



# Blind Terror:

Struck Blind, and Thrown  
Into the Waters of Insanity

A True Story by Richard Westcott



**BLIND TERROR:**

*Struck Blind, and Thrown Into the Waters of Delirium*

*A True Story*

by Richard Westcott

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## **NOTICE**

If you found this book on the beach, washed up and tangled in seaweed (the book - not you): Brush it off and take it back to your beach chair.

This is what you will read:





## **Chapter 1**

### **Drive to Terror**

I think the person next to me is staring at me. I can not tell because I can not see him, or her. I am driving home from work with tunnel vision, and it is shrinking. It comes to me that this was a big mistake. At lunchtime I had my full, normal, quite good vision. Then a half-hour ago, it was like someone blacked-out my windshield except for a glass dinner plate above the steering wheel. Now it has shrunken to the size of a small saucer.

Then it starts to rain. Also, it is getting dark.

I had not expected the traffic to be this backed up. I am on the very straight part of Boston's Storrow Drive alongside the Charles River. Straight is good, but this straight part through the heart of the city is just two narrow eastbound lanes, no shoulders, no pull-offs, bounded by concrete and granite block walls on both sides. I am stuck in the left lane because that is the lane you merge into when coming from the city where I work. I see that I am very lucky. I have a light colored car directly in front of me. It shows up as a blurry light colored blotch in a sea of blackness. I cannot actually see the car, nor any other cars. But I can see red tail lights, thank goodness, so that gives me a sense of whether cars are passing in the right lane beside me. This is important because I will need to shift into that lane to be ready for my exit. At the end

of the straight part, Storrow Drive dives into a short tunnel and thence into “the Twisties” (this is where the SUVs from out of town roll over.) It is just after exiting the Twisties that the drive suddenly widens to 4 lanes, and I will need to be in the right most one within about 100 yards, or I will get shunted onto Route 93 south to Cape Cod. Cape Cod is nice, of course, but I do not live there. If I were to stay in the left lane I will get shunted to Route 93 north to New Hampshire. But I live in Boston Harbor, so that is also not the way home. Therefore, the prudent person heading to Boston Harbor changes to the right lane before entering the Twisties, while still in the straight 2 lane portion. Of course, no Bostonian will let you shift lanes in front of him. (I say “him” because all Boston drivers become macho masculine (male, female, gay, lesbian, trans, bi, queer, and yes, even plus) upon starting their cars.) So I had, after years of training, developed the Special Skill needed to successfully change lanes while in the middle of the Twisties. Since this is such a brazen and fearful maneuver, even Boston drivers don’t anticipate it, and thus this is where I have always done my lane shift to the right.

This evening is the last day I will drive for the rest of my life: but I don’t know that yet. What I do know is that I will have to get creative with my lane change.

#### FOUR HOURS EARLIER

The last few days a pattern had emerged where my vision would be fine in the morning, but sometime in the afternoon, the vision in one or the other eye (never both at the same time) would deteriorate, and be worse in the evening. Then the next morning everything would be fine again. I did not know that this afternoon would be different.

By 3 pm, my right eye shut down. No problem, I still have my left eye. But now, my left eye is starting to develop a tunnel vision. Nothing alarming. I am at work. I am a site Civil Engineer at a prominent consulting firm.

I am now in a conference room meeting with three of my team working on a complex project. I will call them Nathan, Stu, and Jackie, although that is not what I actually called them, since those are not their real names, and it would have been confusing to use pseudonyms. We were close enough to being confused as it was. They are much younger than me. I am the senior voice of reason and perspective. Usually, my perspective is that I wish I was as smart as they are when I was their age. One whole wall of this room is glass to the outside, and it is the afternoon. Many times, the sunlight streams into this room. (How I miss the sunshine.) But now it is overcast. But at this moment, I am not thinking of that. At this moment, I am trying to look at a drawing Nathan is projecting on the big screen. I am getting a bit concerned because my vision is now so restricted that I am having trouble seeing the screen at all, even though it is just a few feet away. I think, this is embarrassing. I have to get out of my chair and lean close to the screen to see the drawing with my one good (but diminishing) left eye. I know this must be somewhat alarming to the others, but not as alarming as it is to me when I move to get back into my chair, and am horrified to find that I can't see it. I need to reach out with my left hand and feel my way back to it so I will sit on it and not the floor. Nevertheless, the rest of the meeting goes smoothly enough. I am pleased to find that I can at least walk back to my office, although I need to proceed cautiously, since I am now completely blind in my right eye, and seeing with only tunnel vision in my left.

Now I am a little worried (but certainly not enough to say anything to anybody. (No need to panic. Right?)). Normally I would work until around 6:30, but this evening is the final game of the baseball American League Championship Series (ALCS). The Red Sox are leading the Astros 3 games to 1, so this is the final game (Spoiler Alert: the Sox won). This game will be an evening game at Fenway Park—what a coincidence. My drive home takes me right by that area. Because of that I decide to leave a little earlier. I go to the parking lot. This might be a good time to mention that I had been experiencing increasingly poor judgement for about a week. I was aware this was happening, but did not know what to do about it. (You, Dear Reader, might call that poor judgement.) I hear a little voice on my left shoulder say, “you should call an Uber”. But I also hear a louder voice crowded into my head say, “Naw, you’ll be fine. Storrow Drive is fairly straight for most of the way, and you’ve driven it so many

times you know it like the back of your hand.” (Of course, if I had checked, I would have seen that I could hardly see the back of my hand). (I will explain how these voices got where they were later.) I did not know it at the time, but I was in the middle of the effects of a rare auto-immune disease. As I mentioned, one of its effects, at least on me, was a sharp decrease in the ability to exercise good judgement. I followed the recommendation of the loudest voice. I got in my car and headed for home. I got through the side roads to Storrow Drive well enough; Then the terrifying part began, and would last longer than I care to remember, although that is what I am doing now.

## BACK TO STORROW DRIVE

So here I was on the straight, easy part of Storrow Drive. Normally I would set myself up for where to make a lane change by the visual clues of bridges and signs (when not watching the sailboats on the Charles). This time I have at least enough residual judgement to know that I will need to change to the right lane in the straight part. The traffic is now all stop and go, and mostly stop. It is the crush of fans trying to get to Fenway Park. I know it is probable that these cars do not have just the single, slightly sluggish commuter in them. These cars are full of crazed fans. Boyfriends and girlfriends. Husbands and wives. Husbands with girlfriends. Wives with boyfriends. Wives with girlfriends. Red Sox fans, some of them perhaps already slightly buzzed. I could not see them, but I suspected that they would not be pleased to know that a blind guy had decided to mix right into the middle of their frenzied group.

I need to know more about the cars in the right lane. Since I seem to be securely stopped for the moment, I decide to do a test. I take a chance and turn my head full right to see if I can make out anything about cars that might be beside me. This is a tricky thing to do, because it means I lose sight of that bright blotch in front of me. I know that when I turn my head back again, it will take a few moments for me to find the blotch, and if, by chance, it had pulled ahead, or please no God, change lanes itself, I will not be able to find it. If I then have a dark car in front of me, I will drive right into it. I would only become aware of it because of the crash. I am still standing still,

so I look to my right. Nothing. But I can sense traffic is still not moving, so I hold my gaze. As what was left of my left eye adjusts to the darkness, to my horror, I become aware I am actually staring right at a very large SUV with a potentially very large driver sitting right next to me. I can only wonder what the driver is thinking with my staring at him like that. If it had not been a dark and rainy night, it might have earned me a punch in the face. The results of this test convince me that I will not be able to continue on Storrow Drive to its end and my exit.

I need to get off the drive, and on to the city streets. That way I can cautiously pull over into a parking space and wait for my vision to get better (good luck with that.)

On any other day I would have put on my flashers, slowed down, put the car in Park and called 911 and said, "Get me the hell out of here". However, I know that I am surrounded by these good people (some maybe slightly buzzed) just trying to get to Fenway Park before the game. It would be about the cruelest thing I could do to become "That Guy" at this time.

There are a few exits along this straight part that would do. But where am I? There is just one exit I want to avoid at all costs: The secret exit of death known only to the Boston locals. It is nearly impossible to do correctly, even when you can see. It is marked by a simple sign, so close to the actual sudden right angle turn you need to make, only the locals are the ones to take it. So as soon as traffic starts to move again, I know it is time to change lanes. I start by paying attention to the tail lights as they come past on my right. I watch a pair pass, and then put on my directional (blinkah). I begin very slowly nudging over, all the time expecting a loud blare of horn as I move slowly to my right. There is no blare, apparently my intentions were clear and slow enough, or this was an out of town driver behind me. I settle into the right lane. A successful step! To my amazement, the light colored car in front of me had also shifted lanes as well, so I still have my light blotch to guide me. By my estimate, based on time elapsed, I have already probably passed the exit from hell, so I need to be ready for the next one, which will dump me into a slightly more friendly area of Boston, beyond the Fenway Park madness.

Suddenly, I am aware enough to see that there is an exit just ahead of my right fender. There is no time to think, I know I have to take it. I do. To my horror, I realize due to the sharp right angle of the exit, that this is the very exit I want to avoid at all costs. I know that as soon as I take it, I have just one car length to stop due to a local cross street, which I dutifully do. The problem is, I cannot tell when the intersection is clear for me to proceed. So I wait for a few seconds, and then start to move slowly forward. I am immediately greeted by a loud horn in my right ear. As I stop and move my limited focus to my right, I become aware of a very large SUV that I have cut off. I did not need to see the driver's face to know what their expression was. Obviously, I cannot back up, so it is left to the other guy to back up, realign himself, and then work around my projecting front end. This he does with great difficulty. I then cautiously go forward. I know this exit. There are no parking spaces in the first block. Soon I will encounter a small unsignalized intersection. I get to it. I can't detect anything in front of me, so I assume the way is clear. I proceed. I quickly find that shifting my eyes left and right to look for parking spaces is not an option, but I am pleased to see that I have enough vision to detect when I am at the next more brightly lit intersection. I stop, and then move cautiously through it. No horns, screaming, or crunching, so everything must be OK.

Now I do not have a light colored car in front of me to follow, so I have to use my best guess to stay in my own lane. I have to hope that if the cars stop in front of me, I will detect that before I hit anything. However, my biggest fear is that I will hit a pedestrian. I just pray that with my cautious driving style, pedestrians can avoid me before it is up to me to avoid them.

I am aware that I have now been through a few intersections, but I am not able to keep a mental map of my "progress". I have not the slightest idea of where I am. Suddenly, I see a large overhead sign indicating something about an interstate, and I am in the lane being shunted onto it. Panic. Now I have no choice but to switch lanes. From what I can sense, it seems like I will need to be two lanes to my left to stay off the interstate. This I do by just moving myself to the left, and yes, this time there are several blaring horns involved, but I have no choice. I just have to do it. After the lanes

change, I can tell I have saved myself from the interstate, but I still have no idea where I am. Then the road I am on ends abruptly.

There aren't any major roads that just dead end in the Back Bay area, so I figure that I am at a tee intersection. I realize that I must be at the western edge of the Boston Public Garden, and if so, my only choice is to turn right. It will be one way here. If I turn left, that would be very bad. I know that this intersection has a signal, but I cannot see it. There should be bright red and green lights, as well as white pedestrian crossing lights, but I can see nothing. But there is still one car in front of me I can detect because of its white license plate. I cannot let it get too far ahead. So as soon as it goes ahead, and thankfully, turns right, confirming, more or less, my assumption of where I am, I follow it. If I am correct, I will now need to go around the Garden. Very soon there will be a pretty quick left turn, which will require shifting a couple of lanes to the left. So, this I do. Again no horns, scraping sounds, screams, nor other untoward incidents. From there, the hope comes to me that maybe I can get to the public underground parking garage which would be a block and a half away if I am actually where I think I am. This sounds like a perfect place for me to slowly make my way into a parking space. Then I will finally get out of the car and walk home.

Although I pay careful attention to my lanes, somehow I never see the entrance to the garage. Next thing I know, I am at another tee intersection and am being forced to take a left turn. Fine. Whatever. But suddenly I am being forced to take a right turn. However, because of that turn combination now I know where I am, maybe. I am probably on the short section of road that dumps you from Back Bay directly back onto Storrow Drive. I really do not want to get back onto Storrow Drive. But as soon as I take this turn (which is not optional anyway from where I am) by a miracle, I clearly see an empty parking space to my immediate right! I cannot believe the first luck of the night! (I did not know this would be the last luck I would have for quite some time.) Needless to say, I got myself into it.

I then carefully open my door, as little as I can, because I do not know if there are any passing cars next to me. Using my hands, I feel my way around the front of the car, come to the curb, and carefully step up onto the sidewalk.

THE DRIVING IS DONE! –

(Oh wait, I am still not home yet)

So there. I have done it! As I stand on the sidewalk in the rain, it occurs to me that I am not home yet. I decide I need to call an Uber. So I take out my phone, but wait, I do not know what the name of the street I am on is. I walk to the intersection to my left. Problem is that I cannot read the street sign no matter how much I squint and try to focus. It is just a blur. So I walk down to the intersection at the other end of this short street. But that sign is no clearer. About this time, a small group of people come walking by. I ask, “What street am I on?” “Beacon Street.” Wow, that is great. Beacon Street is one of the longest streets in Boston. Everyone knows Beacon Street. But wait, where am I on Beacon Street? The people have moved on. The buildings behind me are the typical beautiful red brick townhouses. I can see that they have numbers, but the numbers are black on red bricks. I cannot read any of them. Finally, I find one entrance that has a wrought-iron trellis over the entrance with the number at the top. I cannot believe it - I can read it! 107. So now I know where I am. I now look back to my phone to call Uber, but find that all the icons are so blurry that I cannot read any of them. Still, I have a pretty good idea of where the Uber icon is. Wonder of wonders, I actually make the call and enter my newly discovered address! Uber is on the way! I wait. Then I wait some more. Then I get a call from some one who talks very fast with a heavy accent. I cannot understand a word he is saying. When I ask him to repeat it, he does so - exactly as before. We do this about four times, I become aware that he is telling me he is pulled up partly on the sidewalk and wants to know where was I? Well, I walk up and down my little block, and we do not discover each other. Finally, I tell him to skip it, and cancel the pick-up. I figure I will just start over, but this time when

I go back to my phone, my vision has gotten worse. I can make out nothing on the screen.

I AM SAVED –

AN AMBULANCE COMES! (I sent it away)

Someone must have been watching me, and made note of the obvious, “Something’s wrong with that dude,” because an ambulance pulls up. The EMTs get out and talk to me. All I know at this point is that I want to go home to my boat and go to bed. I’ll be fine in the morning, is my thinking, if you can call it that. The EMTs convince me to get into the ambulance to talk, even though the rain has pretty much stopped by now. Still, I feel bad for inconveniencing them, so I get in and have a seat. Here’s what I learn: You cannot tell some one that you don’t have Alzheimer’s. It just doesn’t work. But the EMTs do their best to figure me out, and I do my best to conceal the fact that I am blind. I might not be very convincing, since they had to lead me by the hand to the ambulance. I keep telling them I just want to go home, and I will be fine. And besides, I think, what would be the point of checking into a hospital this close to the weekend? They would just hold me, and schedule a bunch of tests for Monday. Might as well be home. So finally, I manage to convince them that I am of sound mind (that was a joke), and they tell me that they cannot force me to go with them. One of them walks me back to the sidewalk.

OK time to walk home. I just need to find an intersecting street that I can identify. I start walking. I come to a street of some obvious substance. I take a left. I am pretty sure a left will put me heading east. The ocean, and hence the harbor, are to the east. As I walk along this street, I come to realize that I know it. This is Charles Street. I know my way home from here!

The walk is difficult however, as the sidewalk on Charles Street is the old, uneven brick sort, narrow, with lots of signs, parking meters, and an occasional trash

can. Trash cans are giving me the most trouble, as I do not see them at all, and walk right into them with a waist high metallic clash noise. I can tell that I look like a stumbling drunk to everyone I pass. However I am at least well dressed. I figure that many would say, "Yes, I've been there myself." The intersection at the end of Charles Street (technically, the beginning, but who is keeping track) is Cambridge Street. It is two lanes in each direction. But the good news is that it has stop lights just to the left of where I need to cross so that there will be gaps in the traffic. As I cannot see cars at all, I have to time my crossing based on hearing alone. I get across. However, a bigger challenge lay ahead

### THE MOST TERRIFYING CROSSWALK

I know that the next intersection to deal with is a challenge when you can see. It is the four lane entrance to Mass General Hospital. It is signalized, with an island in the middle. It is a noisy place, as the traffic on Cambridge Street never lets up. I know there will be no doing this based on trying to listen for when there are no cars coming. I get to the curb somewhere near the beginning of the crosswalk at the intersection. I look up to find the Walk/Don't Walk light, but I am blinded by a light so white and bright that I cannot look at it! I think, "Who puts a blinding spotlight at a crosswalk shining right into the pedestrian's faces?" Eventually, I realize that the white light is not constant. It is replaced sometimes by a red light that is not nearly as bright. My brain must be slowing down even more, I think, as it takes me some more time standing there to realize that the red light must be the "Don't Walk," and the blinding white light must be the "Walk" signals. But when the light next turns white, it is so painfully blinding that I cannot see well enough to even step off the curb. "These lights don't include time for thinking," I say to myself. My moment's hesitation means I will have to wait for the next cycle.

Now here's the thing: Massachusetts, as do many other states, has "Right Turn on Red." This means that pedestrians are given the go-ahead to cross, while cars turning right are also given the go-ahead. I assume this was occasion for great

amusement and high-fiving when first thought of. It would have gone like this, "Let's give the pedestrians and the cars a green light at the same time. It will be great fun!" Of course, the way it is supposed to work in practice is that a car should not take their right turn if there is a pedestrian in the crosswalk because this makes for a messy grill. But for this to work in Boston, the pedestrian has to get into the crosswalk. There is a basic assumption that a pedestrian would not step off the curb directly into the side of a car taking the turn. But what if the pedestrian cannot tell if there is a car four inches in front of them? So I know I will have to shuffle my toes right up to the edge of the curb drop off, and then boldly step off when the blinding light next comes on. Of course, the danger of standing right at the edge of the curb is that a truck could go by and its big side mirror will clock me in the side of my head and knock me backwards, thus spinning me around to fall under its wheels. Well, I figure maybe if I just fall backwards that will be OK. Perhaps I will step right into the side of a moving car. Maybe I will get knocked flat, and the car will drive over my legs, catch the fabric of my pants (and the fabric of my legs) and drag me around the corner. I know that anyone taking this right is probably going to get on Storrow Drive, so there I would be, back on Storrow Drive, but this time heading in the wrong direction, being dragged on my back. But perhaps I will step off and not hit the side of a car. I know that I would not be home free. Since the lanes are narrow, if I complete one full step, I will be well into the lane, so that a car coming to take the right with any velocity will not be able to stop. Here's the thing: All these cars are leaving the hospital, so you've got to figure at this time of the evening they are doctors and nurses who have finished their shift. They are pretty much as bleary eyed as I. Probably the car coming at me is an Audi convertible with the top down. They will hit me, and I will go flying up in the air in a great loop, and land into their passenger seat. Next thing I know, I will be back on Storrow Drive, but at least now it would be while listening to the radio.

So I take my bold steps forward into the crosswalk, bent over, with my left hand held forward in the international Fend-Off position. I get past the first lane. But now I have to deal with the next lane, the lane for cars turning left. So I have to go through the same series of concerns when crossing this second lane. Well, I do, and it works. I am now on the center island! Of course, I have taken so much time that I have to wait for another cycle of the Walk/Don't Walk. Then the blinding white comes on

again. I go through the same process of hoping for miracles to cross the inbound two lanes. Finally, I am at the other side. I am now prepared to admit to you, Dear Reader, that frankly I did not think I was going to make it.

Now as I proceed I hear the little voice on my left shoulder say, “Richard, you are aware, are you not, that the walkway to your left would take you right into Mass General?” And I know that Mass Eye and Ear was attached to Mass General. But the louder voice in my head said, “I just want to go home.” So I continue on. I am still a couple of miles from the boat, but these sidewalks and intersections are much less threatening, and anyways, I am becoming a veteran now.

The last lingering question is whether I am going to be able to see the edges of the dock when I get to the Marina. If not, all of this walking will have been for naught. But when I get to the Marina, I am heartened to find that I can easily distinguish the light colored wood floating dock from the black sea. Long story short (I know, too late) I get back to the boat.

The last thing I remember that night is falling asleep on my bunk in the vee birth, looking up at the acrylic hatch which appears as a lighted square. I tell myself, “As long as you can see that lighted square, you are OK.”









## Chapter 2

### Rot To Bones

#### A MONSTER STRIKES

I wake up at what I think might, or might not be, the morning, but the thing that is causing me great alarm is that the light from the hatch above my head is gone. I had expected that I would awake and be fine just like every time before for the last month, but what I am not seeing is not fine. I reach up tentatively and feel around the hatch frame. The hatch is still there, but instead of being transparent, it is black. This is very, very bad. I have no way of telling what time it is. I know it is October 19.

