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### The Invisible Brain Injury Crisis

Michael E. Rosenthal

*Cuny Graduate School of Journalism*

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# The Invisible Brain Injury Crisis

When I was accepted to the CUNY Graduate School of Journalism, now the Craig Newmark Graduate School of Journalism at CUNY, I gave no thought to what my capstone project would be. I didn't know what to expect about the whole experience, really, but nothing could have prepared me for what I was about to go through after one night in November of 2017, during my first semester.

On that evening, I became one of millions of Americans who suffer a traumatic brain injury in a given year after the front part of my bicycle came apart on me. I fell to the ground, and the awkward and violent way my body twisted and jerked around must have knocked my brain around my head and also caused my nerves and spinal cord to stretch and twist and go through all sorts of other nasty changes and insults. According to the Center for Disease Control and Prevention's 2013 data, over 282,000 hospitalizations and 2.5 million emergency department visits were at least in part attributable to TBI. In the same year, about 56,000 people died.

Emergency departments in 2012 treated about 329,290 kids under 20 for TBI following an injury taking place during physical activity. I was one of those kids in June of 2007 when I experienced my first TBI, one that knocked me out so badly that I was unconscious for about 30 seconds and don't remember most of the day. I had post-traumatic amnesia. My sophomore high school gym class was competitive, and coming into the final class of the year, I knew the speedball game would be aggressive. I had no idea that my legs would get taken out from under me, leading to the back of my head slamming into the basketball court, as someone was falling on me. Keep in mind that most of these details come from what other people told me. I have absolutely no recollection of anything that happened in that gym, other than maybe getting pumped up at the start of the game.

While being walked to the nurse's office, a friend asked me basic questions, including who the president was, and I apparently almost said Bill Clinton, in 2007. I also thought it was May and that a couple of events like my sister's birthday party hadn't happened yet, and it took me most of the day to start to remember that I went to those events and it was the first weekend of June. My mom was in the ambulance with me and said I would keep repeating the same exact things, word for word, every few seconds. I kept going back and forth as to what game we were playing in gym class. I simply couldn't even remember.

Shortly after the initial trauma, which is known as the primary injury, medical attention is especially important because of potential complications. The primary injury can cause the brain and neurons to become damaged, twisted, or stretched. Neuronal networks and pathways can

become disrupted and altered. The healing process can take time, but more complications can arise because the brain won't heal back into the exact same condition it used to be.

In general, blood flow can become restricted and blood pressure can drop abnormally low. In the brain, tissue may not get enough oxygen. Swelling and changes to blood flow and internal pressure in the brain can also happen. Sometimes people even start having seizures. The worst-case scenario is death, which can happen from a situation that leads to brain hemorrhaging or from second impact syndrome.

Before I could be released from the hospital after my severe concussion in 2007, I needed to answer some very basic neurological questions. I'd been through one hell of an experience the day before, but it was scary how easy these questions were, like how many ears do you have and are your eyes above or below your nose? As bad as I had it, some people suffer so much trauma that they can't answer those questions correctly.

For many people, the problems are just beginning, even though they can leave the hospital and appear fine. According to the National Institute of Health, about 10 percent of people who had a concussion also had postconcussion syndrome follow. About half of those who developed postconcussion syndrome had symptoms for up to three months.

I felt mostly normal when I went home after my 2007 hospital visit, but it was soon clear that my head could cloud up easily. After the weekend, I attended class, where we were reviewing material for final exams. I would recognize what was on the board, I knew I had the ability to handle the material, but I just couldn't do it. I would feel nauseated and unable to think with any clarity. I wound up being excused from finals, and as great as that sounds, I really was incapable of taking those exams and needed the rest.

TBIs can cause cognitive slowing for weeks or months after the primary injury. Multitasking, complex tasks, and quick thinking are particularly difficult. Focusing on someone speaking can be challenging and sometimes nauseating, and it's easy to completely lose a train of thought mid-conversation. Other types of memory and focus can be affected too, like forgetting to take medicine or pay bills.

Other long-term symptoms can develop after a week since the primary injury. These secondary injuries that develop as the brain tries to heal can vary depending on the severity of the injury, a person's prior brain injury history, and how the person was treated following the initial brain trauma. About 20 percent of traumatic brain injury victims will start to have posttraumatic seizures at least a week after the primary injury. Pre-existing medical ailments like alcoholism make posttraumatic seizures more likely, and in this specific example, alcoholism could make brain injury and repeated brain injury more likely. These seizures can also occur within a week after the traumatic brain injury and are known as early seizures.

