

# CRASHING THROUGH WALLS

*A Memoir of One Family's Life  
After Traumatic Brain Injury*

***Janis Ruoff, Ph.D.***

***With Contributions by Jeff Bouck, TBI Survivor***

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Author's Disclaimer Note: This book is based on actual events,  
but dates may not be accurate. Some of the characters in the story  
have fictitious names and some don't, and I have eliminated or  
altered details in some cases to protect the person's identity.

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*Dedicated to  
the Forgotten Survivors  
of Traumatic Brain Injury:  
The Families*



I wish this book could be available to all families after the initial shock of suffering a TBI wears off. I have felt every one of the emotions Janis so eloquently expressed in her book. Families are the “forgotten ones” when a loved one suffers a TBI. They need to see that there is hope and support even though the struggle ahead of them seems overwhelming. Thank you, Janis, for bringing families into the discussion of life after a TBI.

Kim Callahan, Johnstown, CO

No one can predict how the lives of the family of a TBI survivor will forever be changed. In telling her story, Dr. Ruoff has shared her experiences before and after her son, Jeff's, TBI. Dr. Ruoff's heartbreak led her to find the strength and resolve to cope, and to flourish professionally and personally in a way she could never have imagined prior to Jeff's accident. Jeff provides powerful insights throughout the book about the awakening mind of a TBI survivor. This book should be recommended reading for every family experiencing the pain of living with a loved one with traumatic brain injury. The military should hand them out to all TBI survivors' families!

Betsy Cromwell, Alexandria, VA



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# ***Introduction***

*“General Secretary Gorbachev, if you seek peace,  
if you seek prosperity for the Soviet Union and  
Eastern Europe, if you seek liberalization: Come  
here to this gate! Mr. Gorbachev, open this gate!  
Mr. Gorbachev, tear down this wall!”*

—President Ronald Reagan  
Brandenburg Gate West Berlin, Germany  
June 12, 1987

TIME MAGAZINE DID A SPECIAL ISSUE on the year 1989, calling it “The Year That Defined Today’s World.” Even though I don’t think they had me in mind when the editors decided to do that publication, it was the year that redefined my world. My son Jeff’s car crash in 1989, and his traumatic brain injury (TBI), changed him forever and was a catalyst for me chipping away at the walls of my life to become the person I am today, someone I never knew I could be. As I read that issue of *Time*, I was overwhelmed by the significance of that year for the world and our family. The ripple effects of Jeff’s TBI transformed our entire family just as the effects of certain events in the world changed the way nations relate to each other.

When the Berlin Wall came down in 1989, two years after Ronald Reagan’s impassioned speech in Berlin, I heard about it and reflected back to the year 1974 when my husband, Steve, was stationed in

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Frankfurt, West Germany as an Army officer. After we had lived there a year we took the kids on a trip to Berlin through East Germany on a train that only traveled at night through what was the Soviet Union's post World War II territory, stopping at one point for an inspection by East German soldiers along the way. I remembered the next day we were standing in front of the Berlin Wall on the West Berlin side, at the gate called Checkpoint Charlie, looking at the drab greyness of the East Berlin sector on the other side of the wall. I had one year old baby Travis on my hip and a three-year-old Jeff next to me holding my hand, and for the first time I saw why we needed an army as I gazed upward and met the eyes of one of the armed guards standing on the wall with submachine guns pointed directly at us. I had never experienced anything like that before and felt the presence of a powerful, dangerous government; I was sheltered from that in my naive life as an American. It gave me a new appreciation for our safer and freer way of life in the United States. Even though West Berlin was the "free" side of the city it struck me as a kind of metaphor for my life because it was surrounded by the Soviet controlled part of Germany, with the result being that the so-called free West Berlin was actually the walled in part of the city and not East Berlin on the other side of the wall. It was how I had always felt, that the free part of me was trapped in the midst of a life that I felt was oppressive and controlling.

In the seventies no one expected, if they even thought about it, that the Berlin Wall would come down and when it did, in 1989, I was too involved with our family crisis to pay much attention. Things I barely heard about in the news had far-reaching effects on our world, just as the day of February 17, 1989 would have lifelong effects on my life. But when your child is seriously injured nothing else matters and so world events were nothing but a backdrop to me, a blur of newscasts that I heard through muffled ears and saw on the television through eyes clouded by tears. We were just one small family going through our own little drama.

In the same way that I was oblivious to what was happening in Germany, I did not know anything about a genius named Tim Berners-Lee who created the beginnings of the World Wide Web in 1989. That was going to be a very real part of my life someday but at the time I did not know it. The explosion of new technology and social media has led to advancements that help all people with disabilities, but has especially added to the quality of life for so many who face social isolation due to TBI. And for me personally and professionally, the Internet has been a valuable tool for making change when I was lost and confused about direction in my life.

In 1989, the search for freedom and self-expression was a theme in my life. It was something I had valued and fought for in a myriad of ways including separating from my husband and going against the grain of how I was raised to get my advanced education and become, I hoped, a leader in the field of education and disabilities. I had just turned forty and, like many people approaching middle age, I realized I needed to work on figuring out who I was. I had always been a helper but felt that part of me was exhausted. I had always been a rebel who was perhaps too cautious to fully express that side of myself, so I did it on behalf of others.

As the world witnessed the tragic murders in China's Tiananmen Square, when ordinary people rebelled against the oppressive government and lobbied for free speech, I related to it on a personal level. I applauded their brave fight against injustices in the world. This fighting spirit was one of the pieces of my identity I felt I could be proud of, and I was thrilled later to hear that the tyranny exposed by Tiananmen Square led to other countries taking a stand against oppressive governments.

Even though I had been involved with people with disabilities my whole life, and a crusader for their rights, I was naïve in ways I did not even realize. In 1989, before Jeff's TBI, I thought I knew all about the effects of a brain injury from my years of working as a speech-language pathologist, but I was about to find out that I did

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not understand it at all. And I knew nothing of a new brain injury advocacy movement and had not yet met the leaders of the small but growing National Head Injury Foundation (NHIF) that began in Massachusetts and later moved to Washington DC.

One of the spokespersons and leaders of the NHIF was President Reagan's former Press Secretary James Brady, who would become a part of my life and someone Jeff and I would both come to know. James Brady and the traumatic brain injury he lived through when he was shot in the head during the attempted assassination on the President in 1983 was only a sad story on the television to me at the time. But ten years later, because of what happened to my son, I got the opportunity to know him as a wonderful person and amazing advocate for gun control and people with brain injuries. He always remembered me and asked "How's Jeff?" whenever I saw him, and I was honored to have him as a guest lecturer in my classes after I became a professor teaching courses on brain injury.

1989 was a time of great change around the world and was the year that we saw the Cold War, something I had grown up with, beginning to end as people of numerous countries were speaking out. People who previously were disconnected from each other began to envision a world of globalization and seamless communications among countries and states. It was a profound time and the beginning of enormous change.

But this is not a book about world history; it is about one ordinary family's history and the way that unplanned events transformed our life and pushed me to become a different person able to live without the barriers I put up around me. Like the divided city of Berlin, I had my own armed guards in my head, and I had accepted a lot of propaganda in my life that kept me walled in. I was not happy and it took completely unpredictable life circumstances for me to see that the oppressive force in my life was me.

Walls keep us trapped but they also protect us, and I was afraid. It took a lot of trauma for me to crash through mine and get to a place

of inner freedom where I could begin having a new and better life. In recent years I have come to believe that there are two kinds of people in the world; there are those who live their lives based on fear and self-doubt, and there are those who don't have fears (or if they do they just don't pay attention to them). Before 1989 I led a fear-based life, afraid of expressing myself, and that kept me from doing the things I wanted to and knew I needed to do. I believe I'm a different person now and for that I'm grateful.

