

The Squeaky Wheel: An Unauthorized Autobiography
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Abstract: What if someone walked into surgery and awoke quadriplegic never having been warned of this risk? What if they not only survived but also endured the horrors of this disability with hope and humor? What if they returned to school, earned a Master's degree in theater and then a law degree and got married? What if they wrote a funny and tearful book about it *and* created a new business model to market the story? Brian Shaughnessy did. This is an excerpt from his 2005 memoir.

Key Words: memoir, Hawai'i, disability

Rainbows - 1999

Rainbows float in bubbles over the heads of the wedding guests and out over the white streaked turquoise ocean which looks like precious marble. The sea is sky-blue at the next beach -- then indigo with Koko Head volcano beyond. The water at each beach in Hawai'i is a different shade of blue. Past the guests and bubbles sit two regal Asian women with shoulder length hair wearing white muumuus and playing Elvis' *Can't Help Falling in Love* on the harp and flute. The guests are armed with disposable cameras and bubbles. As the guests arrive a Polaroid is taken of them and the picture glued into a book where guests jot down regards for the betrothed. The table at the entrance to the huge backyard is covered in stuffed bunnies.

The preacher beside me wears a polyester pale-blue suit. He is tall, bald and looks like he just stepped out of the Ozarks. He tells those gathered he has been asked to interpret the ceremony using American Sign Language. I see my sister, Shelley, raise her hands and twist them -- American Sign Language for applause. My best-person, my sister Dawn, is beside me. She has prepared a speech. Dawn has Down syndrome.

The smell of the lawn, the ocean and plumerias waft past us. Down the grassy aisle march the five cutest little brown girls ever. Each looks like she was drawn for Hallmark. They wear the cutest pink dresses ever. Each carries a large stuffed bunny. Now my bride Amy exits the house wearing a *haku* lei made by a law school classmate. Amy's long black hair cascades down the front of her bridal gown. I fight tears. She is a gift from God. The guests stand and smile. In lieu of a bouquet of flowers, Amy carries a pink, stuffed bunny. It is the year of the rabbit.

I wear new black cowboy boots. Actually the boots are entirely made from petroleum products, which makes them synthetic-boy boots. These are complemented by black trousers, a white shirt with Superman cufflinks and a black and blue paisley tuxedo vest. My father has just removed my *tres-cool* tortoiseshell sunglasses. My red hair shines from under the Chinese *bob* hat I wear. The hat is a black silk cross between a yarmulke and a Muslim's hat. My momentarily wife has placed a red circle with the Chinese *kanji* for happiness on the center of the hat's band. I'm sure I look like Hop Sing, the Chinese cook from *Bonanza*, but friends tell me I look like the emperor. The only possible thing that can take away from this idyllic picture is the wheelchair under my ass.

February 2, 1983

"Mr. Shaughnessy?"

"Mr. Shaughnessy."

"Why are you waking me?" I ask. It feels as if it has only been moments since the anesthetic took effect and I drifted to sleep. Ninety-nine, 98,97...

But that was a long time ago in a reality far, far away.

"The surgery is over, Mr. Shaughnessy. Can you tell me your name?" There is a hint in there.

"Brian Shaughnessy."

"Do you know where you are?"

"I'm at the University of Minnesota Hospital," I say as I taste... what is that taste? ...
Lysol.

"Okay, very good. Can you tell me the date?"

"Feb. 2nd, 1983. Can I have a blanket?"

I am freezing. I am certain that they performed the surgery in a meat locker and that I was covered only with frost.

The individual asking questions is moving about wearing standard blue hospital scrubs. These are different than the operating room green scrubs. I know this because I once worked at this hospital... in the kitchen. May God forgive me.

He is checking my eyes with the flashlight and then dons his stethoscope. First, he listens to my chest and heart; then, as the stethoscope slides below my nipples, the sensation nearly vanishes. I start to look down but immediately feel pain.

"You're lucky you're inside today; there was a nasty blizzard."

I am not feeling particularly lucky. I am slowly becoming aware of the fact that a group of people cut open the back of my neck, broke off tiny pieces of my spine to access my spinal canal and performed some surgical voodoo in there. Something is terribly wrong.