I get out of bed. I feel around for yesterday's clothes. I throw them on. I go up the 4 steps into the saloon (Educational interlude: The "Living Room" of a boat is called the saloon. Saloon means "gathering place." This morning there would be no gathering.) I think, I'll turn on the TV, but then I realize even if I can find the remote (I can't), I'm not sure I can remember by feel which button is which. (There's 87 buttons on the freakin' thing, and that's just the front.) I do find my phone. Here's the thing about your smartphone: It is all visual. Even if there were a way to make an

emergency panic phone call blind (You dear Blind Readers know secrets I had yet to learn), I didn't know what it was. I could fumble with my phone all I want. I will never know what I am doing. I certainly cannot call someone. I crumple on the couch defeated. As I sit there in total darkness, I reflect on how long I had actually realized that something was wrong with me. Something that had been getting increasingly worse. I had even given it a name: "The Monster." (I have a way with words.) Perhaps I will explain that further, Dear Reader, you will just have to continue reading to find out.

Getting back to my situation: I imagine how I could die right there on this couch, Starved to death and rot. I would be found next spring, just a pile of dust and bones, holding a cell-phone on my skeletal lap. The darkness is profound. This is not the darkness of a moonless night in the country. This is not the darkness of putting your hands hard-up against your eyes. Your hands are still a little transparent.

When I was a kid, refrigerators still had the latch-type handles. Every so often there would be a story in the paper about some kid who had climbed into a refrigerator and shut the door to play submarine, or spacecraft. Of course, they would be found dead later since you could not open those doors from the inside. Then they passed laws to mandate that no one could get locked in those things. Of course, I did not read the papers back then, but my mother could find a disaster story no matter where it occurred. If a kid was locked in a fridge in Siberia, and it was written up in a Chinese language newspaper, my mother would find a translation and read it to me. Back in the days of my childhood you could still find old appliances in some of the larger woods around my house. Needless to say I found such a fridge, and climbed into it, but I first made sure it was the kind with a magnetic seal and that I would be able to push the door open. What you experience inside a closed refrigerator is how dark it was. That is profound darkness.

Well, I think to myself, at least it stopped raining. I decide I might as well sit out on the back deck. There I will wait for someone to come by. I wait there at least an

hour. Eventually I hear the dock creaking in the rhythm of someone coming in my direction. I try to guess when they are opposite me, and I say, "Excuse me?" I can tell when she answers that she is Joan, the assistant who works at the marina. Now here's the ridiculous part: Instead of saying, "Help Me! Help Me, I've gone completely blind!" I say, "Could you dial a number for me? I can't see my phone." I guess this sounds strange enough to her that she calls Sebastian, the Dockmaster, on her 2-way radio.

#### THE WALK OF COMEDY

A few minutes later he is at the boat saying, "C'mon with me. Put your arm around my shoulder." He then walks me along the floating dock. I am a terrible walking companion. Sebastian is one of the few people at the marina who is shorter than me. (I don't get a chance to say that very often, so I have to take every opportunity that presents itself. (Even if I am the one who presents it.)) But he is strong. In fact, that is something you can notice about all the people who live on their boats. It's kind of a natural selection process, I guess. You wouldn't want to try and push Sebastian around, but here I was, trying to. With my left arm over his shoulder and his arm around my waist, my job is simple: Just let him lead me. But the walk entails going to the beginning of E dock and taking a left where it joined A dock. Now I know this walk like the back of my hand (and we already know how well I know that.) When my memory decides it is the correct amount of elapsed time/steps/movement of the cosmos we need to take the left onto A Dock. If we keep going straight, we will walk into the Harbor. If we take the left too soon, we will walk into the Harbor. Here's the thing that my Monster stricken mind was having trouble sorting out: There are two people taking this walk. One was perfectly normal, and sighted. The other was a blind slug. I have decided it is time, so I keep trying to turn left. But Sebastian is on my left, so I am turning into him, effectively trying to push him off the dock. He resists, which feels to me exactly like he is going to walk us right off the edge into the Harbor. At any rate, we manage to successfully take the left. After this, the dock curves. I know this, so I keep the pressure up to curve left pretty much the whole way. It is a 5-minute walk

when you can see, longer when the two mariners are trying to push each other into the harbor.

### THE MONSTER LAUGHS

Once in the office, he asks me what number he should call. Here's the thing: How many phone numbers do you know from memory? I could think of only one, which was the number of my ex-wife. So Sebastian calls that, and I am lucky. My ex is home. She calls my sister, and that gets the ball rolling. A few minutes later, my sister, Gwen, calls the marina, and Sebastian gives me the phone. I say, "Guess what ...," and brought her up to speed. She and her husband Steve live on the South Shore, about 30 miles away. She says I should go straight to Mass Eye and Ear. I say, "Why would I do that? They saw me a month ago, and they didn't know what was wrong." (Oh yes, Dear Reader, I will explain later). "Why should I go back?" (Additional Note: I was not the brightest bulb in the drawer at that time). She convinces me otherwise, and Sebastian drives me to the hospital.

### THE LIGHT HAS LEFT MY LIFE

Once securely in the grasp of the hospital, Sebastian goes back to work, and since Gwen was still on her way, I face my diagnosis on my own. I did not have to wait long. The ophthalmologist does his exam.

Those of you who have had eye exams will remember how bright that lamp is that they shine right into your eyes. It is so bright that it hurts. I know things are not good when I can tell he has that lamp shining right into my eyes and I cannot feel anything, and cannot detect even the dimmest hint of light. He then pauses, and asks me if it would be ok if he invites one or two other doctors in to have a look. Of course, I say, "Sure, the more the merrier." I imagine him in the corridor, saying, "Hey guys, come here, you've got to see this."

## THE MONSTER GETS A NAME (It's not "Frank")

Here's the thing: One word you don't want to hear when a doctor is peering deep into your eye is, "See right there? That's profound." Nothing "profound" is good when it's inside your body being looked at by a doctor. All the doctors take turns looking in both eyes. Then after the other doctors leave, my doctor gently puts his hand on my shoulder. He says, "I'm going to tell you how I would want to hear it if it were me. I wouldn't want the doctor to try and sugar-coat it, or make it sound not so bad." Here's what he says, "What you have is Giant Cell Arteritis, referred to as GCA.

"You are totally blind.

"This kind of blindness is permanent.

"There is no cure.

"There is no chance of recovery."

I was stunned. At that moment my earth stopped turning, and I was left stranded on the dark side.

However, there is no more time for pep talks. GCA (The Monster) is just in mid-progress. It has much more work to do. The eyes are just the first item on its list of things to devastate. The thing they must do now is stop the Monster's progress. For this Mass Eye and Ear will transfer me to Mass General Hospital, which is just a wheelchair ride away.

But before we get into that, Dear Reader, perhaps this is a good time to step back and get some perspective. I don't know about you, but I could use a breath of fresh air.



## Chapter 3

### A Breath Of Fresh Air

#### FRESH AIR – A Matter of Opinion

I have come to learn that what constitutes fresh air is a matter of opinion. In my family, growing up, fresh air had to be salty for starters. If it contained gaseous 2-stroke outboard motor exhaust fumes, that was like the scent of a spring flower in the breeze. If it included the pungent odor of sulfurous exposed mud flats – well, then you knew you were home. (Unless you were not actually at home. In that case it meant you were aground on a mudflat somewhere.) But it was not always that way, (well, it was for my father, who was born in Provincetown, and graduated from Provincetown High School when the entire graduating class was, if I remember correctly, 19 students.) But my mother was born and raised in Winnipeg. The ocean was a very remote and mysterious place that might be visited no more than once a year. So it was that when I was 8 years old my father arrived home one day from work with a boat on a trailer behind his two-tone (dark and light green) Oldsmobile. It was news to my mother, my brother, and my sister. It was a 14 foot plywood runabout. That was upgraded the next year to a 17 foot Lyman lapstrake which we had for a few years until that was upsized to a 21 foot plywood Scotty-Craft mini cabin cruiser. After a few years of her, we got a brand new, direct from the factory, 26 foot lapstrake Pembroke cabin cruiser (*the Lady Gwen*). We had her for several years, until we finally capped that off with the

crème-de-la-crème 1938 Chris Craft Cabin cruiser, which we considered a yacht in its fullest sense. We had many adventures in her (*The Tally Ho*). We kept her until it just started to become too much for my father to maintain what with, by that time, his oldest son in the Navy, and his second son (me) in college. His daughter was playing folk guitar duets with her mother in coffee clubs, as much as anything else, and not much help in painting the bottom of a 36 foot boat each spring. The point is that boats became ingrained in our family

Soon enough, I started my own serial-fleet of boats, each bigger than the last. It is my observation that people, once taken for a ride in a boat, fall into one of three categories: 1) I will never get on a boat again. 2) That was ok, I guess, but I don't care if I ever get on a boat again. 3) Someday, I want to live on a boat. I was in category 3. For those very few who actually do it (live on a boat) it is called, "Livin' The Dream."

### LIVIN' THE DREAM

This is the apogee I finally reached in my middle years (This is assuming I live to about 115). I was single again, but had one kid in Elementary school, and another in Middle school. (My first child was decades beyond being called "a kid" by this time.) I had already taken many trips on the boat, spending anywhere from a weekend to a full week living on it. Now I suddenly needed a place to live, and so I "took the plunge" (maybe not the best of metaphors).

There was so much to learn – so much. But, of course, I was not the first person to do this. I started by spending my summers at the yacht club I belonged to. It was on a secluded river that was a place of magical sunsets, mystical sunrises, and fog shrouds that put scenes from Harry Potter to shame. But they close for the winter, so each fall I would need to take my boat to a slip at a marina in Boston that catered to liveaboards. I had landed in a treasure trove of experience, and soaked it up like a sponge (again maybe need to find metaphors that don't involve images of potential ill fates with water). But I was as happy as a clam in mud. (Oops.) One old-timer there called it

“Livin’ the Dream,” and that stuck with me. There was work involved - lots of work, but I never had to mow a lawn or rake leaves, so that was a fair trade as far as I was concerned.

And then there was relaxing time: sitting in the sun just looking around, or sitting in the sun with a book, or sitting in the sun with a book and a bourbon by my side, or sitting in the sun with a book, a bourbon, and a cigar. (The cigar was a rare treat, but what the heck, can’t hurt – by this time in life I had come to realize that what I knew as a teenager must be true: I was invincible, right?). There were different places to sit. I could sit out on the front deck, bathed in sunshine, and watch for fish just below the surface in the narrow travelway between E and D docks. What is not common knowledge is that the water in Boston Harbor, and where I was, right at the mouth of the Charles River is actually crystal clear for much of the year. When it is not, it is due more to the tannin of fallen leaves in the Charles River watershed than anything else. If I wanted a change of scenery, I would hop into my inflatable dinghy and motor out the travelway, turn sharply to port (alert for an incoming boat that might take up the full width at the bend), and out into the mouth of the Charles River.

The mouth of the river at this point in history does not look like any river mouth you might be imagining, Dear Reader. Just upriver was the Charles River Dam, which created the broad bay between Boston and Cambridge that is a favorite background for movies shot in Boston. To the south is the filled tidelands of the North End, supported by a bulkhead. It is now a softball field, but was the site of the Great Molasses Flood on January 15, 1919. It happened when a huge timber molasses tank (think Boston Baked Beans) burst, resulting in 21 deaths, and massive damage. To the north is the developed waterfront of Charlestown. I would go a short distance and turn hard to starboard once clear of the Coast Guard Station and enter the Inner Harbor.

In case you already don’t know, Dear Reader, let me bring you up to speed on a few nautical terms (Just because you may have found this book washed up on a beach, that does not automatically establish you as a mariner). The word “starboard” is what “steering board” became after hard use. Ships of old design did not (and still to this

day some of the old style trading sailing vessels do not) have a rudder in the middle of the stern. They steered via a board on the right side of the hull, similar to how a right-handed person steers a canoe, except this board is set in a pivot point on the right side of the hull. (And they weren't wearing L.L. Bean flannel shirts back then (as far as I know.)) This was so that when the ship pulled its left side up to the destination port dock, the steering board would not be crushed. Thus the left side of the vessel was called the "frankenhufflesteinerschlips " side, later shortened to "port."

Once in the hustle bustle of the Inner Harbor I would lazily motor past Long Wharf, and maybe as far as the old Northern Ave. Bridge, with the distinctive Museum of Contemporary Art just ahead. Then, just to make sure I wouldn't have to worry about running low on gas, I would turn around. As I turned, I would see a few of the Harbor islands, and on a clear day, Boston Light (where The USS Constellation, the Constitution's sister ship, was quickly, and easily destroyed on her maiden voyage by the British during their blockade of Boston in the war of 1812. (They have since lifted the blockade)).

#### BOSTON HARBOR ISLANDS IN YEARS PAST

To understand the islands of Boston Harbor, and indeed Boston itself, it is useful to look back to its past. Not back to the War of 1812, but a bit earlier. We need to go back to the end of the last Ice Age, 11,700 years ago. No need to go back to the ice ages before the last one, since the last one really messed up the remnants from the previous ones. And no real need to go back 180 million years to Pangea, when it was the only exposed land mass on earth. However, now that we are here ...

When Pangea split into the "American plate" and the "all the rest plate" the opening was a narrow bay. But, like many divorces between stubborn masses, the separation was a long and messy affair. The bay turned into a sea, much like the Mediterranean (turned ninety degrees), and eventually this sea became the Atlantic

Ocean. If you are fortunate enough to live in an area that gets frozen bodies of water, you may have watched how the chunks break up in the spring. They don't just split apart and go on their way. They split apart a bit, mush back together, open again, mush together, until they finally realize that they are all done getting together. When the American plate left, it broke off a chunk of the main plate and took it with it. This became the bedrock of Boston. Then 1.8 million years ago the last Ice Age covered most of New England. (And all of this without GPS!) The glaciers pushed gravel over the whole area. When the glacier melted 11,700 years ago, it left these piles of gravel all around the place. The piles of mixed gravel are called "drumlins". They are varying sized ovals. The long direction of the oval is parallel with the face of the last retreating glacier. (The very furthest extent of the face deposited the fine sand that became Cape Cod.) When the ice melted, it became water (I am so freakin' smart), and the water filled in the lower areas. The drumlins in the Boston area became Tremont (three hills) and the Harbor Islands.

### JUMPING BACK - BE CAREFUL

If we, Dear Reader, jump back in time to where we were, and get it just right, we will land back in my dinghy as I am in the middle of turning it around. Here we are. I would then put Logan Airport to my starboard, head past East Boston, the mouth of the Mystic River, past the USS Constitution, and back to my boat.

On my boat, if the sun became too much, I could go up and sit on the "flying bridge" (a deck upon the saloon roof, from which I commanded my vessel when in motion (or at least hung on to when I didn't know what was going on during some engine failure, or fog bound, or electrical malfunction occurrence)). The flying bridge had a canvas top, which meant it had full shade. Here is what I could see from my captain's chair on my flying bridge:

- Looking to the north: Charlestown's Bunker Hill Monument. If I were to ask you, Dear Reader, on what hill was the Battle of Bunker Hill fought?, and

you were to answer “Bunker Hill,” you would be wrong. It was fought on Breed’s Hill. This was due to a bureaucratic snafu among the rag-tag American defenders of Charlestown from the British (Revolutionary war this time.) This proves that bureaucratic snafus are part of our American heritage.

- looking to the west: the iron Charlestown swing bridge (over 100 years old when it was demolished in 2021) with the Museum of Science beyond.
- looking to the south: (in order) “TD Garden”, aka “The Boston Garden,” home of the Boston Celtics and Boston Bruins (a 20 minute walk from my boat); The Old North Church, in the middle of Boston’s historic North End.
- looking to the east: the USS Constitution, “Old Ironsides.” I could also just walk along E and G dock to the end, and be about 50 yards from the Constitution.

Living in Boston is a dream location for a Civil Engineer. There are so many interesting things about the place that books have been written about it - lots of books.

For instance: the old cast iron Charlestown bridge (more correctly: the North Washington Street bridge) is in the middle of being replaced with a stellar new bridge as this book is being written. The iron bridge opened in 1900, and included a center “swing” span. In this style, there is a big central granite pier with equal bridge spans on both sides. To open the bridge for river traffic, rather than pivot up as a drawbridge does, the entire twin spans, which are cantilevered from the center, rotate ninety degrees, thus opening a channel on both sides. The whole thing is set on a ring of rollers on the center pier. The rollers are exactly as big and robust as you imagine them to be. When it was built, the rotation was done by a team of horses that pulled from a specially built horse path next to the pier. At the end of the path was the barn for the horses. Much later, the swing span was simplified by just not opening the bridge anymore. “Oh,” you ask, “Why didn’t they just design it not to be opened in the first place?” Because, back when it was built, sailing ships actually went up the river a bit at high tide to shipping wharfs. When the tide went out in the harbor, the whole lower portion of the Charles River between Boston and Cambridge turned into mudflats, with just a stream in the middle. The ships would sit upright in the mud, tied to the wharfs as they

were. They would go back out to sea at a high tide. When the Charles River dam was built in the early 1900's, it created the permanent basin that is there now. Much later in the century, that dam was replaced with a longer one built closer to the Charlestown bridge. By then, the shipping wharfs on the river were long-ago abandoned. Today's Museum of Science sits on that dam.

The 1900 cast iron bridge replaced a wooden bridge opened in 1786. It was known as the Charles River bridge since that was the only bridge over the Charles at the time. It replaced the ferry that started regular runs in the 1630's. The wooden bridge (which had a drawbridge section to allow ship traffic) was privately owned, and was a toll road. When the Warren Street bridge was chartered in 1828 as a toll-free bridge, very close to the Charles River bridge, the investors sued. The case went all the way to the U.S. Supreme Court.

Sitting in my chair on the flying bridge of my boat, the predominant breeze in the summer is from the outer harbor, which is to say, fresh air.

But my life was not all about sitting around in the sun. I danced, sometimes 7 nights a week, but usually at least 4 nights a week. My interest in dancing started in the late eighties when I was invited to a house party. I knew only the person who invited me, and she did not pre-explain the party. Imagine my surprise when I found a large house where every room had the furniture pushed to the walls, the rugs rolled up, and swing music playing on a stereo. Every room was full of people dancing swing. I just stuck myself to a wall and thought "wow – I want to do that." So I took lessons and danced for years. And then several years later someone said I should try ballroom dancing. So I took lessons in that for more years, and learned the Rumba, Samba, Cha-cha, Jive, Waltz, Foxtrot, Quickstep, and Viennese Waltz. Eventually, I reached the point where I was teaching at a local dance studio, and going to east coast dance competitions.

This was all-consuming until I discovered Argentine Tango, and that was when I truly fell in love with dance. Done the correct way, it is the most difficult, but also

the most passionate, dance I have ever encountered, and I could go on, but then that would be another book. Dance has all the elements of a physical sport in that it requires coordination, balance, speed, control, concentration, but then the release from concentration. In these respects it is like all sports that anyone might take up, like golf, basketball, soccer, etc. But dance has something other sports do not have, and that is art. Your sport is set to music. How you dance to that music depends on how you are hearing it at the moment. But dance is a team sport. There are two members on that team: you and your dance partner, so how you interpret the music and the movements are not just up to you. Your partner for any dance will probably vary, from a complete stranger, to someone you know fairly well, to a spouse, to a lover (these distinctions can become quite blurred at times, but that just adds to the complexity and richness). A word about the men in dance: they are all handsome. A word about the women in dance: they are all beautiful. This is true no matter what your gender identity is. It is not possible to dance for years and not be handsome, beautiful, strong, lithe, compliant, zesty, fiery, and wistful. It just happens. At the highest levels, some can reach a mindfulness state where you and your partner are not a team of two, but you are one. This sounds corny, but it is true. In this state, the “leader” and the “follower” are constantly switching back and forth, according to the forces coming from the music.

There is one problem I discovered with dance: you have to be able to see, at least a little bit. A person could certainly dance “legally blind,” as long as they could tell where other people are on the dance floor, and where the edges of the danceable area are, but if a person were to become, let’s say “totally blind” (aka: blind as a doorstop), then they cannot dance. How I miss it, but wait, I have gotten ahead of myself. All that was about to change.



## Chapter 4

### The Monster

#### THE MONSTER CREEPS UP

Thus it was that I was living my life before going blind - very busy; very bright; full of sunshine, with nary a care in the world (ok, I added that “nary” part as an embellishment, but life was good.)

Then came the sunny morning I was sitting on the flying bridge, looking across the harbor.

Just two weeks earlier I was having one of those magic vacations we all dream about. For me, it was a number of things in combination. I had now just entered my third year of working like a normal person (I had been self-employed for 3 decades), for a large company. What happens when you work as a normal person, is that you get vacations, maybe for a whole week, and when you are on vacation you don't work. That's kind of the whole idea. As a former self-employed person, that was new for me, and I was hoping to get used to it. But that was not the only thing for this vacation. It was that I was driving my brand new car from Boston to Nova Scotia (a bucket list item). Perhaps the biggest thing though, was that I would have my two college age kids with me. Working the logistics to get all 3 of us together for a summer vacation

was a major accomplishment. Since it was only a one week vacation, we took the ferry from Portland, Maine to Yarmouth, N.S. But this was not just any ferry. It was the high speed ferry, which goes, like, 40 knots, which is like crazy fast. That vacation turned out to be everything I could possibly have hoped for. As I reflected upon all this, I was therefore totally unprepared to have a monster grab me from behind.