I have spent twenty-seven years going back-and-forth between obsessing over 1989 and trying to forget those painful times in my life. I have told my story, our family's story, in bits and pieces to audiences when I did presentations or taught classes on brain injury, but there is so much I couldn't talk about or was afraid to. Finally, I am doing what people kept telling me to do, and what my inner voice said I needed to do, which was: write that book. This is that book, the book I have been avoiding, had sleepless nights over, the one I can't bring myself to release into a world of people I don't know and potential critics. You'll notice that I chose to tell the story of 1989 itself in the present tense, although the events themselves are long past. That's because it's a year that never fades from memory, a year imprinted on my brain as if it is all still happening. It's almost too personal to write, and yet that is what I hope will speak to someone who reads it and who might be going through a similar difficult time.

I invite readers to see our story as just one example of the millions of families affected every year by traumatic brain injury or other tragedy, and I hope that our story will promote new understanding about the effects of TBI. I also would like to think that our family's journey will help someone to believe that life can go on and even improve afterward. Because of the many veterans affected by TBI and Post Traumatic Stress Disorder (PTSD), and new publicity about sports injuries and concussion, and the terrible effects of repeated injuries to the brain, there is increased awareness of the need for research and programs to help people with brain injuries.

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But I worry that the overlooked puzzle piece—one that has always been missing in the work on the problems of TBI—is the long-lasting repercussions on the family system.

TBI is not a medical event; it is not over when the medical crisis and interventions end. A TBI brings dramatic changes in the person affected that will alter the survivor's life and that of those around the survivor, possibly forever. It is a catalyst for enormous changes, for everyone, though the results will be different for each person or family.

I would love to hear from readers about your reactions after reading what I have written. You may send me a note using the email address of: [Ruoffpubandtrng@gmail.com](mailto:Ruoffpubandtrng@gmail.com).

# Section I

*"A person often meets his destiny  
on the road he took to avoid it."*

—Jean de La Fontaine

*I don't remember much about that time but I know that on February 17, 1989 my life felt chaotic. High school would be over soon and adult life would begin. My parents were separated and I had the social crises common to late adolescence which, of course, felt like major life issues to me. All of this propelled me to crash head-on into a carpet company's van that was on delivery. Aside from the birth of my child and, of course, my own birth, no other events have had such a significant impact on my life.*

—Jeff Bouck, TBI Survivor





# ***Chapter 1***

## ***Saving Jeff***

### ***1989***

FUTURISTS, PEOPLE WHO STUDY current trends and use them to predict the future, say we each have multiple futures and I believe that is true. We start life with all sorts of possibilities, and at any moment we can change the path we are on. Which of the many possible futures we get depends on the choices we make amid unforeseen circumstances. Every time I get comfortable and think I know what my life is all about, something changes and I find out I have no control over anything.

Although I know I may sound crazy saying this, and I am not even sure it's real, I have had experiences that may indicate I have some intuitive ability to foresee future events before they happen. One time when I was pregnant, in 1971, I had a dream about my brother getting married to a woman who, so far as I knew, he had never met and I did not know. I told my mother and we laughed about it because my brother did not date much, but she said he had told her earlier that morning that he had a date with someone new the night before and he really liked her and, coincidentally, she did have the same name I told her from my dream. Two years later that person I dreamt about

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was his wife. A little over a year ago I was driving home from work about a half mile from the house, on our street, and I had to stop because I could not see. I was blinded by a sea of blood red spilling across the road and covering the windshield of my car. I arrived home shaking and terrified and I told my husband, Steve, I thought someone was going to have a horrible car accident on our street. I was afraid it would be my son Jeff, but knew I had unreasonable fears of car accidents from things that happened in my childhood. I pushed the experience to the place in my mind where I put all of my secret ideas and fears, but I still wonder what it means.

My weekdays usually begin with waiting until my two teenage sons, Jeff and Travis, are on the school bus to go to work. But sometimes I have to take them if they miss the bus and then I'm late getting from the Maryland suburbs where we live to my office at Gallaudet University in the heart of Washington DC. I am an Assistant to the Dean of the School of Education and Human Development at Gallaudet and I'm also working toward a Ph.D. although I don't know what my dissertation topic will be or if I will ever finish.

Gallaudet's a special place to me but I'm aware that my friends and family don't always understand that because I'm not Deaf and it's known as the university for Deaf people. It's a university with a heart, an ideal place for crusaders like me. I saw this right away when I first walked into the Department Chair's office to apply for the doctoral program. He had *Man from La Mancha* (Don Quixote), by Miguel de Cervantes, on his office wall, the exact same print that I have in our living room. I knew I had found what I was looking for; a place where I belonged.

And I've learned so much from my Deaf professors and friends there. It's worth the effort to learn sign language, make sacrifices to take classes and work, and spend the extra time commuting. I don't enjoy the drive some days because the traffic is so bad that even screaming ambulances can't get through. At those times I wonder:

what if someone was in there dying? People can be so indifferent to the suffering of others and I hate that part of human nature.

Last year I was involved in a big Deaf rights movement at Gallaudet called Deaf President Now, or DPN, and helped to fight for the first Deaf President of a University that should be promoting leadership of Deaf people anyway. We held rallies that were televised nationally, and we marched on the Capitol. I did my part as a hearing person by collecting linens from local linen supply companies to be used for banners, and I got the experience of listening to some of the business owners tell me their stories about marching with Dr. Martin Luther King, Jr. in the sixties. They were supportive of the efforts the Deaf community and Gallaudet were making on behalf of Deaf people everywhere. I'm proud of that and of my work at the university, and when I'm on campus I feel important. I'm part of the student leadership and President of the campus honor society, but at home my marriage is a mess and the kids pretty much ignore me unless I'm cooking for them or driving them where they want to go.

I am the only female in this family and I resent that what's important to me doesn't matter to anyone else. Sometimes Steve, Jeff, and Travis all stare at me like I'm speaking a foreign language and then go back to talking about cars or electronics or something I find boring like how to use a particular kind of tool in the garage.

I have to work at getting involved in conversations in my own home. Like when I was caught up in the emotional momentum of DPN and I called the Grease Man, a popular and controversial radio host, and told him what was going on. The Gallaudet protests were a big story on the news around the country and my Deaf friends asked me, as a hearing and speaking person, to help get the word out on the radio. The Grease Man even put me on the air and did one of his weird songs about what I said! When I told the boys at dinner that night, Travis, who was fourteen at the time, immediately went from only half paying attention to a look of teenage horror.

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“Mom, you called the Grease Man?” He glared at me and Jeff laughed. Jeff enjoys seeing Travis and I argue for some reason.

“I just hope my friends didn’t hear you!” Travis said. It was all about him of course.

I love my family but life at home has been so distressing for years that I don’t want to be there. Steve and I have been separated off and on for the past three years and sometimes I get lost in depression and frustration because I don’t know what to do; I’m not happy the way things are but I can’t seem to change it. I enjoy the weekends to catch up around the house or spend time with my kids and friends, but the future is so uncertain that much of the time I don’t really enjoy anything. I just smile and try to keep up pretenses of being happy, something I’m good at as I’m discovering. When Steve is living with me I am mad at him, when we are apart I miss him and want to work on our marriage, and at the times I am convinced we are heading for divorce all I want to do is go out and experiment with meeting other men. I feel like I’m as much of a teenager as my kids are and that I should feel guilty for how I’m acting, but the truth is I don’t feel guilty at all and that’s what I feel the most guilt about. I want to be happy and have a stable family life but it seems that it isn’t possible to have both, at least not with Steve.

On a cold Saturday afternoon Jeff and I sit at a McDonalds near our house and talk about the ironic overlap of our lives with both of us, mother and teenage son, out there in the dating scene. I think this is one of the oddest things about being a single parent of two boys and I ask him, “What if we ran into each other out somewhere?” I laugh and he looks disturbed, as if that possibility had not occurred to him before. I am enjoying this conversation.