Deep vein thrombosis can happen in up to 54 percent of victims, and this secondary injury is a good example of why medical attention is so important for traumatic brain injuries. Deep vein thrombosis carries the risk of creating pulmonary embolism complications, which is when one of the arteries in a heart becomes blocked. One serious cause of a headache could be from the pressure created from too much cerebrospinal fluid building up inside the head, known as hydrocephalus. This fluid protects your brain and spinal cord while also serving other functions like cleaning up waste. Hydrocephalus can come in the form of communicating and non-communicating. Communicating, which is when the spinal fluid isn't reabsorbed properly, happens more in traumatic brain injury victims.

Chronic brain conditions become more likely after brain injury. People suffering from a TBI are more likely to eventually wind up with conditions like chronic traumatic encephalopathy, Parkinson's, and Alzheimer's. Some of the post concussion symptoms can become chronic, like dizziness, sensitivity to light, and speech.

Mental health can become a big concern too because of how debilitating and life-changing a TBI can be. If someone suffers through symptoms chronically, then there's an obvious reason for that person's mental health to struggle and for the situation to be emotionally difficult for those around that person. A person can heal up and feel pretty functional again but still suffer mental health problems though.

Months of postconcussion symptoms can be very isolating, and it feels even more isolating when people can't relate to what you're going through at all and you can't do the things you love. You can't even get out of bed. It's hard to snap right back into normal life again, and for some people, this problem can develop into a more chronic depression. Suicide is even more likely in people who experienced TBIs.

It was now December of 2017, and it was becoming very clear that something was very wrong. My thinking was that it took only a couple of weeks to recover from a severe concussion, so there was no way that I could still be feeling the effects from a bike crash that didn't even knock me unconscious. I was desperately doing everything I could to finish my schoolwork on time. I didn't know the full extent of my injuries and didn't think I had a valid excuse to hand in work late. I was so thrilled to have this chance to go to graduate school for journalism, smack in the middle of Manhattan, and now all of a sudden I was faced with the prospect of failing out in the first semester because of this freak incident. Needless to say, I was very depressed.

The depression was compounded by the loneliness that comes with this injury. I was mostly in my own, miserable world. I would spend as much time as I could in bed, alone, in the dark. I would need that time to myself, but it would eventually affect my mental health. When I was awake, all I could think about were my impossible-to-ignore ailments and this constant nightmare of trying to survive the first semester. Almost everything agitated me, and I would have what I called painful impatience. A trip to school provides a good example of how fairly

mundane annoyances could become the worst things in the world.

I would wait for the elevator to go down to the lobby from my mom's apartment, especially because climbing and descending especially made my head hurt. The elevators would take longer than usual, and a rage would start building inside me that's making me go light-headed and feel like passing out, just from thinking about it. If someone was on the elevator with me, I felt fury at that person. Does it make any sense? No, of course not, but that's just how it goes. I'd step outside into an overwhelming atmosphere of noise and light, disorienting and nauseating me at the same time that I'm trying to get to class. I get down to the subway platform and just miss a train, for a third time in a row that week, and I throw my gloves and start screaming. At that point, I could only hope that the elevator ride at school goes smoothly.

The above scenario details some of the symptoms someone can have following a traumatic brain injury and how they may play out in real life, but what shouldn't be missed is how these problems all build up a wall around the victim, brick by brick, making him or her feel more and more isolated from society and peers. Sometimes the isolation comes in the form of getting extra tired and needing to spend multiple days pinned down in bed. I had stretches of time when I would get up every few hours just to go to the bathroom and then would go right back to sleep. I would otherwise spend about 10 minutes out of my bed just to go to the corner store to get some food to bring upstairs. Sometimes I just wouldn't even eat or drink much because I would be too busy sleeping.

I would have to find a way to keep up with reality though because the rest of the world wasn't slowing down for me. At school and out in the field, I would have to do everything I could to muster up some energy and do the job. Around family, I would need to do my best to not look completely out of it. I knew things were starting to get bad but didn't want to freak out everyone. Sometimes I couldn't help it, like when I went to my grandma's house and slept about 20 hours of the day for an entire week. As I laid there, I could feel the anxiety grow from knowing my parents were asking about me and my grandma would have to tell them that I've been passed out on the ground for hours and hours.