It is July 4th. I am sitting on my flying bridge watching the USS Constitution leaving its berth for a turn-around cruise, as it does every July 4th. It is a glorious, sunny day. This event is always a big deal for the City of Boston. This day I am by myself. (I am sure that anyone who has been mugged or assaulted remembers it in great detail for the rest of their life, as if it happened yesterday, and I don't know it yet, but that will be how it will become for me.) I watch the Constitution leave its berth heading for Castle Island. From where I sit, I will be able to see only the first few hundred yards of the trip before the Coast Guard station building blocks my view.

The Boston Fire Department have brought out their fire-fighting boats, and they turn their fire hoses up in the air in order to produce huge plumes of water arcing into the sky. This happens at about 10am. I watch the Constitution being pulled out of its slip, and the fire boats turn on their pumps and start their wonderful display. Then, right as I am watching, they all simply vanish. When I say vanish, what I mean is that they were there and then they were not – that simple. I never see them pass beyond the Coast Guard Station.

I am forced to assume I must have just suddenly fallen asleep, although that makes no sense at all. I know as I sit there, it is the same time of day. It was more like a momentary blackout. (I would come to learn that this was pretty much exactly what it was, although I wasn't able to put that part of the puzzle together until November.) What has happened is that The Monster (whom I introduced you to in Chapter Two) has set its clamp on my mind. I imagine this clamp to be a bright red, steel C-clamp, about an inch and a half by about one half inch thick. It Pulls my mind out of my skull, and sets it aside on my left shoulder. It then puts its own mind into my skull in its place. (The Monster stayed in control of my mind and body for the next 5 months.)

What is weird, and upsetting, is that my real mind is completely aware of what had just happened, but can do nothing about it. I can only watch.

### THE MONSTER SQUEEZES

What I am going to describe for you now is what I call the pre-cursor to my disease presenting itself. I will note that this pre-cursor phase, as I will describe it for you, is not part of any official medical description of the disease that I have discovered. However, I experienced it, so I have to assume it is the medical profession that needs to catch up. Here is what happened over that July, August, and September:

While The Monster had its clamp on my mind I was able to function at only decreasing percentages of my real self. Even in these earliest stages I noticed my poorer judgement. I had to be more careful driving. I gained weight. Most annoying, was an increasing stiffness in my joints. I took this to be age finally catching up with me. I had been successful up to this point by keeping my flexibility due to ballroom dancing, but the stiffness got to the point that I could not cross my legs without reaching down and holding on to my pant leg to keep my ankle in place. This was compounded by the fact that I lived by the philosophy, "never go to a doctor's office." After all, everybody there is sick. My displaced mind knew that this monster's mind could not be trusted. I'll give you an example.

My boat had twin engines. The unique thing about twin engine cabin cruisers is that they are surprisingly maneuverable, since you can put one engine in forward, the other in reverse, and then adjust the separate throttles if need be. The slips at the Marina were especially tight, with just a few inches between boats. There was just enough space between the docks to pull out of your slip, rotate 90 degrees, and motor slowly down the travelway. But this spring I discovered that the port engine would start up, run great for about 20 minutes, and then stall, with no hope of re-starting. This, it so happens, is exactly the time it takes to start your engines, let them warm up as you disconnect hoses, wires, and the lines, then slowly pull out of the slip, followed by

about half of your 90 degree turn. It is at this point that the port engine would stall (remember? No chance of re-starting.). The fact is that a twin engine boat on one engine is just about impossible to maneuver. If the port engine has stopped, you can go forward in a long sweeping arc to the port. If you reverse that one running starboard engine, you back up in more or less a straight line - The shape of the hull and position of the prop in the stern prevent the boat from rotating at all. So it was that in the spring that I found that my port engine would not keep running. Well, no problem, I thought, I have the whole summer ahead of me to get it sorted out.

So I analyzed this port engine problem in my spare time going through all the usual, and not so usual things that can go wrong with an old gas engine. As it got into September, the problem was still not solved, but I knew I was getting close to the solution. One day I realized that it might very well be the Hall Effect Sensor. (Possibly, Dear Reader, you suspected the same thing.) So one Saturday morning I took off the distributor and looked inside the sensor. It was so dirty that you might think the engine was 30 years old (It was 44). The mind in current control of me said, "You just need to clean that all out. Q-Tip and cleaner would probably do it." But then I heard my real mind which had always remained on my left shoulder, sitting next to my ear say, "Don't let him do it". And that was that. I knew my real mind was right. Maneuvering the boat out of its slip was a tricky thing at the best of times. In my current condition, If I fixed that engine and tried to take a ride, I did not have the judgement needed to get out of my slip without creating expensive havoc. Not only that, if I did somehow get out into the harbor, I might do something really stupid. I knew, at some level, my intent was to take the boat out to Boston Light and then speed through Hypocrite Channel at full throttle, because that was a wild and crazy thing that no one ever would do. There is a reason no one ever does this. The channel's name is appropriate. The channel is quite narrow, and then there is the huge sometimes barely submerged rock right in your path. The good news was that my real mind still had enough influence to prevail. In my strange world of 2 minds, my real mind told me, in no uncertain terms, "Don't let him fix that engine. Whatever you do, don't let him take the boat for a ride." My mind knew that the safest way to do this was to stall the fixing of the engine for just another month or so, and then it would be time to say, "Well, might as well leave

this as a winter project.” And in this strange 2-mind world, my substitute mind at its lowest level knew that this was true, and allowed the procrastination to continue.

At the end of that summer I am so happy to go to my friends’ anniversary weekend at Newfound Lake in New Hampshire. The way they do it is that pretty much everyone who was invited to their wedding gets invited to the anniversary weekend. I am one of a handful who has never missed one, that’s how great these weekends are. However, even though I do the usual swimming in the icy, crystal clear lake; kayaking upon it; and hiking in the surrounding woods, there is something wrong. All I really want to do is sleep. If you were to ask me at any given time, “Richard, what would you like to do?” I would have said, “Take a nap.” I know something is wrong, but I do not know what to do about it. On the final day I am helping with clean-up. I am sweeping the wooden floor in the kitchen (with a broom! They still have brooms in New Hampshire!) when I reach to move a chair, a little sepia colored shade closes down over my right eye. It is like how certain reptiles have two eyelids. I say, “I just went blind in my right eye.” That gets the attention of the few others in the kitchen. We all agree I should lie down. This I do. After just a few minutes, there are sparkles in that eye, and the sepia shade lifts. I am to leave that afternoon anyways, and drive my friend Joe back with me to Boston so he can catch a flight home to North Carolina. (He lives on a sailboat. Don’t judge him.) The blind shade does not repeat itself during the drive, but we agree I should stop in to Mass Eye and Ear when we get back.

Joe says he should go with me to see the doctor, but I refuse to let him. I tell him to go catch his flight. As I wait the little shade comes down twice more. Each time for just about 5 minutes, but that gives me a chance to learn how to describe it when I see a doctor. I did not have to wait long. The ophthalmologist does a full exam, but cannot figure it out. My description does not line up with any of the symptoms he presents to me. Dear Reader, if you don’t know how many ways your vision can go all bonkers, I advise you not to ask. Your retina can partly detach and fold upon itself, creating flashes of light, and certain patterns of great interest to your eye. Your view can have a zig-zag rip across it. There can be explosions of fireworks. The doctor shows me photos of examples of these, and more. None of them are what I am seeing.

Nevertheless, he assures me they will get to the bottom of it. He sends me to get a full check-up at Mass General, next door, just a corridor walk away.

I check myself in with the nurse at Mass General, but this is not turning out to be a short wait. The waiting room is stuffed full, the lobby outside the room is stuffed full. I am lucky to find a chair. It is loud. There are some people groaning in pain. Some are crying. Someone is brought in on a stretcher with a police escort. People are telling each other their stories, and none of the stories are good ones. My silly little story cannot hold a candle to these stories. I feel bad that I am taking attention away from someone who really needs it. After about an hour, I figure it is a sunny day, and I should just go home. Leave the eye alone. Maybe it will fix itself. Not only did my right eye not fix itself, my left eye didn't either.

#### RICHARD MEETS AN MRI MACHINE

Only problem was that the tan curtain thing happens a couple of more times, this time in my left eye. Well, nothing to do about it, since the doctor doesn't know what it is, and it always goes away. A week goes by this way. The next Monday, while I am at work, it happens again. This time, it does not go away for quite a while. I decide that maybe I have a brain tumor. I panic. I leave work and drive to the nearest hospital. I don't tell anyone. Why would I do that, since no one knows what is wrong? I think maybe I am dying. Here is a secret: If you want to get faster attention when checking into a hospital, tell the receptionist, "I think I might be having a heart attack." A bunch of stuff is done, including my first ever MRI. If you've never had an MRI of your head, I highly recommend it. It is a terrifying trip. The sounds that machine makes are diabolical. The attractive female operator is quite clear about not screaming and jumping around while in the machine. I am put on a (nicely chilled) stainless steel tray, and she rolls my head into a huge menacing steel tube. There is only maybe an inch of clearance between my forehead and the Machine. She leaves the room. Apparently, she does not want to be anywhere near that thing when it goes off. Then it starts. First there is what sounds like the spinning fans of a turbo jet. Then the other sounds start.

Huge booming explosions, tremendous clashes of falling asteroids, screeching of tortured vultures, and then a final crescendo of all the sounds at once. It goes on for a long time. When it finally stops, she comes out prepared with buckets and mops to clean up the remains of my head (My memory of that may not be perfect). But she finds me alive. She rolls me out and I wait to find out how big my tumor is. She announces they could not find anything wrong. That is a bit of good news.

#### THE MONSTER MAKES US READ CHAPTERS 1, 2, AND 3 AGAIN

Although the Monster wants you to re-read Chapters 1, 2, and 3 again to find your place in my story. I will save you the trouble. (By the way Dear Reader, I'm not sure you should be trying to find your place in my story. I like that you are reading this book, but I would recommend against trying to find your place in it. You are not in it. I am, and I do not think you want to swap places with me.) In the previous chapters you saw how my vision took a nose dive over the next month, resulting in my interesting, but scary drive home, going blind overnight, and then being brought to Mass Eye and Ear for my second, this time definitive, exam, and then being taken, this time in a wheelchair, back to this very same waiting area at Mass General.

Let's pick up the story from there ... Now that you have done that, dear Reader, we are ready to resume where I went to Mass General the second time.

## Chapter 5

### The Taxi Driver

#### THIS TIME THERE IS NO LEAVING

My Mass Eye and Ear ophthalmologist explained to me that The Monster's name was GCA, and total blindness was just its starting point. To slow, then stop it, I will need to see a rheumatologist at Mass General. I am put in a wheelchair. I am not going to walk away this time. I am wheeled down a labyrinth of corridors, an elevator, and finally into a triage room with 137 other people (my estimation, based on audio signals). Next to me is an older dude (probably not older than me, just old), who is there because, he told me, the taxi he drove got rear ended, enough to set off the air bags. I hear his admission interview with the nurse. She asks if he drank. He replies, "Yes, a lot." The nurse explains that she needs something more quantitative than, "a lot," so he says, "A bottle of Chivas each weekend." He says his wife is fine with it. She just knows that is how he unwinds. The nurse gets a little more definitive information. I then hear that nurse talking with a doctor separately. (Apparently, they figure that if you're blind, you can't hear anything.) Turns out that his liver is all shot to hell, and he has diabetes. So there, I think, there is nothing like coming to a hospital to put your own plight into a bit of perspective. Apparently, I ain't got it so bad, as there is absolutely nothing wrong with me, as far as I can tell, except that I am blind as a doormat. Then there is a blank gap in my memory.

The next thing I know, I just woke up in a hospital bed. I am very confused. Here's the thing: there is no day or night if the world is pitch black. Apparently I am hooked up to an IV drip which, in my mind, I categorize as a fire hose. By this time my sister has made it to the hospital and found me.

After a while I am visited by a doctor who explains that the fire hose (not her words) is pumping me full (not her words, I think) of a steroid. The steroid is used to reduce inflammation, especially as caused by autoimmune disorders. She explains that GCA is an autoimmune disease that comes on for no apparent reason. Not common in men (lucky me! No, wait ...) She asks me to describe for her "what happened." I do. She tells me that the disease is not called "The Monster" by the medical profession. (I assume some other disease already has that name.) I already know it is not called "Frank", but I hear again that it is called Giant Cell Arteritis. It is a disease that clogs-shut the small arteries that go through the temples and feed the eyes and the optic nerves. Basically First thing GCA attacks is always the eyes. But it doesn't stop there. The blood starvation continues. Next you lose your hearing. Then your sense of smell. Then you lose your sense of taste. But it does not stop there. It then goes after your vital organs, until it gets to your heart. Apparently the only reason it stops there is because you stop living.

So now that I am hooked up, there is nothing more to be done for me but to see how far the disease (Monster) is going to progress before being stopped in its tracks. Sure, right now I am completely blind, but it might get much worse. The doctor said that it will take at least two days hooked-up to the fire hose before the GCA even notices that anyone is after it. So they will do an MRI after a couple of days to try to quantify the damage done.

#### THE MONSTER'S AGENT

Oh, should I mention that the steroid has side effects? It has side effects - big side effects. For me, it is making me loopy and giddy. Over the top giddy. (You will

have to wait to hear about what happens when the dose is too high. (Hint: it is terrifying)).

I have a couple of days of not always knowing where I am. I continue to have in and out periods. After a while, I realize I am in a duplex room. My roommate is the taxi driver that I had shared the admitting room with. I will tell you this: He can snore in biblical proportions. I am talking about “blow the windows out of their frames” proportions. (Jazmine Sullivan: there’s a song in there somewhere.) This is snoring unlike any other snoring known. The next morning I listen to his nurse ask him, “How did you sleep?” His answer, “Fine.” I think, “You didn’t sleep more than 2 seconds in a row before shaking the windows loose.” It occurs to me that they put him in my room because they know I am blind, so the snoring probably won’t bother me. It isn’t until the next day that I think, “Hold on – that doesn’t make any sense.” (My brain has become significantly slower.)

The taxi driver and I get to talking. Turns out he doesn’t drive a taxi for a company, he owns the taxi himself. Now it is in a shop waiting for an insurance claim to work its way to conclusion, and then the taxi will have to be repaired. He figures he will have no income for at least a month or more. I think to myself again, “I ain’t got it so bad.” After a couple of days he is discharged, and I am left alone, in the darkness, with my thoughts - not a good place to be.

## THE WAKE

However, the next day brings a surprise. Apparently, it did not take too long for word of my new situation to circulate. When my nurse announces I have visitors, I am not prepared for the crowd that streams in. Here’s the thing: When you die, all these people from the various circles of your life come together, many of them meeting each other for the first time. But you are not able to make introductions. You are in a box, and you are not allowed to talk to people while you are in that box. You’re not even allowed to watch. So what I am having is a real treat. There is my circle of friends who

are ballroom dancers, another, slightly overlapping circle who are swing dancers, and another who are Argentine Tango dancers. And then there are my co-workers, and finally my relatives. Introductions are being made all around. The thing all these people have in common is great senses of humor. After a while, there is such a Ruckus that a nurse comes in just to see what the heck is going on. I am in a fine mood, and sure, part of it is because I am all drugged-up, but a bigger part is just having all these friends in my room.

Nevertheless, it is very apparent to me that my life has ended and this is my wake. But I am getting to participate.

I remember that as a fun day. Many days after that were not fun days.



## Chapter 6

### To Die and Become A Ghost

#### BEING BLIND IS NOT THE SAME AS BEING PREGNANT

To be clear, I have never been pregnant, but I am blind. Let me explain: 13 percent of the US population is blind. But blindness is a spectrum. Later on I would meet someone who was “legally blind.” If you met her, you would never know she was blind. She would walk to the neighborhood pub with some friends, get drinks, and socialize. She could watch TV like anyone else. The only thing, she said, was that she could not read the ticker that runs along the bottom of news broadcasts. That very annoying band that runs on about things such as other top stories, etc. How outlandishly ADHD must the total US population be that we can’t just watch the news? But I can’t get into that now. She could walk anywhere she wanted, catch a bus, go to the airport and go anywhere in the world. She just couldn’t get a license to drive a car. The blind spectrum extends down, down, until you hit the muddy bottom. Once you are well into the mud, you are called “Totally Blind.”

I'm part of the 1.5% !

According to the American Foundation for the Blind, only around 15% of people considered Legally Blind are Totally Blind. This means that only about 1.5% of the U.S. population is Totally Blind. I realize I have suddenly become a very special person. Now, let me be clear, I am not disparaging the blind. In fact, my new experiences were to become quite illuminating. But I had work to do before I got there.

So here I lay in my hospital bed. There is no night and day. There is only pitch black night. No moon, no stars, no hazy light pollution. But it is darker than that. Basically, I have no eyes. I am aware of only huge black holes in my skull where my eyes used to be. I am trapped inside my own skull. I discover that being trapped inside my own skull is terrifying. There is no contact with the outside world. Picture being trapped in a room that is only as big as the inside of your head. There is not enough room to stretch out your arms to touch the walls. Every direction you turn it is the same. Now imagine that is your world, now and forevermore. I wake up on the second, or maybe it is the third day, or maybe it is night. I gauge it to be day because I can tell there are more sounds outside my room. I remember something about a nurse telling me that there is a pressure sensitive pad under my back and my bum. If I take weight off that pad, an alarm will go off. The purpose of this is to stop me from trying to get out of bed on my own. (What did they think I was, a helpless baby? (Answer: I was.)) I think she may have said this was so they won't have to use a leather strap, which would be the alternative. Nevertheless, after a few more blackout periods, I need to go pee. I have a general idea of where the bathroom is from some time prior when the nurse decided it was time to see if I could stand, and then check if my plumbing worked. So now by myself, I ignore the sound of an alarm going off somewhere. After all, a hospital is so full of strange sounds, although this one is very loud and strangely close. Soon enough, my nurse comes in. She shuts off the alarm. She reiterates the rule: I am not to get out of bed on my own, or even sit up on my elbows. For these

things I need permission from an authority. I realize that they are trying to teach me a lesson: don't trust your judgement, including not only these things, but everything else.

### FULL SPLAT

So after learning a few more of such things, I have time to reflect on my situation. I conclude what was obvious. My life is over. In a very real sense I have died. Death always arrives at the end of your life. Death is the pointed exclamation mark at the end of your life. It is just that now I am lying in bed thinking about this, which I imagine you don't normally have to do after you die. After you die, you are spared the trauma of reflecting upon what just happened. When people come into my room, I can hear them: but I cannot do anything with them, certainly none of the things I used to do. Isn't that what you do with friends? You see them and do things with them. That is what I used to do back when I was alive.

So this must be how it is to be a ghost. I can do a test: I hold out my hands in front of me. Sure enough, I can't see them. It is confirmed: I am invisible - A ghost. Ok, maybe not a real ghost (apparently, I can't get even that right), but close enough. The best way for me to understand what has happened is to imagine that I have been hit by a truck and I suddenly died. However, and I think this unfortunate, I am left inside a ghostly shell. Forevermore I will drift around as a ghostly shell, haunting people, talking to them if they get too close, confined to a room, maybe a hall, maybe even an outdoor path, but wherever I will be I am just an empty reminder that there used to be a person in that ghostly shell. I often think that it would be easier for those outside of me if I had just died after being hit by that truck in that crosswalk on my walk (stumble) home. After all, that sort of thing happens to people all the time, and usually they are a lot younger than me. Everyone would be shocked. Then they would get over it. It certainly would have been a lot easier for me. Something simple like death where you are looking across the street at a beautiful brunette and the truck gets you full splat. I really was not wishing upon myself pain, long term hospitalization, broken bones, flattened spleen and kidneys, and the usual stuff that goes with a full

splat. What would have been fine was the sudden end, and that's it. Your life is over, and you don't know it. The people who knew you will talk about it a bit, and remind themselves to look both ways. They would remember me as the active, busy person I was, and I wouldn't have to wonder what happened after that because I would be dead. But here I am dead and yet still talking to people. But my life was over. I now have to deal with this new pain in the ass situation I find myself in. People know who I used to be, but I am clearly different now. I have lost nearly 20 pounds, so I imagine I look a bit different. Although I can talk (more about that later).

There will be no more dancing for me – ever. Another part of my identity that is lost is my DIY mentality. I used to fix anything that broke down, including those things that were never meant to be fixed. I did my own repairs on my cars, boats, and motorcycles. At one time I owned 7 gasoline (and two diesel) engines in various things. I even attempted maintaining my own bicycle (I might have met my match there). But now, no more fixing things.

I had two kids in college when I went blind, so our time together was highly valuable. I would try to plan things for when we were together, even if it was simple as a walk along the waterfront, or a boat ride to Spectacle Island. Well, no more taking offspring out for boat rides. No more long ambling walks along Boston's waterfront. And the all encompassing one of no more driving. I am grounded. Grounded similar to buried. Maybe I am not in a box in the ground, but where I am doesn't allow all that much more freedom of movement. So now I know what it is like to die.