“I just thought of something really funny,” I say. “I have a date this weekend with that guy named Jerry, who you have met, and I think he’s in his late fifties. And the other day I had a coffee date with someone else named Jason who is almost the same age as you. He wants me to go out with him sometime.”

He stares at me bug-eyed. “Wait. What? How old is this guy?”

I try not to laugh. “He’s twenty-four but when we met I thought he was about thirty, closer to my age, and he apparently thought I was just a few years older than him. Don’t worry; I don’t think I want to go out with him anymore.”

I am feeling rather cool that I look young enough to do something like that, and I like to shock my sons once in a while and remind them I’m not just their mom.

“He’s a bondsman,” I add to complete the zinger. “I’ve never dated a bondsman before!”

“Mom, you need to stay away from him,” he says in a serious, parental tone. “I mean it. I know guys like him and they’re trouble.”

“Okay, I won’t go out with him,” I say, still chuckling.

I enjoy talking to Jeff and always have. We move on from the uncomfortable topic of dating to other subjects like what’s going on at school and my new car that he wants to drive.

Jeff will be eighteen soon and I know there are parts of his life he doesn’t tell me about, but at least he talks to me. His younger brother, Travis, is a more reserved personality and not interested in hearing about my feelings or discussing his own. I know it’s his age, and that he’s had Steve for a role model, but sometimes it frustrates me because my kids are my family, the most important part of my life. I want us to have the connection I don’t have with my husband and never did.

“You just spill your feelings all over the place,” Travis told me once when I was driving them to school. “I don’t like it.”

I sighed through my tears, but at least he’s honest.

Jeff laughed and said, “I like it Mom, so you can tell me. Having feelings is quite logical you know.”

It’s not that Travis and I have a bad relationship. When he was little he was the cuddly one who said he wanted to marry me. And even though he keeps me at a distance now we do talk, but we do best when it’s about things like what’s for dinner, can he go to the movies

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with his friends, current events in the news, or decisions that need to be made around the house, stuff like that.

With Steve gone I rely on Travis for some of the handyman jobs around the house, things his dad used to do, because he's good at fixing anything and enjoys it. Travis and I discuss literally the nuts and bolts of life more than anything touchy-feely like relationships. My psychiatrist, Dr. Stone, has told me I would do better with him if I stayed out of his head so I'm trying to do that. I think in general I have a good relationship with both of my sons and we function well as a three-person single parent family unit, probably because we've had lots of practice even before Steve and I separated. From the time they were babies there were too many times that Steve was not with us because of being in the Army. I have a lot of resentment and feelings of abandonment that I know have contributed to me wanting out of the marriage. But Steve and I always try to put our differences aside for family holidays and special occasions, and I'm glad we can do that.

On February 1, 1989 we take the boys out to dinner at one of our favorite local restaurants called the Olney Ale House, to celebrate Jeff's eighteenth birthday. I can't wrap my brain around the fact that Jeff is old enough to legally move out, go to college, join the military, or do whatever he wants to with the next phase of his life. Travis will be right behind him too and then what? I'll be alone if Steve and I can't work things out. My father said, in one of his nasty letters to me a few months ago, that I have traded my family for a Ph.D. and will be a lonely old lady who no one will want to be with. He has always liked to predict doom and gloom for me so I try to ignore it but it's in my head and I can't get rid of it. I don't read his mail or answer his calls anymore because of that. In fact, I've developed a mailbox phobia because I never know when he or my mother will send me an upsetting letter. I worry that my relationship with men will always be troubled because of him too. So I am afraid to let go of Steve because he has been the one man I have always been able to count on, at least

until now, even though I have known for a long time we are not right for each other.

Steve and I have a deeply flawed and complicated relationship. We've been moving in and out of each other's lives for years, saying we still love each other and yet doing irreparable harm to one another and our marriage. I hate Steve at times, maybe because he is who he told me he was when we were young and I just didn't accept it. And I hate him because I am afraid I will always love him and I don't want to. He doesn't want to solve our problems; he just wants me to go back to being the same person I was when we met and I can't do that. I'm twenty-four years older and I'm too hurt by his indifference to my wants and needs, and I'm aware now of the way he never asks me how I feel about anything.

I think the biggest problem I have, one I don't like admitting, is that I'm scared that my father is right. I feel like I'll die without people to live with, take care of, depend on, and to call my family. I am trying my best to adjust to a new life without my husband, if that happens, but secretly I am still hopeful that our family will get through this rough patch and be restored to normal, even to a new and improved version. I have an old romanticized idea that Steve and I will develop a different kind of relationship that is not the same as what we had as teenagers.

"How do you know you love me?" I asked Steve in 1966 as we were making out to Johnny Mathis songs in my parents living room. He smiled at me.

"Because I want to take care of you," he said.

That was it; I was a goner. I always called him my Knight in Shining Armor and he loved that reflection of him in my eyes.

"I'm not who you think I am," he told me once when we were about to graduate from high school. "I'm not really a nice person. I don't care about anyone but myself."

I remember that I argued with him because I thought that I knew him better than he did. Why do we women do that? I'm learning that

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men do tell you who they are and I should listen. The guy who says “I’m not good at commitment” isn’t going to be with just me, and the one who says “I’m not very honest” is going to lie. I need to accept how Steve really is but I don’t want to; I still want to change him and us and I keep going back to a belief that maybe, if I try harder, things will get better, who knows.

The other problem I have with Steve is that I can’t stay away from him and every time we are together we end up making love. It feels like he is a drug I’m addicted to rather than a husband, like the way I can’t stop bingeing on junk food when I’m upset or drinking too much at parties. Does that make me an addict? I worry that I am an alcoholic like my father and a few other family members, but I can’t think about that because I am overwhelmed with just trying to put my marriage back together.

We all have a good time as a family celebrating Jeff’s eighteenth birthday and I feel close to Steve because we are parents together and our kids are important to both of us. He stays with me overnight and I am confused again. I know we still love each other. We can work this all out; I know we can.

A few days later I call Steve’s apartment on Saturday morning and a woman answers his phone in a sleepy voice.

“I’m sorry, I must have the wrong number,” I say.

“Are you looking for Steve?” she asks. I am confused so I hang up, my heart racing in panic.

Steve calls me back right away.

“Janis,” he says. “I didn’t want you to find out this way.”

Find out what? My head is spinning and I feel nauseated. He told me he was not dating anyone, he still says he loves me, so what is it exactly that I am finding out?

I barely hear him as he begins to explain that she works in his office, is just a friend, and she’s using his apartment as a place for her and her children to crash while she separates from her cheating husband.



I want to believe him, like I always wanted to believe him when he said he would get out of the Army but never did. Or when he told me over and over he was two, three, or six hours late because he was helping someone in distress. And when the bill collectors called and he explained that they just had their information wrong.

My kids tell me they have known about this woman, Cynthia, for a couple of years. How is it that I had no idea?

I'm back on the roller coaster. It feels like life is once again spinning out of control and I am not in the driver's seat at all. Travis is the one I can count on to tell me the truth and not spare my feelings so I ask him questions until he gets tired of being the informant and says that's all he knows.

"Mom, give it up," he says. "Just get a divorce."

I value his opinion but don't want to accept that it's over with Steve. It's crazy because I'm the one who wanted out, the one who thought for years that I never should have married Steve in the first place, and yet I'm hanging on. I know I have problems with accepting my problems. Dr. Stone says my problems are different than I think they are, but I don't know what to do with that. Steve has always told me I just expect too much and that I need to be happy with what I have. But I've tried and it doesn't work. So Travis is probably right.