I eventually went to a hospital, I got doctor referrals, and starting to see a neuropsychologist gave me hope and a gameplan. My delaying of seeking treatment and the strain it put on my family and friends isn't all too uncommon. Greg Ayotte has been working with Brain Injury Association of America for 12 years and responds to requests that come in from people or caregivers dealing with traumatic brain injuries. He said that a big problem is how there's a general lack of understanding of how brain injuries work and what treatment options are out there. Ayotte said victims may go to the hospital and hear "oh, you're okay, you're fine, you can go home," but just because there aren't any life-threatening complications doesn't mean that the victim won't need to seek further treatment.

Hospitals could give patients a list of resources, including the Brain Injury Association of

America, so that victims and their loved ones have multiple pathways to continued recovery. After being directed to the Brain Injury Association of America, someone like Ayotte can walk victims and caregivers through the basics and the options to consider.

“You’re trying to learn brain injury on the fly, learn who the different professionals are and what they do and what might be covered by insurance, Ayotte said.” Ayotte can even set up people with local support groups when he can’t find medical resources where they live.

Ayotte added that another benefit that comes with early treatment is that people can mentally prepare themselves for what’s to come by setting proper expectations while moving forward. I didn’t seek treatment because every day, I said I would get better any day now, and then all of a sudden, those days add up into two months. It was really hard to hear that I could be dealing with this problem for at least a few months, but in the long run, that knowledge made a huge difference in how I was able to approach and continue to approach my recovery.

“The timetable for recovery is a lot longer than I think most people realize,” Ayotte said. Even when people have more realistic expectations, there’s still no definitive timetable. Once I started grasping how serious my injury was, I kept assuming my symptoms would last for as long as the maximum times I kept hearing from doctors and other sources.

When a colleague said she knew a cheerleader who had problems for over a year after a traumatic brain injury, I set my expectations to match that story. The doctors said my symptoms would last about three-to-six months, and sure enough, I started feeling more normal and returning to more regular activities almost seven months later. I still wake up every day assuming I won’t fully feel better until at least two years after the crash.

Questions about secondary injuries are “another common call we get” at the Brain Injury Association of America, according to Ayotte. Secondary injuries and the development of postconcussion syndrome are the result of complex processes that happen as the brain tries healing from the trauma. While he can point people in the right direction and give them the information they need, he said it’s difficult to know “what will help someone understand brain injury, and that can be frustrating and challenging.”

These are often invisible injuries, and when they take a while to heal, it’s hard for some people to understand that the healing is far from over. “If you’re around, and you’re walking and talking, most people think you’re fine,” Ayotte said. ““Oh, you’re better now.”” Even for the person who’s recovering, Ayotte’s heard he or she ask “why am I not better, why am I not better?” He said that one of his biggest challenges is getting people to wrap their heads around the situation and what to expect.

I couldn’t believe it when I found out the weekend before the second semester started that I passed all my classes. I don’t know how I was able to get almost all of my work done by the end

of the first semester. I would still struggle so much that it took me all of winter break to muster up the energy to finish my final stories, which would normally have only taken an afternoon. At my worst, I would need to sleep about 20 hours a day for an entire week before feeling well enough to attempt working, and I by no means felt great at all.

But the first semester was in the books, and that couldn't be taken away from me. There was certainly cause to celebrate, but I knew in my heart that I hadn't the slightest clue how I'd make it through the next semester in my current condition. There was a surrealness, almost a sense of celebration, when I returned and saw my colleagues again while getting acquainted with my second-semester coursework and professors. I made it to classes but still didn't know how I would get the work done. I went to the Catskills after the first week of class for fresh air and quiet so I could rest and work. Like all of the other times I went on these trips, I would rarely finish much work. I'd spend the majority of the time sleeping.