"Breathe deep," Blue-scrubs commands. He has checked my heart rate, pulse, eyes, etc. Blue-scrubs is around six feet tall and in his mid-twenties, with brown hair, a cropped beard and Buddy Holly glasses.

"Can you squeeze my fingers?"

Oh my God! What the hell did these people do? I squeeze his fingers, becoming aware I have 10 percent of the strength I had before going to sleep. I am definitely beginning to wake up.

"Is that the best you can do?"

What the hell do you think? Wouldn't I break them right now if you gave me the opportunity? "What is going on?" I begin to ask the question.

"Lift your right leg for me."

Okay now, THIS is big. The anesthesia clouding my thinking is hastily pushed out by the nightmare possibilities consuming every speck of gray matter. I make a Herculean effort to raise my right leg. What a simple request and what tremendous effort to accomplish ... nothing. It doesn't move. I hear my leg hit the bed. What the...?

"Very good. Now can you do that with your left leg for me?"

"Do what? It didn't move!" My mind shrieks as I make the effort to lower my head and look at my feet, and I am unpleasantly reminded that knives and other implements have been busy at work for an unknown amount of time. Why can't I feel my leg move? Jesus.

"I didn't feel my right leg move."

"That's okay. Try the left leg for me, please."

Oh, well, if you're going to be polite about it I guess I'll just do as I am asked and not bother you with *my* silly concerns. I make the effort again. I hear the thump back on the bed, but I am unaware that my leg moved.

"Can you feel my hand on your foot?" he asks with the calmness of a stranger asking my occupation.

"Barely," I respond trying not to lose my mind.

"Which toe am I touching?"

I start to look toward my feet but pain stops me. He continues to check for sensation; it is clear that it stops almost completely exactly at my nipples.

"What's going on? What happened? Can I have another blanket?"

"I'll get somebody to bring you another blanket. The doc will be in soon to answer your other questions. He's talking to your family right now."

What the hell is he telling them? I wonder. "Hi, I'm the doctor that crippled your son, brother, grandson...? The surgery went just fine. You should be able to roll him out of here in a couple of days." How does he know *what* to tell them? I don't even know what's going on.

"Can I have another blanket?" I ask this question several times and each time they bring another blanket. The pile of blankets is now thicker than my body. A group of doctors come and give the same tests Blue-scrubs gave. This is intermittently followed by nurses doing the same. No one looks me in the eye.

"Your father and your brother want to come in and talk to you. Is that okay?"

What will I tell them? "Yes, send them in."

"They can only have a couple minutes."

Fine, I think, since I have no idea what to tell them and what not to tell them.

My father and brother enter the room. They are smiling. They know nothing.

"Big Red! How are you feeling?" my father asks. My father is a stocky five-foot-eight inches with salt and pepper hair, a gray mustache and the charm of the Irish revealed in his dancing eyes. As is his custom, he wears a suit. My brother has a similar phenotype to mine. He is about five-foot-ten and muscular with red hair and a large neck.

"I'm freezing," I respond. "Have them give me another blanket."

Another blanket is heaped on and I continue to shiver as my dad talks about the blizzard and my brother Dan talks about a basketball game, but none of it makes any sense. I say I'm fine, tired, sore etc. but my mind screams, Tell them these bastards crippled me. Tell them to make the doctor guarantee I will walk out of this hospital. Tell them I should have died on the operating table because my life is over. No one -- especially not me -- can live this way.

But I fight this urge and a nurse ushers them out. They tell me to get better fast; they will return the next day; and everyone's real proud and buzz buzz buzz.

"We're going to move you to the intensive care unit, Mr. Shaughnessy."

"This is going to go away, isn't it?" I ask.

"I don't know," is the three-syllable answer.

"Well, who does know? Where is the doctor?" I ask looking about the room as carefully as one can when he knows that the slightest movement of his neck will result in ice pick stabs of horrific pain. There are two small beds. I am the only one in the room now although others have come and gone. There are many sets of scrubs in this room and they are all occupied by medical personnel.