I want to think my marriage and my kids are just fine even when the evidence tells me otherwise. My brother, a lawyer, always told me I'd probably be a better lawyer than him, but I know that's not true because I don't trust my own perceptions about anything. I'm at a point now where I'm questioning everything in my life. Have I been asleep at the wheel all these years? How is it that I never saw Steve as a cheater and a liar, just as a nice guy, if a little boring, who was often in the wrong place at the wrong time? He never trusted me and I bought it; I believed I was a flake and the one who was not loyal and consistent. What else have I been misreading? I'm afraid that my whole life has been a lie and that terrifies me.

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Travis also told me recently that Jeff is speeding when he drives, and I know Travis never says things like that unless it is important. He and Jeff have the “brother’s code” as they call it. They don’t rat on each other. They cover up for each other when they sneak out at night, and they don’t tell each other’s secrets, especially to me. When I question Jeff about his alleged speeding he laughs at me and says he is not speeding all that much. He says Travis exaggerated.

I am worried about Jeff because he’s so smart but does some really stupid things. He has a very high IQ but was diagnosed with Attention Deficit Disorder (ADD) two years ago, and maybe that explains his behaviors but it seems to me that it’s more than that. He gets so depressed and then at other times he acts like he’s on top of the world, and that’s when he lies to me. I’m starting to see that Jeff is pretty rebellious and out of control, but I have no idea how to handle it.

Whenever I try to talk to Steve about Jeff and his behaviors I get a response like “Oh he’ll be fine, he’s just like me.” I guess that’s supposed to make me feel better, but deep inside my stomach turns when he says that. That’s a signal I’m beginning to recognize; the little voice inside that says to trust my perceptions. I ignore it though because I don’t know what to do with that kind of problem that seems to have no solution. Better to forget about the problem.

Part of me thinks it’s good that my sons are strong willed and hard for me to handle at times because it means they think for themselves and are able to grow up and be assertive. Dr. Stone, tells me that I don’t need to be both parents, that Steve should be the father and disciplinarian with boys at this age. He says I should just be their mom. We had a discussion about that one day.

“But he can’t do it,” I say when he tells me Steve should be more firm with the boys.

“But he should,” he says.

“But he can’t!” I continue to say, and we go back-and-forth like

that until I give up. I get the point, that if I don't stop trying to father them Steve never will. And it's not working anyway.

Jeff is old enough that I decide I have to let him make his own bad choices and learn from them. Like the time he and his friends drove to Ocean City one weekend a few months ago. He went without permission and the old Volkswagen Steve's grandparents gave him broke down on the Bay Bridge. I left it up to Steve and Jeff to handle. They did, even though Steve probably didn't tell Jeff he should not have been going to O.C. in the first place.

Steve had to go rescue them and have the car towed, and when he was home Jeff and I argued. That's when I told him, "I give up! Just make your own damn decisions!"

After this phone call, I am thinking that it's no wonder Steve hasn't been very actively involved as a parent; he has another family in the wings of his life. I am in shock, realizing that all of them, my husband and sons, are all living a life I know nothing about. I want to run away; I just can't handle this. I can't deal with a deceitful husband and teenage sons who are rebellious and secretive. I can't sleep. I lay awake every night crying my heart out, feeling sick to my stomach all the time. I don't know what to do and can't picture any future without our family together. I can't trust anyone, not even me.

I am not even excited that the Dean, Dr. Dave Martin, has asked me to represent him at a professional conference on higher education in St. Louis, Missouri. I should be happy that I am going to the conference to meet with people about Deaf education and represent the Dean because it's a wonderful networking opportunity for me. But I don't know how I will be able to present a professional appearance when I am trapped in a tornado of emotions and tears.

On Friday, February 17, I pack a suitcase to leave for the conference. I remind myself this is a huge honor and will help to get me out of the anger that turns quickly to numbness, the feeling that nothing about me or my career matters. Jeff drives me to the Rockville metro station about two miles away and we chat about his life and what

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they will do while I'm gone for three days. He's happy to have the use of my sporty new Pontiac Corsica, so different from the Volkswagens and Hondas I'd driven previously. Buying that Pontiac was my nod to being forty years old and entitled to the same midlife crisis as any man.

Jeff assures me that after he takes me to the metro he will go on to the high school and then, over the weekend, he and Travis will stay with their dad at his apartment. I am uneasy about them there with this woman I don't know and her two young children. Steve's apartment only has one bedroom and a small den with bunk beds that our kids use; apparently her kids now sleep in those beds so Jeff and Travis have to camp out in the living room. I hate it that he gave our sons' bunk beds to her kids. It's ridiculous, I know, because Jeff is over six feet tall and Travis is close to that. They outgrew those beds long ago, but still it's as if Steve is giving away our kids and replacing them with hers.

On the Metro Red Line I ruminate all the way to Union Station where I catch a city bus for the rest of the trip, and try to convince myself the family upheaval may be a good thing in the long run. Is it really the end of the world if Steve and I do get divorced? I'll be free of trying to make a marriage work that just doesn't. Even the marriage counselor, and now our kids, have all told me to give up. Steve has probably done me a service by forcing me to accept that the marriage is over. How many people need to show me that brick wall before I stop crashing into it?

I know I need to change direction in my life and go around the walls to see what's on the other side. It might be exactly what I want. But Steve and I have been together for so long that I'm afraid I can't ever let go. I don't believe this other relationship he has is real; it can't be. I can't stop myself from wondering how I could change him, or things in our relationship, and make things right with us again.

Once I'm at the office I talk to Dave about the conference and get my plane ticket. Mid-morning a taxi picks me up in front of the

university to take me to National Airport and after I check my bags I board a Trans World Airline (TWA) flight, find my seat halfway down the aisle, settle in and fasten my seat belt. I try to relax. I close my eyes, take a deep breath, and think about how good it will be to get away. This may be just what I need to get my head straight.

The Captain announces over the intercom that we will depart in a few minutes, and then a flight attendant appears at the front of the cabin and calls my name. What? I look around wondering if I heard right, and then he says it again. I raise my hand and he makes his way down the aisle to my seat, hunches over to talk low and tells me to follow him. As I fumble with my seatbelt, I ask what this is about. He says “There’s been an accident.”

I see other passengers staring at me as I grab my purse, and I feel myself beginning to shake. I follow the flight attendant from the plane down the off-ramp and into the airport and it feels like another ten miles to get through the airport to the TWA office. I am led to a chair and handed a phone, and someone gets me a glass of water as I pick up the phone and put it to my ear.

“Hello?” I say still trembling, my heart pounding. I wait and hear only the muffled, unintelligible sounds of background noise on the other end of the phone.

After a few seconds Steve’s voice is telling me Jeff has been in a car accident, and he does not know yet if he is dead or alive. He says the police are on another line giving him details as they find out. I have the sense that this is all a bad dream, or a lie, and I will wake up to find myself back on the plane, flying through the clouds to St. Louis and the conference. Then Steve says that the police have confirmed Jeff is alive and has been transported to Suburban Hospital in Bethesda. I am to meet him there.

I feel so lost; I don’t know what to do. What about my suitcase? How do I get to the hospital? I can’t breathe and can’t talk clearly, and all I know is that I have to be at Suburban Hospital right now. I have to get to Jeff but I am worried about my suitcase. It’s on the way

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to Missouri. No, I am told, they took my suitcase off the plane. How did they know to do that? Where is it now?

Someone with the TWA staff leads me to the front of the airport and hails a taxi for me, and he tells me the airline will deliver my bags back to my house later so I don't need to worry about that. I think with curiosity that they must have handled things like this before. I wonder: how often does this happen? My thoughts are random and unfocused as I fight against the river of tears that I hear roaring inside my head ready to burst through the dam.