By now, Dear Reader, I suspect you are just about ready to fling this book out from your beach chair, and see if you can scare that seagull who is inching up to the lunch bag of the person on the beach chair in front of you. Or maybe, you are that person on that beach chair, and you were just about to doze off with your straw hat pulled down over your face. You were looking at all the little spots of light that stream in through the tiny holes in your straw hat. You were thinking about the beautiful brunette next to you... then suddenly you hear something plop onto the sand where your lunch bag is. You put your hat back onto your head and look to find a sand covered

book next to your tipped over lunch bag. You look back over your shoulder, but the person behind you appears to be asleep. Now you are awake, so you pick up the book, brush it off, and start reading it

You become totally engrossed, and can't put it down. It is a terrifying tale of adventure and misfortune. Until it gets to the part where the hero starts feeling really bad for himself. Really? Did Indiana Jones ever just fall into a quivering ball of feeling bad for himself when the huge stone door was slamming shut, trapping him? Did Hans Solo ever ... well never mind that. This book is no more fun. So you stand up, rear back your right arm holding on to this book, and send your 95 mile per hour fastball-book into the sea, while you shout, "STOP IT ALREADY!"

Thank you Dear Reader, whoever you are, for finding this book washed up by the waves, lying tangled in the seaweed. Thank you for picking the seaweed off bit by bit (Do you know you can eat the kelp? No – Wait! Let it dry in the sun first. (The seaweed, but also the book.))

Having said all that, I was still aware that I am lucky that my GCA got stopped when it did. But here's the thing: Many times in this story I will be inclined to say, "I was very lucky", but let's be clear, being lucky would have been not getting splatted by a dump truck (aka: GCA) in the first place. We have all heard people say, "I was lucky that I was right in front of the hospital when I got hit by that dump truck." No. Being lucky would have been just walking to work like you normally would, lost in your thoughts, and then finding out that you inherited a fortune from an uncle on the Cayman Islands, and for some reason, you will owe no taxes on it. That's being lucky. So if you get hit by a dump truck, you get minus 10 lucky points. You might say, "But when I got hit, I was right in front of a hospital." I would give you 1 lucky point for being in front of a hospital, but on balance you are still 9 points unlucky. You might say, "But that dump truck had a Texas longhorn antler mounted on the front bumper, and it missed my spleen by 1 inch." No. I would not give you any lucky points for that. I would deduct another 4 lucky points for getting gored by a Texas longhorn. You might say, "But the truck had just bounced over a bump before hitting me, and the

Texas longhorn missed my spleen, and passed just between my legs, a half inch below my crotch." I would say, "That doesn't sound lucky to me at all." You might then say, "But I am a woman." Then, OK, in that case I would give you one lucky point. But on balance, you are still unlucky.

That was how I felt. I did not know that things would get better. But I also didn't know that first, things would get much worse.



## Chapter 7

### The False Bottom

#### THE DIABOLICAL ARCHITECT

This is as low as it can get, I thought, but I am wrong. I concluded that I had been very unlucky. Nevertheless, after being very unlucky, I did have many lucky things happen. The first of these was that decades ago I got a sister, Gwen. She married a great guy named Steve. She now has the unpleasant task of discovering that her brother has gone blind, and is now a useless ghost. The ghost has no place to live. I have been in the hospital for 6 days, and the hospital is done with me. It is apparent that if someone does not volunteer to take me home with them, I will go to some low-budget nursing home. So they stepped up, and boy, did they not know what they were getting themselves in for, taking care of a ghost while he gets his bearings. Sure, that would be time consuming. But that job description was not even close.

The other thing that happens when you die is that your relatives have to go to where you lived and haul away all your old stuff. Sure. This was made somewhat easier since I lived, up until a few days ago, on a boat, but I still have an alarming amount of stuff. Snap decisions will have to be made by the surviving relatives as to what few things might still be useful to the dead blind guy. It is surprising to realize how many things are of no use if you can't see. If you would like to get depressed sometime, walk

around your home and think about that. But then don't blame me when you find out you are depressed, because you could have left this book on the beach.

So Gwen and Steve take me into their home. They have a very nice house. I suspect this house was designed by an architect who was responding to a contest entitled, "Design of the Most Diabolical House for a Blind Person." Although this may not sound logical now, you need to know that this house was designed probably in the 60s, when it was accepted practice to cull disabled persons from the general population. The idea would have been that a blind person would last about one week in this house before he would wind up killing himself. And that was assuming a skilled blind person. I am a novice dead blind guy. But worse, a novice on hallucinogenic drugs, but more about that later. About this house: I will describe it as I experienced it at the time.

Starting at the bottom, there is a cellar; the proper kind of cellar with an uneven concrete floor, concrete walls, bare bulbs hanging from the ceiling, an old washer and dryer, an outboard motor, a treadmill, etc. All the usual stuff. There are four terribly dangerous wooden steps up from there to what could be a basement (but not cellar, because we just came up from that). This floor, if you wanted, you could call it the first floor if it was fixed up, as Gwen and Steve had done. But there was already a different floor that was named the first floor, so something for the blind dead guy to remember. If you started the blind person in the cellar, he wouldn't ever have made it to the next floor anyways because those steps up have only one rickety wooden railing leaning over on one side, and not enough headroom to get up the stairs. So the general rule while I am there is "Try to remember to keep the cellar door shut when the blind relative is in the house." My bedroom is on the first-first floor. This was made possible by my having kicked my lovely niece, Ada, out of her bedroom. Gwen and Steve had told her, "Gotta make room for your ghost of an uncle, but don't worry, it'll only be for a few weeks. Your bedroom will be your father's office. You'll love it." (Little did they know the extended definition of few.) This floor also has a bathroom, so you might think that was good of the architect, but you would be wrong. It is only there because Gwen and Steve added it. Then there are steps up to what you could call the second floor, (if you counted the first as the first), or maybe it is really the first floor because

that's what it is from the front of the house. Except, of course, it is the second floor from the back yard. Now, in a normal house you would walk up the steps from the first floor (or basement) to the second floor (or first floor), stay with me here, because now it gets complicated. In the middle of the stairs up from the former to the later the architect decided to insert the front door. To make this work, he (not she (she would not do this)) widened one of the steps just enough for the door to swing in. But here's the thing, you need to come up about six steps and then stop to let that door swing in, otherwise, if their door were opened, you would get a door smack in the face – backwards down the stairs you go. But then, that was not enough, the architect thought, "why not have the hallway turn 90 degrees?" Ok, I hear you thinking, "Fair enough;" but wait, I am not done. The architect then thought, "Why don't I put a surprise single step in the hallway right after the door. The kind of step that gets a person just when they think, "I'm in. I made it without falling on my face." I won't go into describing the set of steps up to the third (maybe second) floor, since I am prohibited from using those. But I am not done with the stairs, because at the other end of the house there are steps down from the breakfast nook to the garage. These were placed by making a hole in the floor, and putting stairs in the hole. If a blind person were to walk in that general vicinity, he would just get sucked into the hole. I know for a fact this is true. Otherwise, it is a perfectly safe place for a blind person, provided they are not blind. But let's be clear: it is a lovely place to convalesce in, and I am very lucky to be here.

#### SLEEPING – EATING – SLEEPING

I am there to begin my recovery. I am surprisingly weak. I sleep for nearly the first week, and I have lost many of my basic life skills. I pretty much have to re-learn how to pee. I am unaware that I am getting up every half hour through the night to go to the bathroom. Then Steve points this out to me. He does this by hanging out in the TV room next to my bedroom, and then going with me when he hears me go to the bathroom. He makes me realize that I actually do not go pee when I go there. I just pull down my underpants, wait a few seconds, then pull them back up and flush the toilet. I had no idea that I did not go pee. He has to explain to me that I should not get up out

of bed at the first sign of a little tickle. I have to learn to wait, and wait some more until I really need to go. It is a good thing the bathroom is so close and that I have it to myself, because a few times I almost wait too long, but that is what I have to do to re-learn that basic skill we take for granted.

I have to learn how to sleep again, from scratch. I have absolutely no concept of time and night or day. I live in perpetual blackness in my little room. My room is actually not little. It is just that I do not explore it because if I lose touch with the edge of my bed, I will become completely lost. It could easily be 15 minutes before I would find the bed again. Gwen and Steve have positioned my bed so that I am basically an arm span to the bedroom door, and another arm span to the bathroom door.

I have to learned to walk again. After a couple of days, Steve says, “C’mon, it’s time you got some exercise.” He takes me down into the cellar where they have a treadmill. I get on there at a brisk walk speed, and am flabbergasted to find that I am exhausted after thirty seconds. I can’t talk and have to lean against a post while I catch my breath. I have gone from being able to do a three minute quickstep to barely able to do a brisk walk in less than two weeks. This all without any visible physical trauma. Well, things improve, and after a couple of weeks I am up to 20 minutes of walking on the treadmill. Although this is of course, based on my sleeping pretty much the rest of the time.

#### THE GIANT RAT

One of the things that helps in sleeping is that it is also very, very quiet on my private floor. The only sound is the occasional scratching noise from their pet guinea pig. His cage is in the TV room next to my room.

This is a good time to talk about the hallucinogenic effect the steroid has on me. The way it is being used is to give me an elephant dose for the first week or so, until the GCA (The Monster) was stopped. Apparently, it would be very, very bad if

they were to just stop the drug all at once. They know this because that's what they used to do. So now they drop the dosage by tiny increments over a period of months. (I am very lucky I live in the age of incremental withdrawal.) But here's the thing: if you have just a little more of the drug in your system than needed, it builds up. You start to go loopy on the overdose. After a day or so of loopy-land, you go into happy hallucinations. Unfortunately, you go through this happy phase rather quickly and then descend into not very happy, then into definitely not happy, then into scary, and then into terrifying. At terrifying you can settle in for some time.

When I reach this phase, a female relative who lives with me calls the doctor and yells into the phone. The doctor says that maybe this is a good time to step the dosage down a tiny bit. This happens over and over. It is a roller coaster ride. Here's the thing about roller coaster rides: there is a short period of going up where you say, "This isn't so bad," followed by an eternity of horror. So it is during my first roller coaster ride that I have come off the climbing phase and enter the coaster phase that I am lying in bed in the middle of the night (and this actually is the middle of the night). I hear the noise of scratching rodent feet. At first I think, "Oh my, they have mice on this lower floor. Oh well, not such an unusual thing." So I listen for awhile, and decide that the scratching is a bit too robust to be cute little field mice. It must be squirrels in the walls. That is a sound I have prior experience with. But after awhile more, I decide the noise is not muffled enough to be within the walls. Whatever they are, they must be running along the base of the wall in my room. So I give this noise some thought, and conclude this is not several rodents, but in fact, one very big rodent. (A good guess would have been a pet guinea pig: but this option did not cross my mind.) After some more time, I am able to put a visualization to the scratching noise, and imagine how big the rodent feet must be to make such a loud noise. I realize that, to make the noise I am hearing, the feet have to be about 6 to 8 inches long, and red. So this has to be a giant rat. I give this more thought, and am able to visualize a rat as big as a 13 year old cat, black, with blazing red eyes. This is a serious situation. I do not have a phone to call the police. So my responsibility has to be to wake up the household and save them. I have to get everyone out of the house! I gather my courage, bolt out of bed, and run up the stairs before the rat can catch me. All the while I am yelling out a warning about the giant rat with huge red eyes. My agitation only grows worse when it becomes

apparent that Gwen and Steve are not taking me seriously, saying things like, “There is no giant rat.” Imagine my horror, as I try to impress upon them the urgency of the need to get out of the house. Steve tells me I can sleep on the couch upstairs. Really? That is his reaction to this clarion warning I am broadcasting? Well, I am powerless to do any more. The responsibility is off my shoulders. I figure that since I was next to the kitchen, I probably will be safe. What rat would be bothered with me when there is a whole kitchen in the next room?

The next morning I am able to consider the pet guinea pig explanation option, but we will never know what really happened that night. At any rate, things got worse.

#### THE END OF CIVILIZATION (The Pit and the Tiger)

I had never had a panic attack in my life. I was very lucky, but my luck has just run out. I have a nightmare which goes from bad to worse. In this nightmare, I come to realize that I have developed, due to my blindness, special powers that allow my mind to float free from earth’s bonds. I float up, first up to the area of the moon, but soon find I can go beyond that. But as I glance back to earth, I am able to realize that it is all an artificial construct—an illusion. But an evil illusion. In fact, all the peoples of the earth are actually confined to pits in hell. It has been this way for centuries, and a few enlightened people on earth have known this. I realize one of the people who must be aware of this is my mindfulness coach, whom I will call Rinaldo, in Vermont. He led sessions which are designed to soothe us, and let us live in a more relaxed state. But now my mind has drifted free of all worldly restraints. But it is worse, because I alone see the fact that the time of our collective dream state is running out. The construct that maintains the world’s dream state is crumbling! Very soon it will tumble down, and all the people of earth will discover the horror of real life. There is only one hope. If I can get to Rinaldo in time and warn him, he and others like him will be able to spring into action. They will do whatever the secret is to rebuild the Construct. (Author’s note to Dear Reader: Do not go back to see if you missed something, thinking, “This doesn’t make any sense.” It doesn’t.) If this is not done in

time, once people see the truth there will be no turning back. Having become aware of all this, I shrink myself back to earth, but when I do, because I now know the truth, I find myself in an earth pit. The pit is surrounded by a chain link fence. The whole world is about to realize that they are actually confined in this kind of cage in hell. Each cage is guarded by a monster. In my case, I see that it is a tiger. I need to escape! I study my situation. The tiger keeps out of sight, so I can never tell for sure where he is. I might sprint up the pit wall and scale the fence only to fling myself right into his jaws. But time is running out. If I do not escape, the entire world will live for eternity in hell, and it will be my fault. I do not know it at the time, but I am now in the throes of a full blown panic attack. I am somehow aware of a voice (in my head?). The voice seems to be trying to get me to challenge my assumptions, but this voice is only a further distraction, delaying me from my essential mission. I am keenly aware of how much time I have now wasted. I study the tiger some more, and realize he has huge glowing red eyes. These eyes could give away his position. The problem is that there is only one corner of my pit where I might be able to scale the wall and fence. I see that when I look in that direction the tiger's eyes stay in that area. I need the tiger to move away from that corner. So I pretend to be uninterested in my surroundings. I need not to just get over the fence, I have to run from the tiger, and then run to Vermont. I can tell too much time is being wasted, the distant voice is still talking, but then I see the tiger's eyes move around toward the other side of the pit. It is time to run! I get up the slope, halfway up the fence, but it is taking too long! The tiger is coming back! Just before the tiger strikes, the voice pulls me out of the pit. I realize it is Steve, and I am in my bedroom. Still, there might be time enough to save the people of the world! I am beside myself. Gwen is also there, but neither one will listen to me. I have to get the warning out! I cannot remember Rinaldo's phone number, but I have the number of my friend Hannah, who does. Finally I convince Steve to let me call her, but by now I know it is too late. I have failed, and in a short while the whole veil will come down. It takes some time, but I do get my call out to Hannah. She spends some time trying to talk me down, and then promises to call Rinaldo. After a period of time, I float back to reality. Sure enough, I am surprised (shouldn't have been) to get a call from Rinaldo. We have a good laugh about the whole thing.

So I supposed that all panic attacks end with a good laugh. Sometime later, I would learn otherwise. This little “incident” of mine landed me back at the doctor’s office, where my sister asked of the doctor, “WTF?” She did another MRI just to see if anything got recently fried in the brain enclosure (it hadn’t), and then sent me home. They agreed that maybe it was time for a tiny step down in the steroid dose.

But it was also time for my adventure into darkness to continue.



## Chapter 8

### The Monster Lets Go

#### THANKSGIVING IS NOT JUST FOR TURKEYS

All this time, I am still aware that I am living with the Monster's clamp on my mind. By Thanksgiving week, life has settled into a routine. I have been given a "Smart Speaker" (aka: Amazon constant listening device), and have set it to get up at 7:30 each morning. Steve makes me coffee and a toasted bagel. Then I hang out with an audio book Gwen has gotten from the library, and otherwise nap. The biggest event of these days is when I get to go with Gwen and Steve when they take Pepper for a walk. Pepper is a piece of work. She is a Mayan poodle, which means half-size. She is less than 6 months old, and the words "boundless energy" come readily to mind. The Town has a wonderful park where dogs can run free, and a walk there is great fun for all involved (unless you are a squirrel). In the evening, I watch TV with Gwen. Sometimes we find an audio-described movie on Netflix, but mostly that does not seem to be an option. So I listen to other shows, with varying success at following along. (It is amazing how much The British Baking Show is similar to listening to soothing ocean sounds.) On the Tuesday of Thanksgiving week, at 10 pm, I am ready for bed. I embark on my well-learned journey back to my bedroom. The journey involves my walking around the couch to the back, trailing my hand along its top edge, and then about halfway, reaching across to my right to feel for the waist high shelf on the opposite

wall. Since this involves a reach where I have to let my left hand go of the couch, and reach out into empty space with my right hand, it is about a foot of twilight zone until I feel the shelf edge. That is, of course, if I have set up my right angle correctly. A lot can go wrong in a foot of twilight zone. If I am careless with the angle, I will find myself wandering in no man's land. On the other hand, if I do not release from the couch at midpoint and instead carelessly walk all the way to the end of the couch, I will run out of couch. I will find myself in another no man's land. This no man's land is even harder to recover from. Once released to wandering into the twilight zone, it is amazing how long I can be stuck there. Sure, I will find a wall, or a piece of furniture, eventually, but what wall? Which piece of furniture? This evening I set off, fully prepared, and just when it is time to reach across for the shelf, I am very aware of my mind skipping a beat. (If you are familiar with the black cat and the glitch in the Matrix movie, you know exactly what I am describing.) For just a moment, my mind is blank. When I am next aware, I am fumbling my hands around in the twilight zone. I had walked my hand right off the end of the couch. Gwen expresses her surprise, as it has been a long time since I made that mistake, but I am too tired to explain what has just happened. When I get to bed, I just lay there quite awhile as I make sure I am feeling what I think I am feeling.

The next morning, over coffee, I calmly explain to Gwen and Steve how my mind had been displaced (I had never talked about that before. How could I?) Now, for the first time since July 4th, my own mind is in my skull. Everything is completely different.

I am still on a pretty high steroid dose, so it is not too long before I start to enter another loopy phase. But the good news was that I never had my mind displaced again. I was done with The Monster.



## Chapter 9

### The Mad House – Part One

#### OFF TO BLIND COLLEGE

I am lucky. I went blind in Massachusetts, which has one of the best state funded programs for the blind. I am very lucky because one of the best training schools for teaching the blind is in New England. I am also lucky because the Mass. Commission for the Blind has a particular program which says that if you are out of work because you went blind, and if you could just get rehabilitated, you very likely could go back to work, The state will pay the costs. The State was smart enough to realize that spending a little money up front to get you back to work would be cheaper than having to otherwise support you forevermore. I am extra lucky, because Governor Baker has recently approved a new round of funding, and the school for the blind is starting to line-up new students.

By Thanksgiving my steroid treatment has reached a critical threshold. It was not until now that the doctors could finally say with confidence that: a) The GCA was fully knocked out of my system; and b) I had developed no damaging side effects. Therefore, they will begin the long taper down of the steroid to some kind of trickle maintenance dose. They will keep me on that for an untold time (Maybe forever?) That way they can quickly go full strength if the GCA jumps out from behind a tree and

attacks me again. (Actually, since I am already blind, the joke would be on it, since there would have been no need to hide behind the tree.)

Gwen did a lot of research, Steve filled out countless forms, all as I slept on the couch. All to understand the several different programs for the varying goals and degrees of blindness the school works with. There is an in-person interview we attend. Finally we get the news: I have been accepted! Their plan is that the first session will be their how to live independently program. If I successfully complete that program, I will be qualified to continue on to their computer skills program. The 12-week living program is designed to get a blind person up and, if not running, then at least on their feet enough so that they can live independently. The 4-week computer program is intended to give someone skills with common computer business programs. With hard work and luck, maybe these skills would get me back to my job.

I am extremely lucky to work for a progressive civil engineering design firm. It was abundantly clear to everyone there that I would not be able to do my job exactly as I had been doing it before deciding to go blind as a doorknob. But maybe I could do other important tasks.

But before I can begin the living program, I must go through a two-week initial evaluation. It turns out that many people who sign up for the training programs discover that, for one reason or another, they are really not ready for what the programs will demand from them. Not me, I think. Right? If I get approved after the initial evaluation, I will be able to start the living program. If I complete the living program satisfactorily, I will continue directly into the computer skills program. Heck, I could start this whole thing now and be popped out all bright and shiny by summer! Let's get this show on the road!

