we used to know."

I really haven't found her, but since I started cycling with the Ride 2 Recovery Program , I have found joy in life again. Cycling has been my antidepressant.

MY INPATIENT PSYCHIATRY EXPERIENCE

When I told the psychologist I started seeing to help me cope with the stress at my job that I didn’t feel any better at the end of my leave, she suggested I voluntarily put myself in inpatient psychiatry because she could not figure out was wrong -- the medication to treat depression wasn't helping my mood or alleviating any of my cognitive difficulties nor addressing my fatigue issues.

While in the psychiatry unit, I told the inpatient psychiatrist that I didn’t remember my hospitalization. He requested my medical records. After reviewing my records, he said to me: “Why didn’t you tell me you had a subdural hematoma and subarachnoid hemorrhage?". I told him I fell and hit my head and I didn’t remember being in the hospital. How could he even begin to think I would remember the specific diagnosis I might have been told during that time? (I still didn't remember these terms after my hospitalization, so I ordered my medical records to learn them.) I have no recollection of any doctor up to this point telling me I'd had a head injury. In the early to mid 90's they referred to an injury to the head as a concussion, or open (penetrating injury to the head) or closed head injury (blow or jolt to the head). Today a head injury is usually referred to as a traumatic brain injury (TBI).

The inpatient psychiatrist then ordered neuropsychological testing. I learned later the neuropsychologist who tested me recommended I not return to work but if I had to work I should go back part-time. The inpatient psychiatrist let me convince him that I could go participate in my reserve unit's annual training provided I would come back if there was a problem. I thought, yeah, right. I told him exactly what he wanted to hear to get what I wanted. And, I wanted to go on training with my reserve unit. I missed training with my unit the previous year because I was in the hospital.

BACK AT WORK AGAIN

I was informed by the people I was training with that something was wrong and I should talk to my doctors. Doctors need to be educated on the fact that patients who've had a brain injury don’t have the best judgment and some decisions – like this – should be left to the doctor's discretion, especially if they're not willing to share the potential repercussions based on classic brain injury symptoms, including memory and concentration, behavioral and personality changes, fatigue, etc., if someone goes back to work. These deficits can affect a person's contribution to the work place and that affects an employer's productivity. People who have had a brain injury are not good decision makers especially if they really want to go back to work.

I had been working a full-time job and also working at my reserve unit many more hours than the obligatory one weekend a month. Later my neurologist sent me to another neuropsychologist who verbally told me I never should have been sent back to work (but he didn't include that in his written report). In retrospect, I don’t believe the neurologist trusted the results of the “outside” neuropsychologist. This neurologist should have initiated neuropsychogical testing and sessions with an occupational therapist and/or speech pathologist at the first sign I was exhibiting cognitive dysfunction and not after I lost my job.

I worked for about a year. I continued to have issues with fatigue and organization. I got angry easily, and one time I was accused of being threatening and told to go home. I was ultimately fired and later retired on disability about a year and one-half after my brain injury.

MY EXPERIENCE WITH THE MEDICAL COMMUNITY

After losing my job, the psychologist who diagnosed me with major depression provided me with information from Family Caregiver Alliance (FCA) about brain injury support groups. A little too late to save my careers or moreover my reputation -- I believe. I contacted the person who founded the East Bay Brain Injury (EBBI) Support Group and my journey to recovery began. Learning that I wasn't alone and receiving some validation about the realities of having a brain injury was very helpful to me in coming to terms with my disability.

The neurologist I saw after my brain injury failed me in several areas. When I complained of fatigue, he ordered a sleep apnea test, which was negative. Although an EEG done at the time of my hospitalization revealed a possible seizure disorder, I was never referred to the Epilepsy Foundation or any other agency for assistance in understanding this disability. The neurologist never asked me if I had ever hit my head before. (I had been in an auto accident at the age of

21 and I hit my head on the windshield.) The neurologist frequently compared his forgetfulness to my memory issues. He waited until after my inpatient psychiatric admission to pursue neuropsychological testing.

When I asked him why he had waited, he told me "I just wanted to see how much you could take." To this day, I still can't believe a neurologist who specializes in the nervous system said that to me. The brain is often referred to as the central processing unit of the nervous system and controls every function of the body. I never went back to see that doctor again. I immediately went off the seizure medications he had me on too. I believe he had me on them for his protection only and not for my best interest.

A neuropsychologist that I started seeing later outside my medical provider told me after hearing my story: “You were neglected medically.”

I realize now that there were many symptoms of brain injury that my doctors, especially my neurologist missed. My employer and coworkers noted significant signs of difficulty with executive and cognitive functioning and a change in my personality, but I had to admit myself into an inpatient psychiatric unit to receive neuropsychological testing.

Manageable depression turned into major depression after the brain injury and my doctors’ lack of a proper diagnosis exacerbated the condition.

I lost both of my careers (civilian and military) but most of all I lost my self-respect. My careers were my life; my losses were profound. I graduated with a BS in Business Administration with emphasis in Transportation. In September of 1989 my dream to become a transportation management specialist for the Department of Defense was realized.

I began an internship at Military Traffic Management Command at Oakland Army Base and graduated from the program two years later. After graduation, I was hired as a permanent employee. After the brain injury I lost my civilian job because my employer and I were never informed I had a TBI and there were changes in my personality and my cognitive function. My inability to deal with a pre-injury issue due to the deficits of the TBI made me appear extremely angry and I was perceived by my employer to be dangerous. To this day, I still don’t know what I said or did but I do know my lawyer nor my medical provider did anything to help me.

I was also a reservist in the 319th Transportation Brigade at Oakland Army Base. I can't imagine the liability I would have been to this country had I been mobilized with a brain injury. Shortly after losing my civilian job I put myself in the Individual Ready Reserve (IRR) hoping that things would get better but a few years later, I resigned my commission. Resigning my commission was very painful, but the best thing I could do for my country. If mobilized in the event of a war, I could not afford to forget to order food or bullets for the troops, get lost in a convoy or walk away from my weapon. My memory is faultier than the average person and since the brain injury stress really exacerbates my cognitive deficits.

This experience has affected my ability to trust doctors. Doctors need to recognize symptoms of brain injury and make appropriate referrals to specialists and agencies for continued support. Doctors need to learn how a brain injury can affect a person's ability to cope with a preexisting condition. Doctors also need to communicate with each other and their patients.

WHY THE BIC?

The Brain Injury Connection (BIC) was founded because of the stories I heard from my brain injury support group peers and my own personal experience after a traumatic brain injury (TBI). My experience with the neurologist I saw after I hit my head; the outpatient psychologist I had two visits with prior to my brain injury to help me cope with a stressful job situation; and the outpatient psychiatrist who medicated me for major depression were not only not helpful but made things worse.

I am committed to do something to help educate about brain injury and help those affected by brain injury. It’s apparent to me that many primary care physicians, psychiatrists, psychologists, and social workers don’t understand the long term sequelae of brain injury. I am still angry about what happened because of the Neurologist's incompetence, insensitivity, and ignorance who was on call the day I was transferred from the Trauma Center at my HMO. My goal is to turn that anger in to something constructive and work to build the BIC organization to ensure that what happened to me doesn't happen to others.

Read my vision to learn more about how I’d like to see the BIC serve the acquired brain injury community.

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