As I get into the taxi, The TWA representative hands a voucher to the driver and tells him where I am going but the driver doesn't like that. He is arguing in a thick foreign accent about the voucher; he does not want to accept it. He wants cash which I don't have. I start to cry and the TWA representative intervenes and convinces the cabbie to take the voucher. As we drive away from the airport he is still complaining, saying the vouchers are not worth anything because they don't pay him. I yell at him telling him I don't care what he wants because my son is hurt and I need to get to the hospital.

The ride to the hospital around the Washington DC Beltway in late morning traffic is slow. It takes forty-five minutes, maybe an hour, to get there. Tears roll non-stop down my face and I lay my head back against the seat and give in to sobs as the reality sets in. Jeff, oh Jeff; how could this happen to you? I can't stand the images that come into my mind's eye of him trapped in that car, maybe bleeding, hurting, scared, and alone. Oh God, I don't want to lose him.

When I walk into the Emergency Room there are people standing against the walls on the other side of the room watching me and I barely see them through the veil of tears. I try to focus and become aware of the high school principal, the school counselor, and some of Jeff and Travis's friends, and I smile weakly in their direction but I can't talk to them. Travis appears and takes my hand and a nurse guides us to a sofa and begins to explain.

She tells me, “Your son is okay, but he has what we call a closed head injury,” as if I have no understanding of what that is. I bristle. I am insulted and I inform her in a disdainful voice that I know what a head injury is because I am a speech-language pathologist, and I know that it is serious and that he is not okay so please don’t be so condescending. She smiles and asks if I would like a glass of water.

People talk to me, offering their sympathy and support, but the only person I can let into the protective bubble I am putting around myself is Travis who sits next to me holding my hand and trying to comfort me. After a while Steve appears with another man beside him, a friend of his I don’t know but whom Steve has mentioned before. He is a doctor at Walter Reed Army Medical Center where Steve works as a hospital administrator.

Steve is grinning as if he is going to a party and I think he looks psychotic given the circumstances. But he has always done that, acted as if things are okay when they are not. He tells me his friend is a doctor, which I tell him I know, and that he is there to help us understand what has happened. I know the friend is a urologist, so I wonder how that’s going to be helpful since urology has little to do with head injuries. I can barely look at Steve because I am so angry at him, and yet I need him and want him there. I remind him that we have to pull together for our family, for Jeff.

I tell the nurse I want to see Jeff, no matter what condition he is in, but she says we have to wait until the doctors finish working on him. I try to explain that I don’t care what he looks like; I just need to be with him. He is my child and he is hurt, so I need to be there, but she is firm that I have to wait. I hate her.

After about an hour the others finally leave and our little family, plus Steve’s friend, are escorted to another room and told the doctor will talk to us soon and then we can see Jeff. We wait another hour or so and I notice that Steve is not there so I go looking for him.

I find him at a hospital pay phone talking to his girlfriend, and I completely lose my mind.

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“No!” I scream and I begin hitting him. “You can’t do this!”

I feel the blood rush to my head as I pass out, and then someone, maybe Steve, picks me up and carries me to a small room, like a storage closet, where I am left alone. It’s as if there is a different person inside of me who has emerged and I have no control over what I’m doing anymore. I can’t stop screaming and crying because my son has been hurt and my husband is talking to his girlfriend and not me, and because the world is an unsafe place. Travis comes in to try to quiet me but I am still hysterical and he leaves in anger. He thinks I am mad at him and he won’t listen when I tell him I’m not.

When I finally calm down, exhausted, and come out of the tiny room, Steve tells me he was just calling Cynthia to let her know what happened and to tell her that he is at the hospital and doesn’t know when he will be home. So I’m just overreacting? He acts as if I’m crazy to be so upset and tries to hug me but I don’t let him. My tears continue like a leaky faucet that drips no matter how hard I try to turn it off. I walk around and talk, and still the tears just flow all by themselves.

We talk to the ER doctor, and I think how tired he looks and what a hard job that must be. “Your son is in a coma,” he says, “and we won’t know the outcome for at least twenty-four hours. This is a critical period and we just have to wait it out.”

He explains about the brain and complicated medical procedures that I don’t fully understand and he begins talking to Steve and his doctor friend more than to me. I am angry and I interrupt him.

“I probably know more about head injury than they do,” I say. “I’m a speech pathologist, and I would appreciate it if you talk to me and not just to them.”

All three of these very tall men stare down at me in surprise and then the doctor apologizes and includes me after that. I begin asking questions and it feels better that at least I can find out something and not have Steve, or his friend who does not belong there, be the point of information.



The ER doctor tells us, “With a traumatic brain injury the first twenty-four hours will determine everything, whether he lives or dies, so he is being carefully monitored. He had a seizure when he was first injured, which is common during a serious head trauma, and he is now on seizure prevention medication.”

Seizures? I had not thought of that and I worry about what it means. I have worked with kids who had seizure disorders and I don't want that for Jeff.

There is too much information thrown at us too fast and I try to remember it all but I react to everything I hear with such intense emotions that my own brain feels assaulted. The tired-looking ER doctor says that Jeff has a lot of bleeding and hemorrhaging in his brain and they cannot tell yet where the most extensive damage is. His brain injury is diffuse, spread out all over, rather than limited to a specific part of the brain, and as the brain tissue absorbs the blood they will know more. It's horrifying to picture my son's brain bleeding, absorbing blood and making more blood, shrinking and swelling, doing things that apparently no one can control or predict.

The doctor finally tells us we can go in to see him but warns that Jeff looks pretty bad and we need to be prepared, to which I say we are. But I'm not at all. When I see Jeff lying in that bed my heart is broken. How could any mother, or father, be prepared for the sight of her child lying motionless with tubes inserted into him and bandages covering his head? The expression on his face makes me think he is in horrible pain. I hear him moaning in a low, soft murmur. I tell Travis to go spend the night with his best friend, Jon, and they leave saying they'll be back the next day.

Steve and I stay in the intensive care waiting room that first night, sleeping on chairs we push together to make into a bed, but we sleep only a little because almost every hour there are new reports on the various brain scans done to monitor Jeff's brain as the swelling ebbs and flows like the tide. Some of the bleeding

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begins to slow down. He is put on oxygen and his natural breathing stopped. I have never heard of this approach and I question the doctor about why it is necessary.

“Does this mean he can’t breathe on his own?” I ask the doctor. I’m frightened that he has to rely on a machine to breathe.

“No,” he says. “The goal is to prevent further damage that can occur with Jeff’s brain swelling inside the skull.” He explains that the skull is like a box that the brain sits in, cushioned by fluid; the skull forms the walls of that box. Swelling can further damage the brain tissue that is pressed against the bony ridges inside the skull. If that happens, doctors will have to do surgery to drain the blood and other fluid from Jeff’s brain to prevent further damage. The oxygen will shrink the brain and guard against this nightmare scenario. I realize I have to accept the need for Jeff to be hyper-oxygenated and put on a ventilator, but I don’t like it.

It’s a long night and hard to get any sleep. When we are not listening to medical reports, Steve and I argue, going over old, unresolved issues. We argue because I am doing everything I can to convince him to forget about our problems and put the kids first. Jeff will need all the family support he can get if he makes it through this.

“You don’t love her, I know that,” I say. “We need to stop our fighting and put our family back together.” I tell him I will stop dating and we will go back to marriage counseling and make this right. None of those problems that seemed so important matter to me now; what matters is only our family. Jeff and Travis need us to be a family I tell him.

We eat breakfast in the hospital cafeteria, and when we return to the Critical Care Unit the nurse tell us that Jeff has survived that critical first twenty-four hours and that’s good news; they think he will live. All day Saturday we camp out in the waiting room talking to the doctors and nurses and a few friends and neighbors who stop by to wish us well.