On the week approaching presidents day weekend, my class went to City Hall. I'd normally be thrilled and looking to do some reporting, but a few minutes into my time at City Hall, everything started falling apart. I didn't even make it to the steps before I started feeling really nauseated and as if I was in my own world. I got through the rest of the day, but I wound up in bed that weekend. I did force myself out to cover an event and grab photos, which was very difficult to do but really paid off later. After those efforts, I crashed and did virtually no work for the next bunch of weeks. I intended to start doing work but just couldn't do it. Just making it to class was enough of a challenge. Sleeping all other times was the only thing that made sense. I didn't know if or how I should try pushing through and doing work or getting light exercise. I was starting to feel very isolated and out of it during classes too. I started feeling more and more uncomfortable as I felt further removed from my peers. I lost a lot of confidence in myself. I would occasionally try participating and wouldn't be understood because I was so exhausted that I would either slur my words or otherwise sound unintelligible.

At the end of March, as I continued hanging on for dear life, the school wanted me to take a medical withdrawal, which would require sitting out until next winter. I had no intentions of going this route. It sounded as if I had no choice, but I was able to decide to try catching up and using the accommodations that the Americans with Disabilities Act allow for assistance. No matter what, I would still have to somehow do an entire semester's worth of work, starting at spring break instead of the end of January. But how? That's where my neuropsychologist enters the story and helps me completely turn around my situation.

I saw her right before being notified of my option to take a medical withdrawal, and in just that first session, I came out with a game plan and a fighting chance. She taught me how to stay relaxed, how to pace, and other little tricks that gave me every bit of help I could possibly get. Before meeting her, all I knew to do was sleep, because that's what my body was screaming to do. I would almost recoil in fear and confine myself to bed. Now it was time to try grabbing the

reins and taking some control over the situation.

Ayotte said my story sounded very familiar because having healthcare access is especially problematic with this injury. Like other complicated and serious injuries, proper healing can require a lot of devoted time and money for finding out which doctors you need to see, seeing the doctors, and keeping up with medication and medical tests. Mental health treatment is too important as well, and not only is there a stigma around mental health, but it's difficult to even find a psychologist who specializes in brain injuries, like my doctor, who used to be a neurosurgeon and does research. "You can get access to mental health services," Ayotte said, adding though "the problem is that mental health providers don't know anything about brain injuries."

Organizations pick up most of the slack with advancing research and providing resources for recovering victims. "Brain injury is kind of late to the party," Ayotte said about the attention and research dollars paid to traumatic brain injury. Constance Miller from the Brain Injury Resource Center, stresses the strides that the medical community has made since her injury a few decades ago.

Medical understanding traumatic brain injury has even changed since just a decade ago. She said there was basically no information available after her injury. "There just wasn't any, anywhere. Researchers, nobody was paying attention to it. Hospitals, medical providers, most of them were operating under old assumptions about brain injury."

Today's protocols are still geared mostly towards treating the initial trauma, but that leaves people "stumbling and bumbling in the dark" about what to do beyond the basic advice the doctors recommend for taking things slowly and gradually getting back to full speed, according to Miller.

"The other part of that statement should have to do with [keeping] track of your symptoms and if they get worse see your doctor," Miller said. "If they get better, steadily and symptoms disappear completely, you're probably out of the woods." She said that this course of action still doesn't always help people who have symptoms for longer than three months, clinically speaking, but private practices can take a different approach. Even though "treatment does not provide a cure," according to Miller, "treatment helps you get better faster. It gives you tools."

Ayotte's organization is a private nonprofit that's existed since the 1980s, and beyond the information it provides to injury victims and their loved ones, the Brain Injury Association of America helps with professional education, has a certification program, and promotes best practices. The certification program helps to educate and train any number of medical professionals, like a physical therapist, occupational therapist, or a mental health professional, to be able to specifically understand and aid people with brain injuries.

The Brain Injury Association of America also does not conduct any of its own research, and research in the field remains limited. The problem, put bluntly by Miller, is that “the squeaky wheel gets the oil.” Ailments like cancer and HIV/AIDS draw a lot of attention and funds, and people with those conditions cannot ignore the problem without likely dying. As serious as a brain injury is, the symptoms can go away on its own after time, and medical treatment isn’t necessary in the same sense that it would be for a cancer patient requiring chemotherapy or radiation treatment. “The only way you get money for a medical issue or anything else is you cause a groundswell of public demand or you just have a lot of money in contributions to lawmakers,” Miller said.