I see the doctor walk into the room. He is tall with dark hair only beginning to reveal gray. Aside from being taller, he looks like he could be a younger version of my father. He wears glasses like my father wore for many years. He exudes the status of neurosurgeon as he moves. He sits next to the bed and says, "The surgery was more complicated than anticipated because of unrevealed scar tissue in the spinal canal." He says the paralysis is probably just "spinal shock" and should go away in a few days. But "AS WE DISCUSSED" there is a possibility I will remain paralyzed.

What the hell is he talking about? We never talked about paralysis. He said the surgery might kill me. I'm thinking, somebody better do *that* if the surgery did not because *this* is just not tolerable. The intense pain and the shock keep me from arguing with Dr. Liar.

Personnel bring a gurney alongside the small bed I am in. It takes some time to remove the blankets before they transfer me. They slide a plastic board underneath me, and as I slip from the bed to the gurney, I see a nearly pencil-wide tube in my dick. I remember one of the people in the operating room telling me he would need to do this for the surgery. I tried to talk him out of it, but he claimed it was needed, and he would do it after I was under. A nasty trick to pull on somebody sleeping. But there it is. I can't feel it. The doctor lies to me; there is a tube in my dick I can't feel... what next?

I am wheeled from the recovery room to the intensive care unit. As they move me from the gurney to the bed a realization hits. "What time is it?" I blurt out.

"11:20 p.m."

Oh my God! This was supposed to be a four-hour surgery, starting at noon, which means my love, Mary, was expecting a call around 4:00 telling her I'm okay. It's seven plus hours later. I asked my father to make that call. I know that as an attorney he has never returned a phone call in his life!

"I need you to make a phone call!"

"Okay."

"Please dial 785-8914 and ask for Mary."

"What do you want me to tell her?"

Well, there *is* the six million dollar question. What do I want a stranger to tell one of the most important people in my life who is certain I'm dead? "Tell her... tell her... I'm fine. Let her know that the surgery took longer than they thought, and I'll see her tomorrow." I stare about the room. There are six patients, three on each side of the room. There is a glass enclosure where the nurses remain when not tending to patients. The room is dark; death, pain and profound sadness hang in the air. These blue-scrubbed nurses don't laugh.

The night is endless. A pair of nurses comes around every 15 minutes to check vital signs. I sleep but *only* because I am full of top shelf painkillers. Every slight movement of my neck triggers intense pain despite more narcotics in me than a 747 has passengers.

Periodically I am awakened by the sound of clapping. Someone is cupping his or her hands, which makes the sound hollower... and louder. I look toward the bed next to me where two people are pummeling an obese man in this manner. Why? Why? Why? Aren't I being tortured enough without this? Cut it out! Stop waking me to this! Every pore of my body cries out, but I am silent.

I pray. I tell God I can't take this. It would have been better had I died on the operating table. The pain is too great and limitations too profound for me or anyone to endure. My

Catholic upbringing kicks in as I remember scripture, "Take this cup from me." I recall what that line did for Jesus and I cry.

Two nurses check vital signs and have me squeeze their hands. I do it weakly and the sensation is not "normal." One of them commands me to lift my leg. I try but it doesn't move.

"Very good."

"It didn't move!" I insist.

"Yes, it did! They both did! Try the left one again."

I try again. I don't see it moving. "See?"

"You didn't feel that?"

"I didn't feel anything!" I scream, cry. My eyes plead for assurance... a single word of hope. Instead, the two girls giggle... and walk away. I wish I could get up and kill them.

The next nurse lingers.

"Anything I can do for you?"

"This is going to go away, isn't it?"

"I don't know. They told you this might happen, right?"

"Nobody told me anything! I don't even know what 'this' is."

"When the neurosurgeon explained the surgery to you, he didn't talk about the possibility of paralysis as a result of surgery to the spine?" she asks incredulously.

"No!"

"How old are you?"

"Twenty-four."

"You didn't know that surgery in the spinal canal could result in paralysis?"

"I'm sorry; I'm a theater major. We don't know science stuff."