Steve's sister shows up with her two kids and they go in to see Jeff. I'm worried about how this will affect them but our nephew, who is eleven years old, comes back and says, "He looks fine to me." I can't help but laugh that he sees Jeff in that condition and thinks he's fine. We see what we want to see and he's a child so I don't say anything.

In the late morning Travis joins us and tells us about a dream he had. He says he dreamed that Jeff came to Jon's bedroom window and knocked on it to wake them up. Travis tells us that in the dream Jeff laughed and said, "Psych! It was all a joke!"

"I wish it was a joke," I say and he looks away. I know Travis, like all of the kids, just wants to believe Jeff will be okay. I do too. It's too hard for any of us to accept what has happened.

When I am half awake and half asleep on the sofa, the waiting room phone rings and Steve's sister answers it.

"No, she's too tired to talk but I'll give her the message," she tells the caller without even asking me what I want. I'm angry with her for that, but I don't have the energy to argue and I know she means well.

Late in the afternoon Steve leaves the hospital to get some of his things from his apartment, and he's gone for a long time. He returns looking drained and tells us that his girlfriend left him a suicide note and disappeared, and he had gone to find her. That's what took so long he says.

"Don't you see how selfish she is?" I ask him with an I-told-you-so tone. He says yes, and he is finished with her. He says he will tell Cynthia she has to move out.

I have kept a diary or journal since I was ten years old and I try to write something every few days, or at least once a week, to keep track of how I'm feeling and what is happening in my life in case I need to remember and can't. At some point, a few years ago, I began writing mostly my dreams to analyze because I was feeling so confused about my past, what I wanted in life, and how I felt about my marriage. I talked endlessly about my dreams in therapy.

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But usually I do write some day-to-day things about what's going on in my life.

For the first few days after Jeff's accident, however, I am too upset to write anything in my journal, and too busy going back-and-forth to the hospital.

Five days later, on February 22, I write:

*On Friday Jeff, my baby, had a head-on collision with a van and now he lies there in a coma, tubes coming out of him, a machine breathing for him, his poor head all damaged and his knee cap shattered. As he improves a little each day my hopes do grow for a full recovery, but inside I am so terrified. I want to grab him up, hold him close, and take him back in time. I want to take everyone, Jeff, Travis, Steve and me and go somewhere safe. Steve went to his apartment to get things and to end his relationship with Cynthia but said he's worried she will try to kill herself again. Later I called his apartment when he wasn't back by 2 a.m. and Cynthia answered. She said Steve was at the hospital and didn't seem to know he was back with me.*

*I am able to recall what I believe to be the experience of “waking up” from my coma twenty-six years ago. It seemed to me that I was descending from clouds and was suddenly “there” in my body. To me this memory feels like the earliest memory of my life. I was eighteen years old. To say that my life began at a hospital does not quite describe what I mean. Perhaps it is better to say that my SECOND life began at a hospital.*

—Jeff Bouck, TBI Survivor

## ***Chapter 2***

# ***Jeff Is an Interesting Referral***

WE ARE WAITING. When your child is hurt like this, in a life or death situation, nothing else matters; time stops and the rest of the world floats by in suspended animation as you wait to find out what will happen. You remember so much like how he was born after a long and difficult labor during a dust storm in El Paso, Texas and that he had a skull fracture from induced labor, and how you had to put him in the window after you took him home because he was jaundiced and needed the sunlight. You smell his new baby breath and remember how surprisingly sweet it was, and you hear his infant cries from the bassinet beside your bed. You think about his big blue eyes and how smart he was when he was only seven months old and saying his first words: ma-ma, da-da, shoe, and “Maah!” which meant our dog, Max. You remember the way he would lie on his tummy when he was five months old, and how he would cry in frustration when he tried to push himself up and scoot but couldn’t quite do it. You can still hear his baby voice when he was eight months old and would go from room to room in his walker looking for you when you played hide and seek, calling out “Ma-ma!” You think about those

special times like when he was in first grade and all on his own he got the school bus driver, who had a framing shop, to frame your favorite picture of him and his baby brother and give it to you for a surprise present at Christmas.

While you wait helplessly you watch that child go from being an active, strong, fiercely independent, intelligent, and healthy young man to being a comatose patient, a case in a medical file. Whatever other problems you have, like your husband living with his secretary, don't matter anymore. What matters is a lot of technical jargon and medical procedures that you want to object to but can't, and your child's struggle to stay alive. You pray whether you believe in God or not.

I look at Jeff's medical records on February 24, 1989 and read:

"Jeffrey Bouck is an 18-year-old male who was involved in a head-on motor vehicle accident on February 17, 1989. He was brought to Suburban Hospital unconscious but moving all extremities, right side greater than left. A seizure was witnessed with subsequent initiation of anticonvulsant medication. He was also immediately intubated and hyperventilated. CT scan of the head has shown bifrontal contusions with a small right subdural hematoma producing a very mild right to left shift. Follow-up CT scan within the last day or two has shown partial resolution of these bleeds. Additional injuries have included a right patellar fracture which was openly reduced and internally fixated on February 21, 1989. Current medications include Decadron, Zantac, Dilantin, phenobarbital, Carafate, Nafcillin, Gentamicin, and Rocephin. His clinical course has been complicated by pneumonia."

The report describes the clinical examination and goes on to say:

"Mr. Bouck is recovering from a severe closed head injury as well as a fractured right patella. Although he remains unresponsive to verbal commands, he has apparently shown lightening of his coma over the last two to three days."

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The doctor requests physical and occupational therapy consults as well as daily bedside therapy for Jeff. He adds:

“As soon as he is off the ventilator, then remobilization can become more aggressive. The prognosis is guarded at this time. Thank you for this interesting referral.”

My son has become not only a patient in a coma but also an interesting referral with a guarded prognosis. What does that mean, what is guarded about his chance for recovery? There are so many questions and they stick in my throat like peanut butter that I sometimes eat by gobs when I don't know how to cope with life and the hunger I feel for something, anything that will soothe me and make the pain go away.

I feel like both Jeff and I have been invaded. He lies in a bed loosely covered by a sheet—he is naked to let wounds heal—with tubes coming out of him and an artificial machine breathing for him. I can't accept this; I won't.

During the first week after Jeff's accident Steve and I spend every day by Jeff's bedside. Then Steve says he has to go back to work and will be at the hospital in the evenings and on weekends. I am alone each day with Jeff and my thoughts and fears. My new car has been totaled in the accident, and I don't have a rental car yet, so Steve drops me off at the hospital in the morning. I can't go home until Steve or someone else picks me up in the evening, but that's fine with me because there is nowhere else I want to be anyway. I would move into Jeff's hospital room if they would let me.

I do have another child though and I am worried about him and about how little time or energy I have for Travis. I know he is a resourceful fifteen, almost sixteen-year-old but he is on his own too much, getting rides or taking the bus to the hospital after school every day unless he has something else he has to do. There are times I don't know what he's doing. Sometimes he is with his friends and I know they are at our house unsupervised, but I can't do anything about it. I want Steve to be there and to be a firm father to Travis but



he isn't, or can't, or won't and I can't do anything about that. In fact, right now, I don't feel like I have any control over any part of my life. I have never felt so alone and afraid.

I need people to help but I don't know who I would ask or what I would ask for, and I don't believe anyone could understand the deep and profound anguish I carry inside all of the time anyway. I've never been good at telling people when I'm hurting and this is the very worst kind of hurt so, no, I do not want to talk about it. I just want this to be over with. I especially hate it when people tell me we are "so lucky" Jeff is alive. How is any of this lucky? How can people say things like that? I know they mean well but it feels dismissive and cruel like the way my family always dismissed my feelings as a child.