I call my new adventure, "Going off to Blind College." I will be living in one of the Blind College's dorms. Gwen consulted with the doctor about whether I will be able to handle all this, because I am still a bit of a wreck. My body is doing some serious re-building, and I still have not proven I can stay awake for a full day. Then

there is the matter of my mental condition. The steroid is heavy duty. It affects me by scrambling up my mind. So far, pretty much all it has done to me is make me unnaturally good humored (except for my panic attack), but otherwise I am in a permanent state of silly-happy. My understanding is that the mood it puts you into can be an extension of your natural base state. I have heard that is why some people become angry and prone to violence when on the drug. In my case, my natural base state is silly-happy. The concern is whether I can maintain a somewhat even keel when left sailing on my own, or if I will capsize. The other problem is that I am still easily confused. The simplest challenges can reduce me to a blob of babbling blubber. The doctor assures Gwen that I will be fine (enough) to go to Blind College. (You, Dear Reader, might wonder why the doctor seems only to talk to Gwen. "Why doesn't she tell me these things?" You ask. The reason is that both the doctor and Gwen understand that telling me these things would be like telling it to a wet towel. I will only remember that the doctor said something, I won't remember what it was.)

So Gwen and Steve pack me up, and take me off to Blind College. It has been decided that I will start in the first week of December. That way I can get my evaluation period done and out of the way before the holiday break.

Here's the thing: Remember How I had been acing luck all along? Unfortunately, there is now appearing to be an inverse relationship between my luck, and my steroid dose. My mental condition is still sharp as a sleepy slug, and physically just about as strong. But I am lucky, because if I actually knew the work that is ahead, I probably would not have started.

#### MY SHIP TAKES ON WATER

A ship can do two things. One is very good. The other is very bad. The very good thing is to take on water. The very bad thing is to take on water. Perhaps I should explain: a) If your ship pulls into a port somewhere to take on water, that is a good thing, because you, Dear Sailor, should not keep drinking rum for weeks. (Did I hear

you say, “Now you tell me!”) b) If your ship is not at a port, and you are taking on water, that is a bad thing. It means sea water is leaking into the bilge. If your bilge pump cannot keep up, your ship will wallow, become unstable, and swamp, capsize, brooch, or yes, even pitch pole if it is stormy. In all those cases, you and your ship sink. Now, we all take on a bit of water sometimes. You know the feeling. But we know we must count on our automatic bilge pumps to kick in and get us back on an even keel.

So the Sunday afternoon has finally come along for Gwen and Steve to bring me to my dorm. Once there, I insist on unloading my clothes into the provided bureaus, so I will know where the stuff is. Gwen then leads me around my room, letting me feel the walls (innumerable), bed (one), and doors (two, one for in and out, and one to a closet). Then she and Steve leave, having been told that someone will be by soon to show me around the dorm. I do not have a phone, since my phone had been an android, and thus a worthless slab if you are blind (shush all ye who are about to post on twitter, “That’s not true.” If you are totally blind, it is.) I have no way of calling them until Steve gets me an iPhone (which he already ordered from the net, but not here yet.) Now I am alone, and it is very dark (as in black as coal (I am, after all, stuck inside my own skull)), and quiet. I decide I should review the layout of my room. First, I realize that I did not remember where the bathroom was. Here’s the thing: I have never lived in a dorm before. When I went to college, I commuted from home, so I really did not put much thought into dorm rooms not having their own bathroom. (OK, I’m guessing I’m not accumulating a lot of sympathy points on my twitter account. What did you expect from an author you found in the seaweed?) So I feel along the walls, back to my point of beginning (the door to my room), and not finding a bathroom, realize that it must be behind the bed. So I feel my way back to the bed. When I try to go behind it, I hit my head on a wall (This room has walls everywhere.) How can that be? I was sure Gwen walked me behind the bed at some point on my room tour. So I go back and forth a couple more times. I finally have to acknowledge that either, a) the wall has moved, as these things do in the Twilight Zone, or b) I do not have a bathroom. But if I do not have a bathroom, where is it? And will I be able to find it on my own in the dark (remembering that it is always dark)?

Since I have been told that someone will be by to help me get settled, I find my way back to my room door and wait. Next thing I know, I have fallen asleep on the floor. When I am awakened it is by Barb, a dorm supervisor. (This might be a good place to say that I am not using the real names of any of the Blind College's staff in the telling of this story.) She checks to make sure I know my basic room layout, and then takes me on the Great Excursion to the men's room. This becomes an adventure. Let me take you along on it:

#### DAY ½

She explains that, first thing, I am to take a left out of my room doorway. I should use my cane to tap along the baseboard of the brick wall. The baseboard is steel, and the tip of the cane is very hard, so this tapping, if done vigorously, is ear splitting. Barb tells me to keep that in mind. I will pass three (Wait, how many?) doorways. To help me detect the doorways as I pass, I should trail my hand along the brick wall. After the 3 (or maybe 4) doorways, I will come to an open no man's land. I will know when I get there because I will run out of wall. I am to stop when I get to the end of the wall. But I need to remember that each doorway along my route will also feel like an end of the wall, so it is very important to keep count. Part of the problem for me is that each doorway has two brick edges: the end of the wall, and then the beginning of the resumption of the wall. So that means at least 6 edges before the final edge. (Or maybe eight, plus the final one, so nine; or maybe seven total.) I am trying to make these mental notes as Barb keeps explaining more critical things. Another important thing to remember is not to keep walking when I run out of wall, because then I will not know where I am. Sure, I would eventually hit a wall but I would not know what wall. So now, remembering all this, when I get to the end of the wall (not being an interim doorway), I am to back up a step, and turn to put my back against the wall. The purpose of this is to get me set off at a right angle for the next leg of this journey. I am then to walk straight (one of the things that I have learned since going blind, is that I do not naturally walk straight.) After walking straight for a certain distance (Ever notice how distances are always certain? It must be nice to be a distance,) I will walk

smack into another brick wall. Of course, I would be using my cane properly, so I would feel the wall first with my cane, as opposed, to say, my forehead. (This is a useful lesson on which I am still working.)

Now I need to remember, that if I do not walk straight, but instead walked in a left arc, I would miss the new brick wall entirely. I would know this, because I would find myself walking for a distance which would be enough beyond certain that I would realize that I was lost in no man's land. I should therefore, not do that. Once I encounter (hit) the new brick wall, I should turn right and feel along it to the end. However, when I get to the end of this second wall (remembering that all those doorway breaks in wall 1 do not a separate walls make), I should take a couple more steps forward, and then turn 90 degrees to the left. I will find myself at a door. When I push that open, I should find that I am in the men's room. But before we get to that, we need to review what would happen if I did not walk straight (from brick wall 1), but instead walked in a right arc. I would eventually encounter (hit) brick wall (number 2), but I would be beyond the men's room door. The way I will know this, is that the next door I would come to will be propped open (probably), and that will be how I would know that it is the kitchen. If I walked in there, I would know it because I will run into a table with my belly. Barb took me there so I could experience that door and belly crash. Then we turn around, and go back to the men's room. Barb lets me go in while she stays outside and holds the door open. She tells me the toilet is ahead, and if I just walk straight (that thing again) I will encounter it. I will know this because there is nothing like the sound of a metal cane hitting a ceramic toilet bowl. (This is a maxim that has proved to be worth its weight in ... well, no need to get specific.) After I find the toilet, she explains that the shower stall is to my right (if I am facing the toilet. On my left, of course, after I get up), and the sink is to my right (after I get up, but to my left as we speak. She now lets the door shut and waits for me to finish my business. When I am done, I discover that finding the sink is a bit of a diabolical task. Apparently, I can easily sweep my cane back and forth right under it without any detection at all. Thus I go right by it. I know this because the next thing I come to is a door, but it is locked shut. I assume that either a) This is a utility room, or b) Barb has locked me in and gone home. When Barb oriented me to the room, she said nothing about a utility room door. Now, I have a decision to make: a) Should I keep going the same way past this locked door, on the

assumption that I will eventually come to the toilet again? Or b) Turn around and go back to the toilet, turn around again, and start over? But if I turn around, everything will be on my other side. Left will be right, and right will be left. In either case, what if I miss the toilet? How will I know? So I decide to keep going around the room in the same direction with the wall always on my right, tapping along. Very soon I come to a plastic sounding thing, and realize that this must be the curb to the shower. Now, I know from my orientation that I cannot be at the shower without having gone by the bathroom door first (discounting the locked door). This was the Twilight Zone thing. So I keep on going some more. Imagine my delight when I come to the toilet! I check that over, just to be sure. So off I go for another circuit in search of the sink (not to mention the bathroom door (although I just mentioned it)). But the same thing happens. So I do yet another circuit. By now, I guess Barb is getting concerned, and I'm sure she has heard all the tapping, so she asks me, "Are you Ok?" I have to admit, "Not entirely." Well, she helps me resolve things. Here's the thing: apparently, on this floor, all the doors have pronounced metal thresholds, not unlike the metal baseboard along the walls. She showed me how I have to slightly raise my cane at a suspected door so I can feel and hear the steel door, as opposed to the steel threshold. They sound just a little bit different. This is how I will know when I'm at the bathroom door. And I need to remember that if I raise my cane a bit higher along a wall, I will hear it tap a brick. I add that to my mental notes. Of course, there is this need to suspect a door in the first place. From now on, I will have to treat all doors as suspect, I guess. But now it is time to learn how to get back to my room. Just everything in reverse. How hard can that be?

Here's what I need to remember:

- a) Come out of the bathroom door, paying attention to the threshold.
- b) Square myself up with it and step one good step straight ahead.
- c) Turn 90 degrees right (not left).
- d) Take a couple of steps.

e) I will find the brick wall (remembering that this is wall number 2 (unless I want to count it as wall number 1 going in this direction)).

f) Follow along that wall to the end.

g) When I get to the end, stop.

h) Back up one full step.

i) Place my back square to that wall. j) Walk forward, straight (what else), until I hit the other brick wall (number 1 or 2, depending).

j) Upon hitting that, turn left (not right).

k) Follow that wall (counting the doorways, however many there are) to my door. My door is made obvious by having two elastic hair ties wrapped around the handle. There. I am done.

So now I have been at Blind College for about five hours. Only 20 weeks minus 5 hours to go.

## Chapter 10

### The Mad House – Part Two

#### SO IT BEGINS

I finish my arrival Sunday by going to bed and gratefully sleeping the way a log does. The next thing I become aware of is being awakened by a knocking at my door. I get up, and fumble around for several minutes. I find my dorm room door and open it. Barb tells me it is morning. Time to get up if I don't want to miss breakfast. I so do not want to miss breakfast. I am introduced to the routine which will become my way of life for the entire time I will be at Blind College. Each day starts at 7:15 sharp with a guided outdoor walk from the dorm to the adjacent main building where the cafeteria is. We are given a wonderful and hearty breakfast. Each day, I eventually realize, is a rotating, but repeating menu that includes at least a couple of choices. I love everything. 50 (or so) minute classes are scheduled continuously throughout the day to 12:15 lunch. Then more classes until supper at 5:30. So if you had a full day, you will not be back to your dorm room until around 7 pm. If you were like me, you need to be in bed by 8 or 9 at the latest. Most days there are one or two empty slots in my schedule, but there is always at least one day that is all full up. Of course, I have no way of telling time. Heck, I can't even tell night from day. So until I get my new

iPhone, and learn how to use it, I will have to rely on the teacher of whatever class is next to come find me in the waiting area, call out my name, and lead me to the next class. After the class, someone needs to walk me back to the waiting area. Each teacher has to be alerted in advance that there is this one dude, dumb as a doorknocker, who has to be personally found and brought to class. The other problem is that I don't know what my class schedule is. It is different every day. I can tell that other students seem to know their schedule, but I have no idea how they know them. It was at least a week until someone tells me that my class schedule is taped to a wall in my dorm room. Really? A piece of paper with a written schedule taped to the wall of a totally blind person's room? I am left speechless. (This is a state that I am totally unfamiliar with. If I have a middle name, it is Loquacious. (It isn't.))

## THE KEYBOARD TORTURE DEVICE

The blind that already have cane skills, after proving themselves, can go back to their dorm rooms during empty slots, which is a great way to relieve stress or catch a quick nap. There are two dorm buildings. To get to either of them from the main building requires taking different outside paths. A great number of "clients" (students) are like me, newly blind, with no cane skills. We cannot be trusted to go outside and not end up in the middle of some highway someplace, trying to sell pencils from our hat (which would have been empty anyways). So we have to wait out our open time slots by sitting in the waiting area of the main building.

I am unlucky because the steroid keeps me in a wash of hazy confusion. (Is there another type of confusion? Is there "focused" confusion? (I bet there is)). Relatively simple tasks are very confusing. This is layered over the fact that I do not know how to do anything blind. For instance, I thought I was lucky because I knew how to touch-type. When I went into business for myself years ago I had to go through the difficult, and slow process of teaching myself how to type, but once learned, I could rip along as fast as I could think. (Sometimes faster (not recommended)). I thought I was so freakin' smart. Then I met my instructor, Ava, who is to teach me how I will

be able to type blind. That is when I learn I actually am not the sharpest knife in the chandelier. She explains to me that the blind can still use a computer, type reports, surf the web, etc. They do this by using a “screen reader” program. I learn that a screen reader is a computer program that reads aloud whatever is on your computer screen. In some circumstances, they work great. In others, not so much. But it will take a lot of time to learn how to use them. The good news is that Ava is going to teach me how to. But before she can start, she has to just confirm that I know how to touch-type (which means, Dear Reader, if you are less than 50 years old, how to type using all your fingers without looking at the keyboard).

So it is that in my first technology class I tell Ava I am anxious to get started. She says that sounds good to her. She asks if I know how to touch-type. I assure her I do. She says that in that case, she just needs to find out how fast I am. So she starts a typing training program. (I must pause here while I get up and punch my head against the wall a few times. OK. I’m ready to continue.) The way this program works is that each time you press a key, it speaks aloud. Ava sits next to me and makes sure I am positioned correctly in front of the keyboard. Here is how it goes:

Ava, “Type ‘a’.”

Me, I type what I assume to be “a”.

Computer, “aeah” buzz sound.

Ava, “Type ‘a’.”

Me, I type the same key.

Computer, “aeah”.

We repeat this at least one more time (maybe more).

Ava, “Do you even know where the ‘a’ is?”

Apparently, I do not know that “aeah” is not the computer’s word for “a”. It is its error horn. All along I thought I was pressing the “a” key. I think about this for a minute, look down at the keyboard (silly, because, I could have looked into the sun for all the difference it would make). I then realize, for the first time, that I actually have no idea where “a” is. All these years that I thought I was touch-typing, I was actually quickly looking back and forth between the screen and the keyboard. Painful Truth: I don’t know how to type. Even more painful is the realization that Ava must have begun to think that I was brain damaged in some way as I just kept typing the same incorrect key each time she asked me to type “a”. I hastily explain that I didn’t know that the error sound was not its “a” sound.

So now ensues weeks of training with the keyboard training torture device. The way it trains you is by voicing a sentence (simple at first, growing more complicated as you progress), and you try to remember what it said and type it. Each time you screw up you get that error horn while it keeps repeating itself, which is why the astute can recognize a student who is going through that training, because they are looking down with a constant twitch of their head, and are muttering to themselves as they drool.

Let me explain how the program is actually a diabolical torture device. Each time it starts up, it plays a little inane pin-ball machine jingle. After only a few times, you cannot get that out of your head. It is a signal to your brain, “Aggravation To Come.” It also has a problem enunciating its words. For instance: It says to you in its rapid machine voice, “Sally has a red dress dot space.”

So you (having been hit with the stupid mallet) type, “Sally has a red dress dot space.”

But then it talks over your typing by repeating the sentence again and again while you are still typing.

So you type it again, carefully, but it just repeats its sentence.

This cycle repeats until you call Ava over from the other person she is helping, and say something along the lines of, “WTF?”

She says, “What you have to remember is that it calls a period ”dot”, and when it says “space” at the end, it doesn’t mean to type “space”, it means to hit the spacebar to continue. Good luck.” Then she leaves.

It also has a problem with enunciating its words. For instance, it says, “Ken takes tea dot space.”

You type, “Ken takes tea (and not being a Cro Magnon, remember that dot means period, and space means spacebar)”, but it just keeps saying the sentence again.

You call Ava.

Ava says, “Oh yeah, when it says, “ken” it is really saying, “can”, and, “takes”, it’s really saying, “apostrophe”, and when it says “tea”, it means “t”. Got that?” Then she leaves.

There are so many other similar instances that they all merge together. It is like walking through a thick fog and getting hit in the face by ice needles blowing in from the harbor.

All this might be set aside as a minor annoyance, but the damn program keeps score. I cannot move on to the next lesson until I hit a certain proficiency. Fine. As I write this, I’m over it. (Hold on, I’ve got to wipe up the spittle from my keyboard).

## THE FUN THINGS

Braille is fun, at least at first. I learn the letters using a peg board where each peg is about 50 times bigger than an actual braille dot. Oh, sure, I can learn the letters then. But when my instructor, Fran, then takes that away, and puts in its place an actual braille piece of paper, well that is another story. In braille, there are spaces between sentences, but not the individual letters (Ok, Dear Reader, I here you saying, “is not that the way it is with print letters?” To that, I say, “Shut up, I can’t tell the story with you talking in my head.” A smart retort from you could be, “You want that I should come over there and yell it in your ear? “Ok,” says I, “You win, but we’re not done here.”) But there is another factor at play. It is not until much later that I realize how much my steroid has numbed my fine motor movements; and especially, the feeling in my fingertips. The result is that all those tiny, tiny, dot bumps run together. This results in my assessment of braille as being “Stupid-Hard”. Fortunately, it is an optional course. But there is an upside: I can now read the braille floor designations on an elevator button pad (provided the building is not very tall).

## O&M – NOT JUST M

It is not all hard work. One of the classes that everyone likes (except those with one (or two) bad hips (or knees) is O&M. O&M is short for Orientation and Mobility: Learning to get around with a cane. The cane for blind persons is the thin, white walking stick you are used to seeing them with. However, it is not called a “stick,” it is called a “cane.” The white cane is specifically designated for blind persons so they can be identified right away (for instance, when only the cane and a couple of shoes are showing from under your car). First thing that I learn is that all my information about what is in front of my feet comes from what the tip of the cane touches. If the tip doesn’t touch it, it doesn’t exist. Even more important, if the tip of the cane doesn’t touch something, there is nothing there, as in I am now at the top of a stairway, or at the edge of an open manhole. Point is:

a) If you feel something, and don't know what it is, stop walking (as in now, not think about stopping).

b) If you feel nothingness, see a) above

Later on, I will learn how to augment the information about my surroundings through sound, smell, wind, and the feeling of sun, or lack of it, but primarily, it is the tip of the cane.

#### YOUR FOREHEAD IS NOT A BUMPER

Here's the thing: the tip of the cane tells you what is on the ground in front of you, but from the ground to the top of your head, you have no detectors, other than your body parts. It turns out, one of those major parts is your forehead. So much of the training is focused on teaching me how to minimize the use of the forehead as my major detection sensor. (I cannot tell you how many cuts (little) and bruises (big) I accumulate on my forehead.) The other problem I have is my habit of doing only the Mobility part of O&M. I take off walking and sweeping my cane. After a few steps, I realize that I am in the middle of nowhere, with my cane not detecting an edge of anything. Here's the thing: You are supposed to Orient (the O part of O&M) yourself first, so that when you head off, you actually know where you intend to go (or you, at least think, you know).

#### WHAT TIME IS IT MR. FOX?

If you have taken children to swimming classes, you may remember the game the swim instructor might have taught the children. The kids line up against the pool wall, holding on. The Instructor stands in the water a couple of strokes away. She thinks of a random number, and then asks, "What time is it Mr. Fox? The kids shout out

guesses, and when she hears the right one, she says, “Right!”, and the kids all race with their newly learned swimming motion to be the first to touch her. My life was like that. (Not the touching the female swim instructor part. The what time is it part.) The current time can be any random number. I never know what time it is. As I mentioned, I have no phone, and it is always as dark as the middle of the night (on a moonless night).

The beginning and end of classes are announced by a two tone chime system, but I never can make sense of what the various chimes mean. There seems to be a chime going off at all kinds of different times.

I only learned many weeks later that the system is:

- a) A chime that is a 5 minute warning to the end of a class.
- b) A chime for the actual end of a class.
- c) The classes were not all the same length, and sometimes you have a double class, which means that some chimes are to be ignored.
- d) The fact that I do not have a class schedule, so I never know when I am due for a class.

For this two-week Evaluation Period I talk to no one except my instructors. It is not that I am not a friendly person, it is that I don't know how to relate to other people while being blind. In general, during breakfast, lunch, and dinner, the place is a cacophony of loud chatter. Since the learning programs start and stop at different times, the result is that when I came in, it felt like everyone already knew each other. That is because they do. I need to speak up and insert myself. But I am not very good at this, because I cannot see anyone. I cannot judge when I might speak to someone without interrupting them, or just as likely, introduce myself to an empty chair. (Ask any empty chair at my Blind College, and it will probably know who I am.)

## WHY IS YOUR THUMB IN YOUR POTATOES?

At any rate, I do not really have any time for talking at meal times because it takes all the allotted time just to eat my food. Turns out, I am a very bad blind eater. Here's the thing: Not only can't I see the food, but I can't see the plates, the forks, knives, and yes, cups of juice. It goes like this:

- a) I try to feel for the outside edge of my plate.
- b) I place my finger into my mashed potatoes.
- c) I find my napkin and wipe my fingers off.
- d) I repeat from a) above.