"No, I guess you wouldn't." Heavy sigh from her. "That should have all been explained to you, written down on the consent forms and put in your chart. What *did* the doc tell you?"

"He said I might DIE, but that that was not likely because of my age and health."

"The surgeon should inform you of ALL risks and this is an obvious one to anyone with a medical background. Let me look at your chart, and I'll talk to you on the post-op floor, ok?"

I never see her again.

After a night in the intensive care unit I am moved to the post-operative floor. It is a regular hospital room with two beds. It looks straight down the hallway to the ward I was on before the surgery. I see the doctors and others from that side who were so friendly to me before the surgery. Now they look in and don't even acknowledge my existence. I wonder what I am going to tell my family. My friends? *My mom?* Mary. She'll be here soon...

I have been unable to move my neck because of the profound pain. I watch TV mindlessly as doctors, nurses and med students enter, examine, and speak to and about me in a detached manner as if I am a frog in the pan of a high school lab experiment.

Mary arrives. I see her lithe, animated step and smiling face as she approaches the room – singing "Make 'em Laugh" from *Singing in the Rain*. Mary loves movie musicals. *Singing in the Rain* is her favorite. Mary's hair is almost my color. She is fair, freckled and slight of build. More than once we have been asked if we are brother and sister. I have been told the ultimate form of egotism is to copulate with someone who shares your features. She comes bearing outside food and drink, aware of the heinous reputation of hospital food (food I once prepared may God have mercy on my wretched soul). Her eyes meet mine and I turn away. She comes to me, setting the food on the hospital table. She sits next to me on the bed.

"Hi Honey," she says with an innocence and trust for human beings that will soon disappear forever ... maybe in the next sixty seconds. My eyes meet hers -- brown to brown. Immediately, I begin to cry.

"What's wrong?" She tries to put her arms around me and becomes aware of the staples and bandages behind my neck. "Oh, can I hold you?"

"I wish you would," I struggle to say through a cracking voice.

"What's wrong?"

I explain to her that right now I can't stand up, can't go to the bathroom, can't sit up, can't hold the sandwich nor the drink she brought, and although they tell me my legs are moving, I don't know they are. I tell her there is a tube in my dick I can't feel. A single tear appears in her right eye. I tell her I have very little sensation from my nipples down and now her tears flow as quickly as mine. I tell her the doctors say this may be temporary or it may be permanent, but my mind is made up: I will walk out or kill myself. I tell her of the nurse's nastiness. I need an ally and now I have one.

"You know," she begins. Her eyes no longer dance. "By about six o'clock I was pretty sure you were dead. By eight o'clock I was sure. I was sort of mad at your dad for not calling and telling me that but... I mean, you're dead and who the fuck am I? I'm just some chick his son goes out with."

I try to shake my head and feel an immediate stab of pain. I struggle through sobs to speak. She puts her finger to my lips. "So, from eight until almost midnight I was going out of my mind. The phone rang and I figured one of your brothers finally got the idea to tell me. I cannot *tell* you how glad I was to hear the nurse say that you were fine and that you would see me today. These assholes don't know you. I know you're going to walk out of here," she sobs, "and I'm gonna walk out with you and tell that nurse and the rest of them to go fuck themselves. Let's eat!"

We make out. At my encouragement she pulls the curtain and places a breast in my face. I ask for more but she claims the request is absurd. She is feeding me. This is the first time. It won't be the last.

Brian Shaughnessy graduated from the William S. Richardson School of Law at the University of Hawai'i in 1999. In the same year, Brian married his wife, Amy, and has since been an attorney, public speaker, Director of Special Education litigation and instruction at the Disability Rights Legal Center at Loyola Marymount School of Law and a writer. Brian has just signed an option contract for the movie rights to the *Squeaky Wheel*, which can be purchased at www.squeakywheelbook.com, Amazon, and other on-line as well as physical edifices that tender books. At Brian's web page you can buy the book, participate in his unique promo-plan (which awards PRIZES!), get other "Squeaky" merchandise and support others with disabilities in their legal and artistic endeavors. Brian considers his most important job to be father to his five-year-old son – Amadeus Yun Chi Shaughnessy.