I somehow was able to turn the corner and get my work done for the second semester, even though it became one of the most stressful experiences of my life. Every day was such a struggle, and I had to catch up on so much work all at once, which made every waking moment feel like a crisis situation. Adrenaline constantly flowed through my veins, and I still have no idea how this high-stress scenario impacted and continues to impact my recovery.

My postconcussion syndrome finally started to significantly subside as the second semester ended, about seven months following my crash. During the first week of my mandatory summer internship, I was so exhausted that I had no idea how I’d get through the summer. I somehow did, but not without continued problems. As supportive as my family and friends were and continue being, I could at times still feel so isolated from them, and I could tell that they still didn’t understand the severity of my situation. Miller told me about how people have to change careers, marriages end in divorces (not the same person I married, I didn’t sign up for this, etc), which was a very upsetting thing to hear because those were and still are very real fears of mine.

Finally biking again during the summer was an important part of my recovery, especially because riding a bike is such a key part of who I am. I have a nice group of friends who also love the environment and riding bikes, and after all the support they showed me during my months of struggle, I was eager to finally ride with them and have a good time. I had already been worried enough that my updates about my brain injury were becoming too much for them to bear and could jeopardize everything.

After a few weeks of feeling fine on the bike, I started developing some more anxiety. One of my friends happened to get hit by a car door while biking, which was always one of my biggest fears. Something about her story took my anxiety to the next level. I felt such anger and anxiety on the bike at times that I felt like I was going to pass out from a headache. These emotional problems spilled into my daily life, and I worried that my frantic behavior would be off putting to my friends. During a group ride to the beach, I even stayed away from my friend, who was still injured from the car door crash, because my anxiety and stress were getting so bad that I knew there was a chance I would say something really mean and regrettable.

These are ongoing problems that are difficult to discuss with friends because of the stigma

around mental health. I'm not afraid to speak about my mental health but don't want to suck up all of the air out of the room, so I would find myself conflicted and not knowing how to talk about my feelings and problems. I would have been completely on my own without my neuropsychologist.

Somehow, by some way, I made it through the third and final semester. I came in feeling anxious and depressed. I associated the campus so closely to the feelings of being on constant red alert. When I walked into the newsroom on my first day of classes, I felt such a rush of anxiety that I ran upstairs and went right to one of the soundproof booths so I could have peace, quiet, and isolation. During the middle of the semester, I hit another roadblock with some illnesses. I still to this day am dealing with exhaustion and immune system issues. At least my situation wasn't anywhere near as extreme as it was in the prior two semesters, and my confidence and class participation was slowly coming back piece by piece.

As I started to get ready for the end of school and entry into the real world, I needed to start thinking about how my brain injury, and the topic in general, intersected with real life. For one thing, getting and maintaining a job would be a challenge, considering that getting through even a single week can seem impossible. As a member of the media who has personal experience with brain trauma from physical activity, I wanted to make sure I knew how to best approach talking and writing about these issues.

Brandon Boyd, the programs manager at the Concussion Legacy Foundation and the manager for the foundation's media project, studies how to best communicate brain injury messaging through the media. His foundation works to make sure sports writers are knowledgeable about brain injuries and that the science becomes a part of the sports conversation, in the same way that analysis of a game would be a part of the conversation. "When in doubt, sit them out," Boyd said about athletes who may have suffered brain injury during action. This type of protocol has made its way into leagues and is something which advocates have pushed for, but Boyd believes the media has a responsibility to elevate the discussion.

Segments on sports shows or sports columns in newspapers could focus on a league's concussion protocol and any recent times it was used, or not used when it should have been used. "When fans are watching or reading about sports, they're learning by proxy because the announcers and broadcasters and those involved in sports media are more educated themselves," Boyd said. Reporters should also come into press conferences and interviews ready to ask detailed medical questions instead of asking only about X's and O's. "When that happens, then you have people learning by proxy, as we know, people aren't getting the concussion knowledge through conventional channels, so the media project is one of our ways that we're hoping to really fill in those gaps of education," Boyd said.

During games, the announcers need to understand the protocols and science so that they can walk viewers through the protocols when a player is being evaluated, and the announcers would also be able to call out the league for not properly following protocol. Boyd said that "then you

can very easily tell your audience that that's what's supposed to happen and whether that is or is not happening so that the audience at home learns that there is a standard of medical care that we hold these professional or college athletes to so that maybe they now know what a reasonable standard would be for them in their own competition."