The staff are good about keeping an eye on me. Eventually I learn the basics.

So those are the daytimes. Let's now get to the nighttimes. As I mentioned, there is not much to do in the evening, except to do some floor exercises, go to bed, and get up at night to go to the bathroom.

## YOU ARE KNOWN BY THE CIRCLES YOU TRAVEL IN

I am presenting as a dude with a serious learning disability, as far as going to the bathroom goes. On the second night, the first time I got up to go pee, I leave my doorway, take the left, like I was told, and as I tap and feel along the wall, I lose my train of thought (or: That train had already left the station). When I come to the next doorway, I trail off into the cosmos. Within a few steps, I had lost all track of the wall. Soon, I have no idea which way I should go. You know how a space capsule loses its

propulsion, and starts tumbling in the weightless void? That is me. I am left no choice but to just stand there until a dorm supervisor eventually finds me. It is Julio. He asks me where am I trying to go? So then ensues another lesson on how to get to the bathroom, but this time by a different person. (This is not good for the reputation I am building.) Later that same night, I get up again, and actually get to the bathroom (eventually), but coming back turns out badly, and I have to wait to be found again, this time by Jim.

After a few nights, I learn that the whole dorm space is just a big circular void. (The building had formerly been a silo). This means that if I miss either my dorm room or the bathroom, I could just keep tapping along and I will eventually come around to my point of beginning, which I might miss, but I could just keep going around again. I do this many times in the course of those two weeks. Poor Julio. Poor Jim.

Julio and Jim are nighttime dorm supervisors. Julio's room is the last door on wall #1. The dorm supervisors have the un-enviable job of having to leave their door open all night so they can hear anything out of the ordinary. Julio soon learns to recognize the sounds of my navigation, as it were, to the men's room.

Going into the second week, my steroid dose is building up again. One of the effects of this is that I absolutely cannot respond correctly to "left" and "right" directions. (You, Dear Reader, will be quick to remember that knowledge of these is critical to getting to and from the men's room.) Late one night Julio is with me at the exit from the men's room where he found me going in small circles. He sets me parallel with the men's room door, and tells me to step forward, and then turn right. I turn left. We do this again and again. Now I am feeling bad for him, because I can tell he is tired. It is then that I remember that an additional steroid side effect is that while words give me great trouble, numbers are fine. So I simply tell myself that left is 01, and right is 02. From then on, whenever he (or anyone else) says "left" or "right", I simply convert that to "01" or "02" in my mind. I never make another left or right error again.

Jim is another night dorm supervisor. His room is way on the farthest side of the great circle. The only reason for my walking past his door would be that I headed the wrong way out of the men's room, and now am walking the "great circle" around to my room, maybe even finding my door when I come to it. By this time I know, at least, I cannot get lost. I try to be quiet as a mouse going by Jim's open door (a mouse tapping a metal cane on a metal baseboard), but sure enough, Every time I try to sneak by, I hear him groan and come out to salvage my sorry ass.

#### A SOUP DISH IS NOT A FACE RECEPTACLE

Have you ever fallen asleep in your soup? Here's the thing: It's not embarrassing, when you do it because you are asleep. Now I'm sure it's a bit alarming to those around you because there wouldn't be much difference between face-planting into your soup because you are tired, and face-planting into your soup because you just had a massive heart attack. Either way, not embarrassing at the time to the face-planting person. Well I did that sometime later in my second week.

The staff, of course, are well trained for this, apparently, because they get my face cleaned off, carry me back to my room, and tuck me in, all without my ever knowing it, until it is mentioned to me the next morning at breakfast.

The amazing thing is that, in spite of my having the mental clarity and physical attributes of a wet bath towel, I am still learning stuff. Suffice to say, although I cannot see it in the instructors' eyes, I can sometimes detect the surprise in their voices when they find that I have actually learned things.

I am certainly not surprise that at the end of the two week evaluation period Blind College decides that I need some more time to dry out before starting into the next program

They do not know it, but they have released me just in time. I was headed for rock bottom.

## ROCK BOTTOM

This period is quite fuzzy for me to recall. I know that I am acting increasingly like a Roomba vacuum bot stuck in a corner. It is decided that I should have another MRI to see if maybe I had a stroke. I am getting to be an old hand at this MRI thing. I suspect it is getting harder to evaluate my mental state since I am so loopy. After the MRI I am kept in the hospital. I descend deeper into blackness.

## TOM BRADY IN THE SUPER BOWL – AGAIN?

I spend my nights in the hospital (remembering that all 24 hours are night.) The season's Super Bowl occurs while I am in that hospital. The Patriots are in it (again). I am lucky to be living in Boston during the Tom Brady (and, oh yeah: Paul Pierce, Kevin Garnett, Big Papi, and Claude Julien) era. Although I am a huge Patriots fan, on that particular night I don't care about the game a single bit. I don't even listen to it on the tv in my room. I just don't care.

After a few nights, they determine that nothing new is wrong with me, and it is safe for me to go back to Gwen and Steve's. A week or so after that, I have gotten my senses back enough that I am ready to get back into blind college. Much to Blind College's credit, they realize that somewhere below the surface there is an actual person that would benefit from getting back into the program. But I am lucky. This happens just as the winter holiday vacation comes upon us. It will be possible to dry me out for a couple of weeks, and then get me back into the program when it next starts up. So you can well imagine the glee with which Gwen and Steve welcome me back into their home. I don't know if I have earned the nickname "Giant Rat Detector". I'll

have to ask them. My job now is simply to not go crazy with boredom. Not to worry, there was plenty of excitement to come.



## Chapter 11

### The Mad House – Part Three

#### NEW DOORWAYS FOR MY FOREHEAD

It is now that, in all fairness, I must point out that the place I fondly call “Blind College” that I went to is not actually a Mad House. But here’s the thing: If you are on a high dose of anti-inflammatory steroid my experience is that wherever you are is a Mad House. As I entered my second phase at Blind College, my dose was much more reasonable. I was, rather than being a lunatic, just a happy, but loopy, newly blind person.

I am delighted to find that for this phase I am in the second dorm. This dorm is also a former farm building, but it’s transformation into dorm rooms has resulted in a much more traditional layout. Imagine my delight when I find that the men’s room is very close to my room. So close in fact, that I am able to quickly reduce my travel to it to two arm spans. No cane needed. No tapping along walls. The layout inside my room is also simple and logical, although I think this realization is just a matter of my mind being less of a puddle on this go-around. Not that this dorm did not have its own issues. These doors do not have thresholds at all. The carpet is just continuous from inside my room to the corridor. In addition, the doorway to my room is not exactly square with the room walls. Here is what this means to me every time I leave my room.

- a) I feel along the wall until I find the heavy door handle.

- b) I now open the door.
- c) I swing the door into my room, thus clearing my way to leave.
- d) I now take one step forward.

But here's the thing: Forward is a relative thing, and never more so than when you are blind. So, if when I swing my door into my room, I allow myself to rotate a few degrees with the door, I might be facing not the corridor, but in fact the door jamb. Since there is no threshold on the floor, there is no reference line for me to realize this. Thus when I take one bold step forward I am actually taking one foolish step across the doorway opening. I will boldly take another step forward. This is enough to drive my forehead strongly into the door jamb. With the steel door jamb embedded into my forehead, I will become aware that something is not ok. Alternatively, my initial angle might be a little off in the other direction, such that my first bold step forward is followed by a second bold step and even a third, as I start walking down the corridor at an angle. Now if I had brought my cane, I would be OK, but of course, I have not. At some point I will realize that something is not right because I will have driven my forehead into a wall, but of course now I have not the slightest idea where the freak I am. This is when I start walking in alternative directions. Sooner or later I will drive my forehead into a different wall, but I still will not know where I am. I have already been taught that I should hold my free arm casually across my body, a few inches in front. This then, does not look like a lost blind person fending off dump trucks, but is just casual-like. This casual arm becomes your bumper (at least at that height. I, however, not being the sharpest boulder in the channel, have not started doing that. It turns out that I only need to do this a few (several) times before I learn to finely tune myself to that doorway angle before heading boldly off. Then there is the phase of feeling along the wall for my open door, which may, or may not, actually be my room.

Thus, I was firmly ensconced and ready for my next phase of Blind College. This phase was much more successful.

The steroid has adjusted my maturity level to that of an 11 year old. However, it seems that I can still function in my classes, with the side benefit that those students that share my comic tendencies are able to flourish as well.

#### SOMEONE IS A CLASS CLOWN

How many of you are thinking, “What I would give to re-live my 11 year old phase?” Ok, none of you, but here’s the thing: You would have a different answer if you were the class clown when you were 11. Blind College is accustomed to all types of persons, going through all types of personal trauma, with the result that they are not heavy on discipline. Thus, I am a class clown with no restrictions. Imagine that, fellow class clowns! (I didn’t realize until later how loud I was.) This is compounded by the fact that the main building has three floors that are all open to a large full height atrium. So, let’s imagine a class clown having two friends visit with him while he is in the atrium with two other like minded students. What you would have is a very loud group in the middle of the large open atrium, such that there would be no one in the building who was spared the hilarity. I give Blind College so much credit for not whacking me upside of my head with a wooden pointer. (For the record, to my knowledge, the instructors do not go around with long wooden pointers (like the ones your elementary school teachers had if you grew up when men were men, boys were boys, and teachers were pit bulls. However, just a thought, how would I know if the instructors all did have long pointers, and did go around whacking students? I am blind. All I would hear would be random whacking sounds followed each time by yelps.))

All during this time, not known to me, the steroid dose was just a bit too high, so it is building up in me. The initial effect of this is to make me even happier. So happy that I achieve a class clown pinnacle that I will treasure forever.

I was in one of the first floor classrooms with Ava, who was my keyboard torture device operator, and is also my iPhone instructor. She is maybe my favorite teacher. There happens on this occasion to be a teacher in training present, Monica. So,

in other words, from my point of view, an audience. Ava is trying to teach me to push the button on the iPhone, and then say:

“Open Tap-Tap C.” Simple enough.

Me, (quite honestly, not being a clown), “Open C Tap-Tap.”

This is followed by Ava explaining that the name of the app is “Tap-Tap C.” She has me practice saying that three times so that it is drilled into my head. Then, when assured that I’ve got it, she has me press the button, and:

Me, “Open C Tap-Tap.”

This is done quite innocently enough, as pressing the iPhone button apparently has the effect of erasing my brain. But it does bring on the laughter from both Ava and Monica.

This happens four more times. Finally I sit poised over my phone button ready for my next attempt, and before I can do anything, I break down into uncontrollable laughter – the contagious kind. Within moments both Ava and Monica are also in uncontrollable laughter. Such laughter that none of us can recover. If anyone gets themselves under control, the others set them off again. We are laughing so long and hard that our sides hurt. Finally, Ava just has to motion and say, “Go, go.” I have gotten my classroom locked in stiches. It just doesn’t get any better than that. Such an achievement.

#### THE iPhone AS AN INSTRUMENT OF TORTURE

As I mentioned earlier, I had always been an android phone user. Due to excellent recommendations from my teenage son Ben, I usually had the most advanced model (for the money). I had several of the best music player apps (especially if they

had pitch control, useful for slowing down a song when teaching dance) and a cool app that shows you the night sky, with all the stars and planets (labelled if you want). It shows you the night sky at your location. As you move your phone around, pointing to the sky, the stars and planets come into view. When we were in Nova Scotia, we had a cabin for a few nights in one of the purest night sky spots in the northeast. We anxiously drove the car a mile or so from the site to get away from its one overhead lamp, and got out of the car to see the rich night sky as few ever get a chance to see. Oops. I forgot to check. The moon was about half full, and was about as bright as any city light. So we all did the absurd thing of opening the night sky app on our phones, holding them to the sky, and seeing the stars and planets.

I was pretty familiar with all the android phone's functions, controls, and camera. In short, I loved my phone. (If you, Dear Reader, just picked this book up out of the seaweed at the beach, first, brush any tiny baby turtles off. Then go back to Chapter 2, and you will learn how my android seriously let me down.) If you can't see the face of an android phone, you might as well throw it into the sea. Although people may tell you that you can do all the things on an android that you can do on an iPhone, they lie. It might be possible that you can, but as I understand it, no one has ever done it.

The iPhone has something called "voiceover". It announces what icon your finger is on, and you can activate the button by double tapping it. How hard can that be? But hold on—you might actually, in a particular case, need to swipe right briskly to find it. "Ok," you say, "how hard can that be?" Hold on, "Not so fast." It might be that, in another particular case, you need to swipe up with two fingers held together. "Ok" you say, "I can remember that. How hard can that be?" But hold on there tiger. In this particular case (obviously, a different case, but note that the logic of the different cases will escape you), you may need to use 3 fingers, held together. "Ok," you say, "Wait, what?" But hold on, it might be that you don't swipe up (or maybe it is down (or maybe it is that it doesn't matter if it is up or down)), you need to swipe strongly directly right (or left, but only if you wanted to go back). "So what?" you say. But wait, I am not done. Voiceover can get "funky" (which may, or may not be a technical term),

so that, even though you did the correct action, you got no response, or maybe you slipped off the edge of a virtual cliff. Don't worry, if that happens, just restart your phone. How hard can that be? But wait, if you don't do the restart procedure correctly, you will instead butt-dial 911. I know because I accidentally dialed 911 at least 4 times in one week when at Blind College. One time, I was waiting in line at the cafeteria and I faintly heard a voice saying, "What is the nature of your emergency?" After hearing this a few times, I listened carefully. I realized it was coming from within my pocket. I took out my phone and assured the dispatcher that everything in my pocket was fine. Fortunately, they were used to the explanation that you are a student at the blind school, and the phone is new. (Heck of nice people there.)

## WHO NEEDS FINGERS

For all of us, one of our favorite classes is woodworking, taught by Bob. First off, Bob is just a hoot. Second, we get to work with incredibly dangerous tools in a dangerous environment. There is the long woodworking bench, as you would expect, but what is different is that all the tools, including those with power cords, are hung up on a peg board behind where we sit. This means that when you walk into the workshop and make your way to a chair at the workbench (being blind and all), you might have to walk across some of these power cords strung across the floor. I think the thinking was that this is how things are in real life, so learn how to deal with them now. There is a technique. It is called "pick up your freakin' feet."

We learn how to use power drills, power sanders, planes, hammers, nails, screws, and other sharp objects. By the end of the semester, we have used the electric rotary chop saw, learning how to feed our piece into the saw lined up with our scribed line by using just our knuckles. (Don't try doing this yourself with your eyes closed just because you read about it here. Remember, if you chop off all your fingers, it will be harder to flip the pages of this book, and harder to throw it into the sea).

Each of us had to pick a project to make that we could get done in the time we were going to be there. Some people made impressive things. Not me. I made a stained wooden box with a hinged lid. (It is now on my kitchen table holding tea bags.)

Bob is a joker. I was a class clown. If one of us did not have some discipline, nothing would ever have gotten done. The way the class schedules work is that you have the same classmate for each of your classes. For safety reasons, woodworking classes only have two students per class. My classmate is Alfred, who is from a small Caribbean isle. Alfred is as serious as I am silly. He knows why he is there, and he is all business. Alfred has this great Caribbean accent, and he is in our dorm. Early on, he got one woman's name wrong, and always called her Miranda. It was maybe the last week we were all there that while sitting among us he realized that he had always called her by an incorrect name. He asked her, "Why didn't you tell me that wasn't your real name?" She answered, "I just love the way it sounds when you say Miranda with your accent."

As far as I can tell, Alfred has no sense of humor. I only learn otherwise when one day I have to leave class to go pee. It turns out, there are consequences to having four cups of coffee with breakfast. When I return from my adventure (because leaving the woodworking shop and finding the bathroom on the first floor is always an adventure), I let Bob and Alfred know what I had learned. Namely: The rim of the ceramic urinal and the rim of the ceramic sink are at exactly the same height, and they both sound exactly the same when struck with a cane. Now, the fact is that I had not made any critical errors while in there, but that was only due to my very careful checking each object for other tell-tales. Upon hearing that story, Alfred pretty much lost it, and Bob could not help himself either. I had scored another class clown victory!

However, with my steroid, when there is a bright side, it is followed by a dark side.

## SPINNING - SPINNING

A few days later, I am awoken in the middle of the night: time to go to the bathroom. Nothing wrong with that. Unless you do what I did: I sit bolt upright in bed, and instantly in the same motion rotate 90 degrees to swing my legs over the side of the bed. (Try that sometime, Dear Reader (don't.)). The effect is instant and intense dizziness. The whole room swims around me. Remember, I am blind as a doorlatch, and still need to go pee. So I try to get out of bed, but my legs are rubber. Useless. I sway, stumble and crawl around the room. Each time I try to stand to find the door, I bounce off walls and furniture. I could call out, the dorm supervisor is just a room away, but asking for help is not my style. Also, I know if they find me in this state, they might ask me, "Are you ok?" I would, of course say, (from my curled up position on the floor) "Oh yeah, I'm just fine." I know all too well that a decision might be made that I need to go to the hospital again. So I grab onto my desktop the next time I bounce into it. I hold on there, reminding myself not to throw up (because, apparently, the biggest reason people throw-up when they get dizzy is that they forget to remind themselves not to do that). As I sway there, I wait until I think I can take maybe two steps in a row without falling down. Eventually, I feel confident enough to let go of the desktop and, hunched over close to the floor, feel along the wall to my door. Once there, I pull myself up on it, and ready myself for the surge across the hall to the bathroom.

I make it there. I manage to go pee successfully, and make it back. But when I get into bed, my head is still swimming. Very soon, I get swept into an adjacent reality. I decide that Jed, the Blind College's student counselor, is sitting in my room across from me with his notepad and pencil at the ready. How did I know this? I can hear him breathing. (Ok, fine, I can hear someone breathing. Probably it is me, but on the other hand, he is breathing somewhere, right?) So I prop myself up in bed and begin telling him some kind of story that goes on for the rest of the night. I only realize he isn't there when Barb knocks on my door and says, "Aren't you coming to breakfast?"

I have to ask her to come in. I am forced to explain that I am too dizzy to get out of bed. Time to dry out (again).

Well, wouldn't you know, this results in a call to my sister. She has to drive in from the south shore. There ensues a consultation with the school's nurse in the hallway outside my room. It is concluded that I should be kicked out of school and sent home to dry out again. So I pack up and get taken back to Gwen and Steve's. My doctor is called and told what has happened. (No one, apparently, is very good at keeping secrets around here.) She thinks she should have another MRI done just to see if I have had a stroke, or whatever (it's the whatever's that they are actually looking for.) Gwen reached a compromise with her. I would get the MRI, but Gwen didn't want to take me all the way into Boston to get it done. It is decided I can have it done at the local hospital.

It is while in the hospital's waiting area, I have another panic attack. This one is triggered by all the bells and horn-like tones that constantly are going off in the large area I am waiting in. The horns keep getting louder and louder. They are in a distinct and very sad minor chord. I wonder why anyone would choose such a sad chord for use in a hospital. Eventually, each one is like a drill boring a hole into the side of my head. I grab the arm of a passing nurse and can hardly talk, but manage to get out something about the horns. I know he got the message, because I hear him relaying it to someone, but to no avail. I am in full submission to the steroid by now. I can feel myself slipping away. Then I crumble.

They realize what is going on, and move me into a private room. Then I am startled by my first wife, Beth (not her real name. I didn't forget it, I'm just not using it here.), holding my hand and talking to me. We were divorced over thirty years ago, and I have not even talked to her since our daughter's wedding more than five years past. I know this must be a hallucination. But she keeps talking to me. She explains that her sister is a nurse at the hospital. When I got my private room, her sister heard that I had been admitted. So she thought just to call her sister and tell her, "You'll never guess ..." Beth lives in a neighboring town and was on her way home from work. She

thought, "Why not? I'll stop in for a quick visit." She is not a hallucination. Boy, did she get a surprise. I can tell you, as I told her, I was so very grateful for her visit. She talks me down from my panic attack, then goes on her way. How's that for checking in to see how your ex has been getting along without you?

The next morning, I am amazed to listen to the horns. First, they are not loud. Second, they are not in a minor chord. They are most definitely in a pleasant major chord. I guess G. My MRI is done. Nothing untoward is found. Gwen and Steve collect me, and are just delighted to have the crazy relative back in their house

My dosage was adjusted downward, and within a day or so I was fine, but now I had slipped in Blind College's schedule. It was two weeks before I was let back in. I did not know how many strikes you could have before you were out for good, but I suspect I was pushing up against that limit.

#### YOU CAN'T KEEP BLIND PEOPLE DOWN

I get back into Blind College with just enough time to finish the Program before they break for the summer. I am still on a sizeable steroid dose, but now I am relatively stable. However, I remain in a bit of a fog of confusion. Some of my best friends are still there when I get back to the Center, so I have a pretty good time of it. I can feel the steroid (even with the downward adjustment) building up, but I think the summer break will come just in time. Not so fast.

#### THE MOVIE SET - PART ONE

Let me tell you the fundamental reason for my belief that it was a movie set. ("Fun da mental?" Really? That it is mental cannot be doubted, and at times it is fun. But at other times it is distinctly not fun. So I don't think the word "fundamental" really makes sense. Yet I use it.) Dear Reader, no, not the ocean again, please!)