Steve called my parents the day after Jeff's accident to tell them what had happened and they said that they would fly to Maryland and plan Jeff's funeral. I guess to them he's already dead? My sons are their only grandchildren and I want support from them that I know I will never get so I don't even let myself think about it except that I can't help but think of it; I have friends who I know do have families that would help them when they have problems. I've begun to realize, however, that my parents never make me feel better when things go wrong in my life; they just point out all of my faults and how I need to change who I am. Right now I can't handle that.

I started therapy two years ago after years of running away from my fears and depression, and right now I'm so grateful to have my standing appointments with Dr. Stone, even though there are days I show up and spend the entire fifty minutes doing nothing but crying and saying things like, "Jeff doesn't deserve this; this can't be happening to him!" Sometimes I feel like I'm going to levitate from the couch because I'm in so much emotional pain I just roll around holding my stomach and sobbing.

The process of psychotherapy is always hard, but Dr. Stone is wonderful. I don't know how old he is, and he wouldn't tell me if I

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asked, but I like to pretend he's a lot older than me so he can be like the father I wish I'd had. He just listens and verifies that what had happened in my life, and what has happened now to Jeff, actually is as awful as it feels; that I'm not imagining things or exaggerating like my parents always tell me.

Loneliness and anger threaten to consume me, and I hate it that all I know to do in retaliation is to consume too much food. It's a problem I've had my whole life but right now I don't know what else to do. Last night I ate pizza with Travis and then devoured an entire frozen cheesecake in front of a TV show I wasn't even watching.

There have been friends and neighbors calling or visiting, but I'm not able to tell any of them how I feel. My two best friends have not been to the hospital and I assume it's because they have kids and this is a parent's worst nightmare. So I just go through the days, sleeping only a little at night. I now live at the hospital trauma ward.

We haven't even met the hospital social worker yet but she left her card and some brochures and pamphlets about TBI and I read them while I sit by Jeff's bed. I try to focus on every detail because I want to understand what has happened. They, whoever wrote these things, say that you should act as if the person in a coma can hear you even if you don't think he can and it's important to talk about things going on in the world. So I do that. I miss Jeff so much I can hardly breathe and it helps to tell him my feelings while I'm with him, except for the big one. I know I can't tell him my fear that he might die. I hope he hears me but I have no idea what is going on with him and what his damaged brain is doing in there trapped behind closed eyes and walled in inside the box called a skull.

"Jeff, I miss you so much and I need you to wake up," I say. I ramble on and on, talking to him like I did when he was little and could not understand everything I was saying but I knew he just enjoyed the feeling of conversation.

“Hey, guess what? Your friends made you a mixed tape with all your favorite songs and groups like Guns N’ Roses, Depeche Mode, and The Clash. They said they are bringing them over later!”

Or I say fake cheerful things like “Hi Jeff, it’s Tuesday and you would be at school if you were not here in this hospital. I think your friends and teachers will be glad to see you when you get back. Travis even misses you and oh yeah, he’s dating a different girl now, but I can’t remember her name.” I pretend he is laughing with me about that because he would if he could.

The rest of my life is on hold. The world outside of the hospital has become non-existent to me, and I have not been in to work at all nor do I even think about it. I called the Dean’s office at Gallaudet the day Jeff was admitted, to let them know I did not go to the conference, and Dave told me to do what I needed for Jeff and to keep them posted on his progress. He knows my kids and has become a wonderful friend as well as my mentor and boss. It’s reassuring to know that my Gallaudet community will be there for me when I go back. But right now work and my Ph.D. program are the farthest things from my mind.

I eat my meals alone in the hospital cafeteria and get candy bars from the vending machines, and at night I go home and eat too much and drink too much wine so I can sleep. Steve is still living with me at our house, but he has started going out in the evenings and sometimes does not show up until midnight or later, or even the next morning. I know he’s lying to me and I smell cigarette smoke on him, which is the scent of a stranger because I don’t smoke, none of our friends smoke, and he has always been adamantly opposed to people smoking and never did smoke himself. He’s seeing her I’m sure, but at this point I don’t care.

I mark time by how many days Jeff’s been in this damn coma. It’s the second week. Jeff has developed medical complications like pneumonia and infections. The nurses tell me it is normal for that to happen to a comatose patient because he is inert and has the

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various tubes for breathing, urination and fluids, liquid food and medications, which can all cause irritations. It still terrifies me that a machine is breathing for my son and I can't stop obsessing over that. He has begun to run a fever. They did tests to rule out meningitis, and more tests to check for reactions to the many drugs he has been on. I am just so scared for him.

The hardest part is that I don't know how I am supposed to feel. My question is this: what exactly is the proper way to feel after your healthy eighteen-year-old son has a car crash that causes his head to be rapidly thrown back-and-forth, causing brain damage? How should I feel when I hear that his forehead slammed into the rearview mirror of the car and that all of this caused massive bleeding in his brain? I hate that he is unable to move, speak, eat, drink, open his eyes, or be continent of bowel and bladder when he's an eighteen-year-old young man who had so much potential. How is a mother, any mother, supposed to feel knowing that her child's life is in jeopardy and at best forever changed? The future, as everyone tells us, is impossible to predict. I understand because I've told people in the past the same thing when I was part of a rehabilitation team; but now I'm a mother and not a therapist so how is it that I'm supposed to be okay with that? I actually know what I feel and it's rage. But maybe that's not how I'm supposed to feel? After all, people still tell me how lucky I am that he's alive. Should I feel grateful for this?

I read in the pamphlets on TBI that about one-and-one-half million people sustain brain injuries each year. I can't believe this happens so often in the world and people don't notice. I wonder how I never thought about it before, how we all go on with our normal lives, laughing and enjoying conversations, while so many endure the unbearable sorrow of having someone they love in a coma or dying. I feel sorry for myself, our whole family, and everyone else in the world going through this torture of waiting to find out if someone will live or die or return to normal.

I feel like Jeff has died, but he hasn't. He's fighting for his life in there, in that little hospital room. So I felt guilty if I give in to my grief, and fear of losing him forever, because then it's like I am betraying him, giving up on him. I don't want to ever give up on either of my kids or ignore their pain like I feel my parents did with me.

When my babies were born, and I held them for the first time, I whispered a promise to each of them that I would always love them and take care of them no matter what. My mother always told me that when I was born her thought was "here is someone who is mine, all mine, and will always love me." That seems backward to me and Dr. Stone agrees. Parents are supposed to want to take care of their children and expect to love them no matter what, not the other way around. I will love Jeff no matter how brain-damaged he is when he wakes up.

I show up one morning to find that someone, maybe the phantom hospital social worker, left a brochure in the waiting room that says "brain injury counts as a death," and that helps. When I read that I cry and give myself permission to go ahead and grieve as if Jeff has died. I am allowing myself now to have a pity party. I don't want to live in the shadows of avoidance and denial anymore, about anything. I want to live in reality, but reality sucks right now.

Every day I station myself next to his bed, like a guard dog, watching anyone who comes near him. No one I think might be incompetent is going to touch him. It's the second week of Jeff's coma and yesterday a young respiratory therapist was working with his ventilator while I hovered a few inches away monitoring her every move. Probably I made her nervous, but whatever the reason she made a mistake and knocked the IV needle out of his arm. Blood spurted onto the floor and she became flustered as she tried to reinsert the needle.

"Get away from him!" I yelled, running to the doorway to get the nurse on duty.

The poor girl left the room crying and later I heard it was her first day on the job. Today I feel bad for upsetting her, and if I see her I

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will apologize, but my focus is on Jeff's safety. And I feel like there is no time to be nice now; it's not my priority. This is about saving my son's life.

Even though my friends rarely visit, Jeff and Travis's friends do and they talk to me in that uninhibited way teenagers do when they are nervous. It's great and I enjoy their company maybe even more than I would my adult friends; plus I am slowly learning more of what happened the day of the accident.