While it may not sound like much to ask for when Boyd recommends that media have the right knowledge and vocabulary surrounding brain injuries and league protocols, the reality gets dicey when money comes into the equation. Even though the Concussion Legacy Foundation's media project has good intentions, former National Hockey League Daniel Carcillo thinks these ideas are great but naive, akin to "throwing a penny into a fountain and making that wish." Because the league is big business, outlets like NHL Network and NBC Sports are disincentivized from ever discussing brain injuries, which could put the league in a bad light.

Carcillo played for multiple teams over his career that got him two Stanley Cup championships as a Chicago Blackhawks. Now, his former teams like the Blackhawks, won't help him with his medical bills. Carcillo had to quit the game after his seventh concussion and has been living with symptoms related to his brain injury ever since.

With three young kids and a wife in his life, he needed to do something to get his life back on track, even though his brain will never fully and properly heal. He still loves the game and the way it's trending, and he spends most of his time advocating for brain injury awareness through Twitter and his Chapter 5 Foundation. He always carries his dead friend, former hockey player Steve Montador, close to his heart. Montador died at the age of 35, and doctors found that he had chronic traumatic encephalopathy, a degenerative brain disease that started garnering attention when Dr. Bennet Omalu discovered the condition in a number of brains belonging to former National Football League athletes. A review study done by the Journal of Neuropathology And Experimental Neurology found that athletes with repeated head trauma developed chronic traumatic encephalopathy in 17 percent of cases.

The condition can only be formally diagnosed after death, and those living with it will start to exhibit patterns of deterioration that would be similar to a dementia patient. CTE will make a younger brain, like Montador's, look similar to a geriatric dementia patient. Carcillo has talked about the noticeable decline in Montador's mental capacities before his death.

Even though CTE and brain injuries didn't start getting much attention until a few years ago, Carcillo pointed out that decades of research show that the evidence has existed for quite some time. Back in 1949, a British neurologist named Macdonald Critchley published a paper called "Punch-drunk syndromes: the chronic traumatic encephalopathy of boxers."

Carcillo feels that the league didn't warn him about any of the risks associated with playing hockey and how that could impact his brain. He fought a lot during games, something which he saw as an incentive in the NHL because it was another way to get noticed and keep getting paid. The sports leagues acted more like the tobacco and fossil fuel companies by denying the

science and casting doubt, most notably the NFL. “Everyone walks on eggshells around the NFL,” legendary sportscaster Bob Costas said in a recent interview.

Costas comes closest to what the Concussion Legacy Foundation has in mind when it wants sportscasters to report on more than just the action. He’s used live segments during major sporting events to talk about controversial issues like gun control. He said that his comments about concussions lost him the chance to host the most recent Super Bowl, alleging retaliation by NBC. The allegation bolsters Carcillo’s argument that the media carrying sporting events have a vested interest in not making the leagues look bad. When ESPN’s investigative news show “Outside the Lines” and PBS “Frontline” teamed up on a documentary based on the book “League of Denial” in 2014, ESPN backed out shortly before the release of the film because of pressure from the NFL, according to the New York Times.

As an athlete and sports fan myself, it’s helpful and meaningful to see someone like Carcillo go through hell and work so hard to make sure other people don’t have to suffer too. Hearing a voice saying that it’s okay to feel sad, or that I’m not going crazy when I feel like I’m constantly tired, helps me not feel so helpless and alone. People like Carcillo and everyone else who’s helped me with my story and with my recovery have really impacted my life and helped me get through the day-to-day grind. As I continue recovering and try to eventually move on and live my life to the fullest again, I need to adjust my thinking in order to protect myself, protect those for whom I care personally, and protect others with the power of my pen. There’s no way I would be where I am now without the unending support of my family who suffered through every moment with me.

My future is uncertain, and I still don’t really know why I’m having the lingering problems that I’m having. Every time I get back on a bike, or every time I go to bed at night and think about riding, I have to think about when my next crash could happen. I worry that I’ll injure my brain again and have to go through horrible postconcussion experiences again. It’s very upsetting to even think back to those times. They seem dark, but I keep my focus on how much progress I’ve made and hope to make. That and heal from the neverending love and support from my family. One day at a time.