Let me start over. While, from the outside, I may appear “normal”, in my head I am living on a movie set. I had become aware of a rather pleasant, but odd, observation: Someone was filming a documentary movie about me. More and more I felt a film crew always in my periphery. Now you must realize that I subjected this observation to critical analysis, and logical challenges. It was no surprise that I could not see the crew. There was the fact that I was blind. Also, the film crew wanted to film this documentary as it actually happened. Obviously, all the people with sight could see the crew, but they would have been alerted in advance to ignore the filming. I did have to ask the question to myself, “Why me?” I have to admit, I never really came up with an answer to that. Just suffice to say that someone decided that I would make a good story. Anyways, I did not let that small detail bother me.

At this point let me lay the groundwork for such an outlandish thought process. When I was a freshman at college, I had the real experience. My father had done a series of acting gigs for WGBH Boston (the local PBS affiliate). When he heard they were planning a documentary about the rigors of high school seniors planning to go to college, he volunteered my name as a person who could play one of these seniors. Thus it was that one day I found myself being followed around by a film (ok, it might have been tape) crew as I walked the halls of Roslindale High School on a Saturday. The camera followed me as I “found” my room, and settled at a desk. I then “took an exam,” all while being filmed.

Growing up, my mother and father had both done a good deal of acting, and I have fond memories of going to the theater as a youngster with my coloring book. I would busy myself with that because my mother and father were in the play, and I was too young to stay home alone. (I will not mention the time when my father took me to the theatre because he was in the play. My mother wasn't, but this time couldn't stay home with me for whatever reason, so I sat in the audience alone. I colored in my coloring book. When the play was over my father forgot about me and went home. My sharp-eyed mother noticed my absence. She may have said something like, “Ashley dear, where is Richard?” My father may have said something like, “Oops.”

He went back and got me. I actually never noticed he was gone. I just thought he was doing his socializing thing he always did at the end of a play).

The acting bug never left me. Much later in life I listed myself with Boston Casting as available for work as an extra. I did get in several movies that came through Boston. (If I told you where to look, you could find me in “The Pink Panther Deux,” standing right behind Steve Martin. We are the only ones in the shot. He is focused on Emily Mortimer (makes sense. I would be too.) I am focused on the both of them (but really more thinking of Emily Mortimer.) Sadly, going blind put a screeching halt to that meteoric career track.

## RICKY GERVAIS AND ME

(Anytime you can use the name Ricky Gervais in a book, you should). As I continued to subject my assumption that a crew was filming a documentary about me to hard critical fact analysis, the explanation finally hit me. My reputation for being a Grade A Class Clown has reached Ricky Gervais. Here was someone who could fully appreciate my unique talent. (Fun fact: I once went to an acting workshop in Rhode Island. There were about 7 participants. Six of them were beautiful women. One of them was me (the students, not the women). At one point when we were all sitting together, the instructor, Jane, asked, “Who is your favorite director?” She went around the room, starting with the women. They all gave the classic answers, revealing the great depth of their acting studies. When she got to me, I said, “Ricky Gervais,” because it was true. He is my #1 director. The room erupted in stifled giggles (“What an idiot” they were thinking. Perhaps they, in their brilliance, did not know that he is an Emmy award winning director for his series “Extras.” I will pause the book here if you want, Dear Reader, while you go out and buy the series on DVD and watch. But please don’t forget to come back to reading this book.) The only one who did not flinch was Jane. She recognized that as a valid choice).

From that time on, whenever the film crew was around, I could sometimes hear that distinctive Ricky Gervais bark-laugh. One time it was late in the evening and the dorm supervisor was sitting alone in the kitchen. Everyone in the dorm was asleep. However, I had decided it was morning, got up, got dressed, and headed out for breakfast. As I passed the kitchen, the dorm super called to me. He informed me of my mistake. For whatever reason, I decided he was quite tall and thin, and therefore was obviously Stephen Merchant. (Co-creator of “Extras”, but more important to me, he played Ricky’s useless, but hilarious agent in the series. I didn’t go back to bed. I stayed up and talked. We shared a boatload of laughs until he finally recommended I go to bed. Fine, who am I to argue with Stephen Merchant? I went back to bed.

I did successfully finish the program I was there for. At the end, they have a Graduation Ceremony, where everyone gets to stand and offer a few words of thanks. I remember that I said, “Life happens, and you change. Life happens and you change. Life happens and you change some more. I've changed a lot since I've been at this school.”



## Chapter 12

### *My Summer of Delirium - Flood Tide*

#### LIVING IN A PLANTING BED

The end of my session at Blind College coincided with my daughter's graduation from college. We were both in a quandary, as neither of us had a place to live. This put us in a fortuitous situation. She didn't make enough money to get an apartment on her own, and I was still not in a state that I could live by myself. So it was that, after a harrowing few weeks of apartment hunting, we found a perfectly delightful apartment in a well cared for complex of four connected brick buildings in central Massachusetts.

Our apartment is on the "first" floor. But here's the thing: The first floor is half sunken into the ground. The windows in our apartment are large, and at the normal height from the floor—on the inside. But on the outside, they are level with the planting bed. This gives us the distinct impression of living in the planting bed. I always have this image of people walking by in the parking lot, glancing into the planting bed, and saying:

Edith: "Why look at that Harold, there's a family living in the planting bed."

Harold: "They must be trolls."

But we are happy trolls.

#### THROWN INTO THE RIVER OF DELIRIUM

I was lucky my spring term concluded before the steroid dragged me down into the drowning depths of delirium. Next to my real reality was another reality, but this time there was more than just the Film Crew. There were at least three, but probably more like five realities. As hard as I tried, I could not keep them straight. My ability to drift among these realities only increased now that I was not anchored to an active school schedule. At my new apartment, my daughter and I lived alone. She had a regular cadre of friends, and I had the inside of my skull. Now, don't get me wrong, the inside of my skull is a pretty entertaining place, but at that time especially, there was very little of what one might call check and balances. One difference now was that my realities tended to have dark sides. After a short time, some of these dark sides grew terrifying sharp edges.

I now have a new appreciation and respect for those around us who suffer from the forms of mental illness that involve losing your grip on reality. We all act as if we have an assigned place in reality. If we leave, we assume it will be there for us when we return. I have now learned a few things about this that I am happy to share with you, Dear Reader.

Reality can be viewed from the outside looking in, and it looks different depending on the angle you look at it. It's like looking at the little guppy in the fishbowl. If you move yourself around the bowl, the guppy looks different, sometimes even disappearing. Of course, the guppy doesn't even see you, she just sees her reflection in the glass, and the secret is, she's no smarter if she's a male. You, Dear Reader, may very well say, "Richard, you don't know that." I tell you in reply, "Yes I do, because I have been in that reality."

But in our lives we don't see the glass fishbowl. It is invisible to us. Our outer world, and the guppy-in-the-water world are all blended together. I now could move seamlessly through the adjacent reality currents. No amount of effort on my part had any effect on which reality I was in. What I experienced was that all the realities are limitless, but the further you drift away from the reality boundary that we call "real life," the further you get into the alternative currents of delirium. In a world of delirium a thing that you might have sensed was unlikely can become completely rational. What I learned is that it is a falsehood to think in terms of "having a grip on reality."

### GET A GRIP

Here's the thing: You cannot grip reality. There are no handles. There are no edges you can grab hold of as you drift (or blast) by. Being in reality is not being in a safe, quiet fishbowl. You are in the center of a flowing river.

### THE RIVER OF REALITY

There is the reality that is the main current of the river. Let's call it "the true course" of the river of your life. But that is not the only current in the river. There are others. They can come and go, and some of them can be stronger than the true current. If you are lucky, your reality is a wide main current, and you flow along in this current, trapped, as it were, never aware of how close you are to the edges of your reality current. So your current reality and your reality current are similar, but not the same. For many stretches of your river, the riverbed has a steep slope, so that the current is well defined. As you travel down from the headwaters (the uterus) you might get trapped in a stagnant pool somewhere. Here you have to wait until a storm comes and flushes you out of your funk and back into the stream. But as the river gets closer to the sea, it flattens out. It will eventually get so flat that the waters come under the influence of the lunar (as in lunacy) cycle. You start to feel the push and pull of the tides. On the incoming tide, the flood tide, you are stalled, as the waters become deeper.

On the ebb tide, the waters resume flowing back to the sea. It gets shallower. Perhaps you even touch bottom. You are unaware as you drift around how close you are to the edge of your main reality current. But if you drift too close to an adjacent eddy current, you might get sucked into a swirl. Perhaps as you travel down the river of your life you might come to a sharp bend, and the main current might shift to a fast flow along the far bank. If you are not paying attention, you might find yourself in a slow moving flow to the shallows in the inner curve. Heck, you might even run aground, or get tangled in twigs, branches, and weeds. To get free of your restraints you will have to struggle, and then struggle some more to get back into the flow of your river of life. Perhaps your head is enough above water that you can see where you need to go, but perhaps not. Perhaps your head is awash, your vision is blurry, but you know you are out of your channel. You don't know which way to go. Maybe you hear the faint voices of your friends or relatives calling to you from the distant shore. Perhaps you are fully underwater. Perhaps you don't even know that you are not in the main channel. But you know you can't breathe.

Here's the thing: whether you are in actual reality, or floating in an orbit of circles, you are still in some version of reality. It's just that the reality of orbiting a rock on the stream bottom, or maybe in outer space and the rock you're orbiting is Pluto, it still is your personal reality. And for the sake of moving this discussion along, Dear Reader (did I hear cheers?) I will call this Alternative reality the Reality of "Delusions" hereinafter (or Dear Reader, you may be tempted to hurl this book into the roiling ocean surf in front of you again).

#### CANNONBALL INTO THE RIVER

Thus, I was frog-marched to the deep side of the river's edge where someone had built a crude diving board. I was carried to the top of the diving board and shoved off. I gamely pulled up my knees and cannonballed into the Waters of Delusions.





## Chapter 13

### My Summer of Delusions - Ebb Tide

#### SWIMMING THROUGH THE WATERS OF DELUSIONS

In the previous chapter I talked about my entry into the waters of delusions. I say this here on the assumption that you did not read that chapter. In fact, there is a good chance you are not reading this one either. Here's a test: If you are not reading the chapter right now, raise your hand. I thought so. For the rest of you, I am going to say more about the summer between my spring and fall sessions at Blind College. Again I say, although I make light of my experiences with delusions, I want to be clear that I do not make light of the pain and terror those challenged with the disorders we mainstream people blissfully plunge through life without. So when I talk of my strange Summer of Delusions, I am talking about how I experienced it myself only.

As my tide of delusions came in, I realized it was in waves. I analyze these while laying in bed at night. There would be a downward plunge into depression that would not be complete until I came to a rocky bottom of terror. Then I would bounce off that and rise through a neutral zone, which would extend into a stratosphere of looney happiness. This would crest at the edge of earth's atmosphere in space, and then begin the plunge back into terror. Thus I would be either anticipating oncoming

happiness, or oncoming terror. During these waves, I mistook the neutral phases as passes through clarity(That makes sense, right?).

Simultaneous with my Movie Set reality came another reality that I was living as myself in Nova Scotia. My bed had been moved, with me in it, to a train and then a ferry. All while I was asleep. The next morning I was in an apartment building in Shelbourne, Nova Scotia. It just so happened that this apartment building was identical to the one in Massachusetts.

#### SO MANY REALITIES TO CHOOSE FROM

It was during this time that I went through the following additional realities:

- I am an Actor
- I am a member of British Royalty
- I am The King of Spain
- I am a cat

You should know that I understood that these realities were strange. For that reason, I used the midnight hours when I slept through my neutral phases to test each reality. For instance, I would ask myself, “Richard, what reason do you have to think you are the King of Spain?” I would answer, “Well, you have to admit that the belt you found mysteriously in your drawer was incredibly elegant and expensive, right? You have to admit such a belt would be made for royalty only? This belt could not be for British royalty. It is far too flamboyant. Thus, there is only one conclusion available: It is a belt for The King of Spain.” Yes, Dear Reader, I would listen to this test and conclude yes, the belt was truly conclusive. However, there actually was another explanation. First, the belt was just an ordinary belt from Target, with double stitching

and a heavy buckle. I was the one who bought it. But that was several years ago when I had a 33 inch waist. As the belt gradually grew too short for my waist, I stopped wearing it and forgot about it. Now I was back to a 33 inch waist, and had re-discovered it. I had only my fingers to explore its surface, and thus it passed all my tests for elegance.

I clearly remember my defining tests for all my other realities, but I will not set out to describe all of them for you, Dear Reader, because I am quite worried you may have already thrown this book into the sky, and these words are floating out to Pluto and that icy asteroid beyond it.

#### THE ASTEROID CRITTERS

Asteroid Critter 1 (Harold): “Do you hear that? “

Asteroid Critter 2 (Edith): “Yes. It’s English. It must be more of those transmissions from Earth.”

Harold: “They just won’t shut up.”

Edith: ”Maybe if we answer them.”

Harold: “You forget, we don’t have a transmitter, whatever that is.”

Edith: “We should just go down there ourselves. How do you steer this thing?”

Harold: “Follow me up to the front. If we kick this thing in unison, we should be able to get it to spiral towards Earth.”

Edith: “OK. Who is Unison?”

Harold: "It means with vigor. Come on."

Edith: "OK. Who is Vigor?"

Harold: "Just come."

Let's examine my Movie Set reality, perhaps my longest and most convoluted reality, which also had some real world consequences.

## THE MOVIE SET – PART TWO

I concluded from the evidence I detected that my apartment building had been originally built as a movie set. That there was a basement area under the building (there isn't) with corridors and stairways for the actors and crew to move among the various sets. In "real" reality the building is actually four separate buildings that are just connected to each other. The southernmost one (mine) is at a 90 degree angle to the others. This orientation was a source of endless confusion to me. After careful deliberation, I decided the obvious reason was so that this last building could be rotated through about 30 degrees back and forth. Why this should be an advantage was also a point of confusion for me, but I decided it must have something to do with being able to change the interior sets while shooting could continue in others. However, at ground surface there was no indication of this except two very prominent grooves in the pavement. One in the front, and one in the rear. Aha! Now I had figured it out! If the grooves lined up (they don't) these grooves had no other explanation than being the places where one slab of pavement that was attached to the southern building could slide under the main pavement when the building did its rotation. The fact that these grooves could also just be cracks in the pavement did not occur to me. I would lie in bed at night and try to catch them rotating the building, but I never could.

In our apartment, the door to my bedroom and my daughter's are adjacent, but at right angles to each other (here's that Angle thing again). The doors confused me. I

decided there actually was a third door between our doors. This third door must be the secret door the set crews use to come up from the basement. One night I felt all around, trying to figure out how this door opened, but I never did.

Chloe had told me, in no uncertain terms, I could not go out walking around with my cane by myself. I thought about Chloe's prohibition, and after a few days, and careful analysis, I decided that this prohibition was actually part of a test. After all, I had spent six months learning independent living skills at Blind College. This must be a test to see if I had learned my lessons. (Answer: Not). So when Chloe was at work, I would go out and take walks along the front of the buildings. This was possible because across the entire front of all four buildings is a continuous curb that I could tap along with my cane. At the far northern end the curb ends, and several times I tried to figure out what was beyond the end. I listened carefully, and decided there was a cliff down to the ocean about 40 feet away (actually it's about 40 miles), so I always told myself not to explore in that direction. (Also, There is no freakin' cliff.)

In my left eye I had a persistent light colored splotch, very small and faint. Imagine you are outdoors in the middle of a moonless and pitch black night. Imagine you look across a parking lot and see that a neighbor has their porch light on. That is what my light blotch looked like.

#### I AM AN ACTOR

I have also decided that although these four connected buildings had been originally built as a movie set back in the 70s, eventually they had been sold off to be used as full-time apartments. However, the producers of a new film have rented the entire complex and converted it back to a movie set. So since I have a whole apartment to myself, I am obviously one of the principal actors.

This made sense, because for awhile I was convinced that I was Jim Carrey. You, Dear Reader, may ask, "Why did you think that?" The answer was that I could

remember pretty much all of the scenes, and all of the lines from the movie *Truman*. (Full disclosure: I owned a DVD of *Truman*, and had watched it numerous times. After awhile, however, I came to realize that I could remember only the scenes that were in the movie. My brow would furrow as I pondered why it was that I could not remember anything about the making of the movie other than what was actually in the movie. I eventually caved in to this logic, and concluded that I was not, in fact, Jim Carrey.)

In this new movie being filmed now, I never did figure out what part I am playing, and that bothers me. I only hope it will come to me before anything starts happening where I am expected to know my part. I hope that when I go in to Wardrobe and Make-Up, it will hit me. But the disadvantage of being a principal actor is that, since I'm not bunking up with another actor, it is up to me to get up on time and get over to the neighbor's house, which is where the producers have placed Wardrobe, Hair, and Make-Up. So this morning I get up, have something for breakfast, and set off to Make-Up in the neighbor's house. I go, what I imagine is straight. Across the parking lot and use the porch light as my only guide. (Imagine a Lantern Fish following its own light as a guide across the inky black ocean floor, littered with parked cars.) Now on this particular occasion, I cannot find my cane when I leave the apartment, but I do find our Swiffer mop, so I take that. It turns out, if you hold a Swiffer upside down, it makes a pretty serviceable cane. As I head for the porch light, I encounter a fence. So I try to go around it. But I find myself deeper and deeper in heavy underbrush. I can still see the porch light through the fence. I know make-up is expecting me, so I need to find a gap in this fence. I put down my Swiffer next to me where I won't lose it, and start pulling out all the loose underbrush and brambles I can. When that isn't enough, I retrieve the Swiffer, and use it as a hook to loosen more of them. As I am in the middle of doing this hard work, I hear Chloe come up behind me. She asks, "Dad, what the hell are you doing?" My answer is that I am just clearing out some of this underbrush (which is, of course, true.) She leads me back into the apartment and as she does so gives me a stern talking to.

## THE MOVIE CAST PARTY (at the hospital)

I decide the talking to is just for the benefit of the crew filming my documentary, and that I am still expected to demonstrate what I have learned about independent mobility by going out alone. So the next evening that she is at work, I go out again with the Swiffer, (I still don't know where I have put my cane) and head off across the parking lot, using the porch light as my guide. As I said, the porch light is always in the same place no matter where I turn my head. Wherever I point myself, I have a porch light just ahead. After a bit I find myself bumbling around in a grassy area (which probably is the grass area between the parking lot and the street.) I guess someone from the building has noticed me, because the next thing I know, a nice woman gently leads me back to my building. She asks for my daughter's phone number, and Chloe has to come home from work.

The steroid dose has been building up, and now, as I sit on the building's inside entry-way stairs waiting for Chloe with a couple of concerned neighbors, I get sillier and sillier until I just can't stop laughing. An ambulance is called. The EMTs get a good look at me. They decide to take me to the hospital. There I wait on a bed in some sort of triage space for a long time. I can hear voices beyond me, and reach the logical conclusion that there is a final wrap cast party going on for everyone in the movie. Apparently, they have rented some of the larger rooms next to the ER at the hospital for the party. Natural, makes sense, I conclude. I am very disappointed to be missing the party. Time passed. (Why do writers feel the need to say, "time passed?" Does time ever do something else? Does time ever stop? Well, yes, I guess it does when a book author stops typing, but how does that work for the Reader when that happens? What does time do then? I'll tell you: It passes. So now that that is settled, I will stop with all this. (Which is to say, I will continue)). I don't know exactly how long I have been in the waiting area, but it must be pretty late, because the whole area is quiet. They decide I don't need to be admitted, and can go home.

So that adventure was over, but I was not done yet.

## I AM IN A VIDEO GAME

Here's an idea for you, Dear reader: Take a break from this book, and get the video game *Portal 2*. Now play it, but first line-up a teenager who has already played it to act as your coach. Before going blind I got hooked on it, and played it at least four times. Actually, on second thought, keep reading this book, and play the video game afterwards. The short description of the game is that you are trapped underground in a very complicated series of collapsing rooms. You are trying to work yourself up to the ground surface where you will be saved. Now, imagine you have been submerged in the waters of delusions (that's me).

In this eddy of delusions, I decide that my test is that if I can work myself up through the apartment building and stand on the roof I will get my sight back. So this evening when Chloe is at work, I set off with my cane (yes, I found it) up the interior stairs of my building to the floor above us, the second. I very gently try to find an unlocked door. I am convinced there is a door that will open to a secret corridor to stairs to the roof. I feel along the wall until I find a door, and then I listen very carefully to hear if anyone is on the other side. At each one I hear voices. So I keep feeling along. I find one that is quiet on the other side, so I very carefully try to open the door handle. It is locked. I am pretty sure now that I have checked all the doors on the second floor. So I feel my way back to the stairs and go up to the third floor. I check all those doors. But I come to one that opens. I enter very carefully. I am in some kind of tight corridor. I take some stairs up. I realize I must be in the attic of one of the buildings. I'm not sure which building, because the corridor seemed a bit long. Doesn't matter, now I must get up onto the roof. Every so often I lift my cane over my head until it hits the roof. I tap around to check for any hatches to outside. I continue along this way until I can go no further. I have reached a wall I cannot find a way around. Since opening the hatch is the secret to getting my sight back I am quite deflated. I turn around. I feel for the stairway down. As I get back from the attic to the third floor, a woman comes out of an apartment and asks, "Do you need help?" My first instinct is to say, "No, I'm fine." But I think about it a second, and realize I actually am not fine. I have no idea

where I have gotten myself to. So I admit to appreciating some help. This kind woman then leads me down three flights, outside, through the parking lot, and then back to my building.