Jeff and three of his friends were planning to skip school that day as a senior skip day, and they were all going to the beach for the weekend instead of Steve's apartment as I had thought. It seems Jeff was at our house on that Friday morning, after he took me to the metro, with a girl named Deidra who I knew as the girlfriend of Jeff's friend Aidan, but now I wonder if she and Jeff were together. They packed some things and headed to the high school in separate cars, Jeff in my Corsica and her driving her car. Their plan was to pick up the others and leave for Ocean City.

So what happened was that Jeff and Deidra were racing down our street, a long and winding country road with plenty of twists and turns and blind spots, and poor Deidra saw in her rearview mirror that Jeff and a white van had collided head-on. She raced to the high school, about a half mile from the accident, to get boyfriend Aidan and then they all went to Travis's class to get him. Someone, we think maybe a neighbor, called 911 and when they all arrived back at the scene the kids saw Jeff being loaded into an ambulance.

I feel sad for all of them, especially Travis who was there watching from behind the police barricade as rescue workers put Jeff in the ambulance. He was not allowed to go with his brother in the ambulance. He's angry about that and I don't blame him.

"I told them he was my brother," Travis said when he told me the story. "But I guess they didn't believe me and wouldn't let me go with him."

Travis and all of their friends are facing a harsh reality they should not have to know at this age. I wish I could help them, but all I can manage right now is to be at the hospital for Jeff. I told Travis I love him but he needs to talk to his friends and maybe the school counselor. She's been great and offered to help in any way she can.

Time passes, and I think ironically it's like when you are pregnant and the baby is late, only it's definitely not the same excitement and positive feelings of a new baby coming. I hate waiting. Between being an Army wife and having a husband who was so often gone and late getting home at night, and the mother of teenagers who don't come home when they are supposed to, I have had enough of waiting. It's been two-and-a-half weeks, and I can't take it anymore. One day I sit by Jeff's bed and begin crying, and I throw myself on his bandaged chest.

"Jeff, you have to come back to me!" I tell him as if I have that mother's right to give him orders even if he is in a coma. "I don't think I can go on living if you die!"

Suddenly I feel a hand on my back gently patting me and I realize it's Jeff.

I sit up and stare at him, my crying abruptly stopped by the surprise of what just happened.

"You can hear me, can't you?" I say.

His eyes are still closed but his right hand, loosely tied to the railings to prevent him from pulling out tubes, moves slowly. I watch and see him form a weak fist, bobbing it a little up and down for the sign language word "yes."

I am afraid to believe it. I need to test what I am seeing, so I ask him yes-no questions, like "Do you know your name? Are you awake? Do you know where you are?"

He answers my questions with a signed "yes" even though his eyes remain closed and his lips unmoving.

Jeff is coming back to me just like I told him to! He is coming out of his coma!

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I run to the nurses and get one of them to come with me and watch as I ask him more questions. I explain that I work at Gallaudet University and Jeff has been around Deaf people and sign language for years. She says, yes, he is definitely responding.

“I’ve never had a patient use sign language before,” she says with a smile, “but this is good!”

I call people to tell them Jeff is awake and then I go to lunch at the hospital cafeteria, eating quickly so I can get back to Jeff. When I return his eyes are open and he is staring at me as if I am a stranger. His expression scares me because he has the dark brooding look of a demented soul and not my son whose beautiful blue eyes are usually bright with wit and intelligence. As I read in the brain injury literature, the lights are on but no one is home. It’s unnerving.

His haunted gaze follows me as I walk around the room and we watch each other. I watch him watch me and my excitement grows because I know this is Jeff becoming aware of his surroundings and visual tracking means his brain is healing. As I talk to him he does not respond but I feel he is listening.

Steve and Travis show up later that afternoon and they are excited that Jeff is awake. We all begin to fantasize that Jeff will come home before too long, continue to recover, go back to school, and life will return to normal. One doctor tells us that Jeff is young and healthy, and that someday this will just be “a bad time in his life” and I want to believe that, so I do. I’m learning in therapy that I’m good at believing what I want to or what others want me to. Sometimes it creates problems for me, but at other times it helps me get through something until I’m ready for the harshness of truth.

As the days pass I arrive at the hospital to find Jeff awake for an hour or so, and then I see him go back into his “gone place,” wherever that is. He still does not speak but he does nod once in a while and he continues to use some signs and gestures and to watch people. There is a person in there but it isn’t clear yet who that person is.

This sitting by my son’s bed all day is so hard because I’m his



mother and yet I'm also a therapist, a speech-language pathologist, and I feel like I should be doing more to help Jeff. Why not? I worked in hospitals, rehabilitation centers, and schools for years helping other people recovering from traumatic brain injuries, strokes, and all sorts of brain-related problems and now I am supposed to just sit by Jeff's bed and do nothing? I can't.

The hospital has started to provide bedside physical and occupational therapy but I'm told they have no speech therapy available right now; they are short-staffed. So I decide that I will do that therapy myself and I come up with strategies to stimulate the parts of Jeff's brain involved with speech and language. Steve and Travis are there one day as I get the bedside jar of sponges on a stick, those used to wet the lips of a tube-fed, non-eating patient like Jeff, and I rub a wet sponge and ice around his lips. His eyes light up; he likes it. Then I make sounds that he can see, focusing on simple consonants, and wait for him to copy me.

"Buh, buh, buh," I say slowly, smiling encouragement at him and using a sound that he can both see and hear. I switch from a voiced consonant to the voiceless equivalent. "Puh, puh, puh." When he doesn't copy me I try the one that babies love to imitate: Mmmm, mmmmm, mmmm."

He stares at me in confusion and then it all seems to register at one time as if that part of his brain has been stimulated enough and has popped open. He looks surprised as he begins to make noises. We repeat the sounds in unison one at a time and then I try a few simple one syllable words.

After three weeks of silence, Jeff utters his first post-injury word and it's "Mmmm...mom!" I am in tears.

"He's talking!" Travis says in amazement. He and Steve are our audience and they are all smiles, and I am excited. I feel like a healer, a miracle worker.

Jeff keeps saying "Mom," over and over, as if he's amused by the sound of his voice, and I watch new lights come on in his eyes. It's as

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if his damaged brain in trying to make sense of what he is doing and can't quite grasp it yet.

I am not sure if he even knows that I am "Mom," but so what? Jeff is talking and I get to watch new parts of his brain waking up. What an incredible experience this TBI recovery thing is. He is coming alive and just hearing him speak gives me a new euphoric feeling of hopefulness. I feel privileged to be a part of my son getting a second chance at life. But he's not the same Jeff who dropped me at the metro stop on the morning of February 17, three weeks ago, and now I am troubled by questions no one can answer about what kind of life he will have. Will he finish high school, drive again, go to parties, go off to college?

I know, from reading more these days about brain injury than I ever did before, that emerging from a coma is something people sometimes describe as being like a butterfly coming out of the cocoon. That's a lovely image but I can't help but think that there is another part of the analogy no one goes to. The part I most worry about.

What if he emerges as more of a moth than a butterfly? I think the cocoons look pretty much the same for both moths and butterflies, and you can't tell which it is until the adult insect emerges. Seeing Jeff emerge from his coma is like watching a cocoon open and wanting to see him as a beautiful butterfly spread its brightly colored wings and fly. I feel giddy after being sad for so long, kind of bipolar in a non-chemical way. I'm up and down emotionally, and I am wondering if that's how my life will be for as long as this takes. I'm on the roller coaster of TBI and I can't get off because I feel that if I do, someone—either Jeff or me—will die.

As the days pass after Jeff's awakening, my happiness hangs entirely on him making progress, and I watch for little signs of his brain healing. He has begun to smile with the weird, lopsided smile of someone with the one-sided paralysis called hemiparesis. His entire left side remains paralyzed but his right side is improving