Many times I re-lived that excursion, and am grateful that I never found a hatch onto the roof.

#### I AM A CAT

Then there was the time I was a cat. I realized that I had reached such an enhanced level of mindfulness I could fully absorb the essence of a cat into myself. I would nap on the couch with my paws curled up under my chest. I would walk around very quietly using my ankles like those wonderful flexible cat ankles that seem to have extra joints. I thought this was a remarkable accomplishment, and was worried that if my eyesight got better, I would lose this talent. Fortunately I never exercised my cat abilities by, let's say, washing myself with my tongue, or say, chasing a small bird up a tree. So I passed through this reality without incident.

These times were not all fun and games.

#### NATHAN LANE IN THE BEDROOM

As you will no doubt remember (right? Or did you fall asleep in your beach chair?), during the bottom troughs of my waves of depression, I experienced sessions of terror. There was the time that in the middle of the night (remembering that all times were the middle of the night to me) I awoke in bed with my face facing into my room.

I become aware of a man standing about two feet from my bed. He is looking right at me. I am terrified. It is interesting how the mind can insert circuit breakers of sorts, as a means of self-preservation. Thus it is that I become aware that the man

standing as a dark shape is actually Nathan Lane. Still terrifying, but really, how terrifying can Nathan Lane be in the bedroom? (If you know, don't tell me. I don't want to know.) I need to go to the bathroom. So I, ever so carefully, slip out of bed, and sidle past him. I make it out my bedroom door, and quietly go the two steps along the wall to the bathroom. When I come back, he is still there. I slip back into bed. Then I talk to him from the safety of my covers. He doesn't answer, but I think it would be helpful to let him know who he is, in case he is actually a figment of my imagination. So I explain to him that he is Nathan Lane, and I talk to him about his movies and the time I saw him live at the Huntington in Boston. He accepts my observations without comment (as of this writing).

#### THE BEAR IN THE KITCHEN

Then there was the time that I got up to go to the bathroom, and as I entered the hall, I become aware that there is a very large black bear standing in the kitchen looking at me. I wait to see if he is going to charge, since I am still at the bedroom door and could rush in and slam it if necessary. Of course, the doors in our apartment are made of cardboard, painted to resemble doors. If the bear wanted to, he could dispatch that door with one swipe of his huge paw. But the bear doesn't move. He just watches me. So I go carefully and quickly to the bathroom, and quietly but quickly shut the door. Then, before I leave, listen very carefully at the door to detect whether the bear is standing just outside. Now just because you can't hear anything, that doesn't mean there is not a large, angry bear standing inches from you on the other side of a cardboard door you have your (very sensitive and exposed) ear next to. I wait. (Time passed.) Finally, still hearing nothing, I open the door and rush back to my room without looking back over my shoulder.

## MY APARTMENT IS A SHIP AT SEA

Then there was the time that I got up in the middle of the night with vertigo (a steroid gift). You will remember that sometimes my apartment takes the ferry to Nova Scotia. I can feel the building rocking on the waves. I am not overly concerned. I get as far as the bathroom, and decide that maybe I should explore further into the apartment, because I do not know this new apartment very well at all. However, as I take a few steps toward the kitchen, the rocking becomes more severe. Each time I retreat it lessens. Each time I advance it gets worse. I decide to try and push through it. I am almost knocked on my face by a really big wave. So I decide that a guardian angel is trying to tell me that there is something in the living room that is very dangerous (a black bear probably), so I decide to just use the bathroom and then get back into bed.

And so went a most extraordinary summer.



## Chapter 14

### The Baby Turtle Runs To The Sea

#### A NEW LIFE BEGINS

My summer of fun and games has come to an end. I am still on my steroid, but the dosage has been reduced to a level where I am finding myself able to function very similar to the way a mainstream person appears to. I feel just a little bit like maybe there might be a new life on the other side of my unexpected death, now almost a year ago.

But this rebirth was not going to be easy. You know the documentaries that show the little tiny baby turtles scrambling to the sea? (How do we know they're not just running from the photographers?) I feel like I am one of those just hatched turtles; Bits of sand stuck all over me, not knowing where I am going or why, just running from a film crew (Not true. Anyone who knows me knows that I would run toward a film crew). The next step in my quest to live life less like a ghost, and more like a baby turtle, will be the Computer Training Program at Blind College. So off I go, back to Blind College.

## BEING BLIND USED TO BE A PROBLEM

Ok, it still is a problem, but now we have electronic devices. The trick is, how do you use them? The most important one to me is the computer, but how do you use one without using your mouse? And without being able to see the screen? Part of the answer is to remember that computers didn't always have a mouse, or a touchpad, or joystick, or track wheel. Although the mouse had been invented many years earlier, the first computer designers did not see any advantages to it. Back before Apple revolutionized the computing world by incorporating a mouse into the user interface, you had only that blinking line between the letters. The only way to move around the screen was to move that blinking line around with the arrow keys on the keyboard. To help things along, Microsoft invented myriad shortcut key combinations. It is extremely fortunate that many of these old key combinations survive to this day. Some of them may be familiar to you. They are faster than using a mouse because using a key combination is quicker than taking your hand off the keyboard to move your mouse pointer to a button on the screen, clicking on it, and then moving your hand back to the keyboard to resume typing. In the Microsoft products that represent the majority of the business programs in use today, many of those key combinations are still listed in little letters written on the on-screen buttons. There are many more key combinations that are available if you know how to get the list to open up. Thus, if you are using a Microsoft business product (and I am told the same is true with the Apple line) it is possible to work faster without using a mouse.

The question then becomes, how do you know what you are typing if you can't see the screen? Those of you who have read through this book to this point will shout "the keyboard training program!" (Those of you who just found this book upside down opened to this page, tumbling in the surf, will have to go back to Chapter Eleven.) Although the keyboard training program would be a good guess, that is just for learning how to touch-type. To actually get work done (rather than push you to the brink of nursing home stuffing) we need a more robust program. That is where a screen reader program comes in. A screen reader says each key you press aloud, and the name of the screen buttons when you land on them with your arrow keys, (or special key

combinations that get you to the screen buttons when the arrow keys are too slow, or don't even work.) If you're using a Windows computer, press the Control key, the Windows key, and the Enter key all together. You will hear the built in Windows Narrator screen reader program start up. Don't worry, it is a toggle. Hitting Control-Windows-Enter again will shut it off. (The Windows key is the one with the little Windows flag on it.) If you leave Narrator on, you will soon become frustrated however, because it is not going to pay attention to what you do with your mouse, nor where that little arrow on the screen is. You will be in the mouse-free world! A fine place to be, but it is a world with a steep learning curve. There are other free screen reader programs, but many of the blind prefer to pay the yearly subscription to have the *JAWS* program. This program has a few useful features the others don't. Oh – but here's the rub: all the programs are similar, but different enough that you don't want to be using more than one on a regular basis. Pick one, and then buckle in for blast off. (You know the video of the astronaut grimacing, with his lips pulled back, cheeks flapping? That's you.) You learn one, and that is the one you go with. But I have jumped ahead of myself. When I started back at Blind College I did not know all this.

#### CRACK OPEN BRAIN – PACK TILL FULL

For this four week computer intensive program, we are paired with just one other student for the duration. We report for class in the neighboring building right after breakfast. There is a short morning coffee break. Then class until lunch. After lunch afternoon class. The good news is that we end at 3 pm, which leaves the afternoon for practice. The bad news, if there is any, is that it requires repeated walks on the outside path from one building to the other, but how hard can that be? (I will tell you later.) It is also nice to have a fixed schedule.

I am put in the same dorm as I had for the spring, but now on the second floor. The second floor is quieter, and it allows me more opportunity to practice on the stairs. Of course, the dorm has an elevator, but I use that only when I am carrying my bag down to the basement laundry room. For me the challenge of mastering how to use

stairs while blind started to create some separation from my self-image as the ghost of a dead person that won't just go away.

This dorm crowd is the best mix of all my sessions. Some of my friends from the spring session are back: Michael, Denise, and a few others. It just happens that all of the new people are also simpatico. My Mad House days appear to be over.

During this session, I get to know Michael, my tech classmate better than I had in the chaotic spring. He and I have a similar offbeat sense of humor, and when the two of us are together in the cafeteria things tend to get loud. I refer to Michael's friend John, who always sits with Michael, as Vince Wilfork, after the Nose Tackle for the New England Patriots. I call him that because he seems to be as large. That is to say, over six feet tall, and just as wide. Michael and John are both black, which I could detect only from their accents. It turns out that I, Richard, also have a pretty darn good black accent despite being as white as British royalty (or Jim Carrey). (I did go to high school in Roxbury, after all.) So one evening at supper, I decide to go mano-a-mano with Michael, black accent on black accent; full attitude. I think I am doing pretty well, but think again for a moment. I say to Vince Wilfork, "Maybe I should stop now, because I think I know how this will end." Vince counseled that would be a good idea. So I tell Michael, "You win." (I wish I was always that good at avoiding self-inflicted disasters.) To be clear, it was all in fun, a good time was had by all, and no one had to be tackled to the turf by Vince Wilfork.

Those of us who are old hands at dorm life are allowed to stay a little later in the dorm in the morning, have our own first cup of coffee, and then tap our way over to the main building for breakfast. Denise and I had hit it off back in the spring when I found out that she had a musical theatre background. You, Dear Reader, will recall that I am nothing, if not a theatre savvy person. (Dear Reader, that is meant as a comment, not a choice requiring a response.) Denise and I develop a routine where we walk with each other over, arm in arm, and pause on the outside path in just the spot where the morning sun breaks through (whatever it is that it is breaking through – maybe satellite debris), and turn to face it. It hits us full in the face with warmth. After

just a couple of minutes, it passes. We check with each other to see if the sun-hit was done for both of us, and then continue onto breakfast.

It is also during this period that Beth (my ex—see Chapter 11) came to visit one Saturday. We went for a walk along the Charles River. As you can imagine, there was a lot of catching up to do. We grabbed a quick lunch, and she dropped me off. She repeated this for the next couple of Saturdays. When we talked, it was as if it was not thirty years ago. It was more like it was maybe last week. Unfortunately, it wasn't too long before we both came to realize that this was not necessarily a good thing. We remembered there was a reason we got divorced. We decided we should stop while we were still ahead. (If they made a movie about Beth and me, Matt Damon would play me, and Sandra Bullock would play Beth. The only reason they haven't made the movie yet is that I haven't yet written the book, and I do not intend to. But I would definitely go see the movie.)

### PAN-PAN-PAN

In the nautical world we have “Mayday-Mayday-Mayday” as an emergency call for help. On land, we just call “Help.” But what if it's not an actual emergency, but a cause for alarm? On the water we call “Pan-Pan-Pan.” It means you are notifying anyone nearby that you are in a situation where you may need help, depending on how things go. It means at the moment you are not on the rocks, but you are drifting that way. Also, you are out of rum. On land, we don't have any such term. Let me illustrate for you:

Let's suppose you are blind. (Calm down. This is just imaginary.) You are taking the path from one building (say the computer classroom building for instance), and are heading to the Main Building for lunch. Suppose the procedure is to leave the classroom building, turn left at the exit door and take just a few steps to the edge of the building. Suppose there is then a short distance of no man's land you must traverse at about a 15 degree angle until you hit a waist high railing (usually with your belly).

Then you are to follow the railing the rest of the way by trailing your left hand along it as you sweep your cane with your right hand. Note that the railing has at one point a sharp 90 degree angle away from you, so you have to be careful to not let your left hand trail off the railing and miss that turn. Now, suppose that, instead of taking a 15 degree angle out of the classroom building, you take more like a 30 degree angle. Well, it turns out that your belly would never run into a railing. You will miss the railing entirely because you will have walked beyond its 90 degree bend. But you are blind. How do you know this? You know this because you are supposed to hit the railing after about 8 steps, but you have now gone maybe 15 steps. You are just sweeping your cane in wide sweeps across what is apparently pavement. Now, you know that somewhere, not very far away, is a street because you have learned that where there is pavement, there is frequently a street not far away. So you just keep sweeping in larger and larger circles. Eventually, your cane hits something. (Something. Anything is good.) A little tapping around confirms that the something is a car. You assume no one is in it, since there has been no response to all the tapping and touching that has been going on. You, being the sharp bulb you are, conclude you must be in a parking lot for the classroom building. So that is ok, but you have not the slightest idea of which way you should go to get out of there and not miss lunch. If you were in a boat, you could shout “Pan-Pan-Pan”, but, of course, if you were in a boat, you wouldn’t have gotten yourself into this parking lot in the first place. Also, no one would know what to make of you yelling, “Pan-Pan-Pan” in the middle of a parking lot. So you call out “Hello?” It doesn’t really make much sense to yell “Hello”; because you are not answering your phone, but it is true that after calling this a few times, someone will look out their window to see why someone is yelling “Hello” in the middle of the parking lot. Now, I am not saying that happened to me, but it is a good illustration of how we need a land-based equivalent to “Pan”.

#### SOMEONE (OK, THINGS) TO LOVE

Besides the screen reading programs, there are several other good things. I was quite happy when I got my new *Victor Reader*. (Actually, it is the newer *Stream* model,

but everyone still calls them Victor Readers.) This is a little hand-held device that is about the size and weight of one of those old flip phones (ok, fine, maybe you're not 50 years old, but I know you've heard of them.) It fits beautifully in your hand, and has a solid heft to it. It does not have a screen! Imagine their audacity. At its heart, it is a simple recorder. But it is much more than that. It is your notepad. It is where you scribble all the little things that you used to jot down on the backs of receipts, scraps of paper, and the little folded pieces of paper you found in the bottom of your pocket. And, even as you scribble the note, you know you are going to lose the little scrap of paper. But there is more. It connects to the internet so you can listen to, and save if you want, podcasts, keeping your favorites in a list. You can listen to the radio, since nearly every station has an internet portal. Again, there is a favorites list for that. It has a direct link to Wikipedia. And you can load books onto it. This is where I listen to all my books. What makes this device so delightful is that it is controlled with real buttons - not pictures of buttons, but real buttons. (Imagine that concept!) There is an old fashioned phone style number/letter pad, with special function keys above and below it. The special keys have different shapes so you can detect which one you are on with your fingertip. Of course, because it does so much, there is a learning curve. Many keys do different things, depending on what feature you are in the middle of, but here is the real beauty of it: If you make a mistake, there are no serious consequences. You cannot accidentally delete your beautifully crafted note. (Nor the personal phone number the beautiful bank teller Samantha wrote on the back of her business card. (I actually have done that with two different women. They are still waiting for my phone call)). You have to confirm any deletion, and if you have hit a key by mistake, just cycle back to where you were. Perhaps, one of its most brilliant attributes is that its top is different from its bottom. Yes, you heard correctly, you can tell the top from the bottom, so there is no excuse for holding it upside down. (Note that I didn't say that I never do that.) It is hard to quantify how much this little device contributes to my freedom.

That is not the only device made to help the blind. There is the magical Pen Friend. This is an oversized battery powered pen-like device that reads magnetic labels to you. What do the magnetic labels say? Whatever you record on them. The labels are companions to the pen, and they come in several sizes. You stick the label on the mystery thing that you are likely to wonder about, such as a can of soup, a bottle of

pills, a shirt in the closet, whatever. Then you hold the pen friend to the label, press the correct button of 3 buttons, and record whatever you want the label to say. In fact, the message is actually in the pen, the label is just a trigger code to that particular recording stored in the pen. You can re-record the label as many times as you want, and the message can be as long as you want. If you wanted, you could have a notebook and have a label for each of your classes, and record the entire hour-long class. Unfortunately, although you can re-record the label, you cannot peel them off and put them on something else. There is a learning curve to the pen. I can honestly say that it was about six months before I learned how to remember the button press combinations, and that was only when I discovered by accident that the lid to the plastic box it came in has instructions saved in little magnetic squares in the cover. But imagine being able to tell your allergy pills from your sleep aid pills, supposing that they were the same size and shape. Imagine your surprise if you were to discover one Saturday morning that you had taken the sleep aid pill instead of the allergy pill. You probably wouldn't make that mistake again. (I didn't.)

(Oh, I forgot to mention, you can stop imagining you are blind now.)

Another electronic invention that is a huge help is the compass on my phone. Now, from my nautical heritage, it is natural for me to navigate by compass headings. Thus, when a frequently used route has a stretch of no man's land, I find what the successful heading is when I am with a friend. I note this in my Victor Reader, and then in the future just pull out my phone and traverse by compass bearing, just like going from Boston to Provincetown across Cape Cod Bay. What could go wrong with that? (I could tell you, but that would be another book.)

Thus, the school equipped me with these modern contrivances that make living blind an interesting new adventure.

## GLIMMERS

From the earliest days of my blindness, I was occasionally presented with flashes of vision. I was also aware that the steroid could present hallucinations, so I had to always try to discern between an hallucination, and an actual flash of vision. When I had what I thought might be an actual flash of vision, it was always the same. I would get a quick as a flashbulb picture. It would be completely unexpected, and not repeatable. I learned that there seemed to be two pre-conditions: 1) That I was well rested, perhaps just having awoken from a nap, and 2) I was slightly startled. It was aggravating that these pre-conditions did not always result in what I called a "Polaroid" picture. It never worked if I was expecting it, even if I tried to deceive myself by pretending, "Nothing to see here." It had to be a complete surprise, as in I was thinking of something completely different. I clearly remember three examples from that period.

The first was when I was sitting in the dorm kitchen one weekend morning with several others. We were all having breakfast from whatever leftovers there were from the week, plus things David, the cafeteria chef, would leave for us. The night dorm supervisor was rushing about us pulling her things together to leave as soon as the day supervisor came in. At one instant, she flitted by my right eye and I caught a flash Polaroid picture of her. She was short, about 5'-2", young, and wearing a white top with a bare midriff. She was leaning a bit forward as she was rushing past. It was a very memorable picture. Later, I casually asked the others a few questions about her, being careful to conceal any dirty old man tendencies that may, or may not, have been present. I did not ask about the bare midriff, as I could not think how to innocently phrase that question. But they offered-up their own descriptions which were enough to confirm my Polaroid as very likely a true picture.

I had a very similar flash one time when I was sitting in the waiting area of the main building. A classmate in our dorm walked by my right eye and the flash went off. I was very surprised to see that he was actually fairly short and probably a teenager. I always had pegged him as a rather tall middle-aged man. Once again, I was able to

confirm the accuracy of my Polaroid snapshot by asking my neighbor on the bench a few questions.

But perhaps the most interesting occurred one day during my afternoon computer class. Michael was off doing something that needed to get done, so I had our instructor Daniel to myself. Daniel described himself to me as being as blind as I was. He was teaching me something about my Victor Reader, and I was listening carefully. Then I was distracted by the glow of dancing sunlight upon the wall beside us. I knew that this wall was opposite the windowed classroom wall, which was itself separated from the outside by the corridor and a windowed wall. So it was at least possible that the afternoon sun could actually be shining through the windows and onto the wall. The light would be dancing due to the outside bushes blowing in the wind. This was especially exciting because, unlike my Polaroids, this was a video. It must have lasted a good thirty seconds before fading away. That evening at supper I asked Nate, another tech instructor who I knew had a fair amount of vision about my video. He told me that yes, that dancing light happens sometimes. The next day at class I apologized to Daniel for not remembering what he had explained to me the previous afternoon, and why. He said that was an understandable excuse.

As you can imagine, these flashes of vision (and a few others, not quite as remarkable) seemed to tell me that on some level critical parts of my eyes might be intact. My analysis (As you know, I am never at a loss for providing explanations to events based on critical analysis.) was that perhaps what was going on was my optic nerve was hanging on by just a thread. That HD insulated cable had been fried by The GCA, and there was just one frail fine wire left. Probably the wire was broken, but the ends were not that far apart. The nerve was trying to fix itself, but every time the wires touched, I would get a flash of vision, and then the connection would fry itself.

What was concerning was that I had seemed to detect a relationship between my steroid dose and my flash-vision. I had better vision episodes when my dose was more built up. This actually made a lot of sense, since the damage done by the GCA (Monster) was by restricting the blood flow to my optics. The steroid is an anti-

inflammatory, so the higher the dose, the greater the blood flow. So I was left in a quandary. I welcomed the increased blood flow from the steroid build-up, but definitely did not want any more delusional excursions. Later on, I would share these stories with my ophthalmologist, and wondered if there was a treatment protocol for this kind of thing. She assured me there wasn't.

#### SLIPPING UNDER THE SLAMMING DOOR

You know the scene in Indiana Jones where he is running, sticks his feet out, lands onto his back, and just barely slides under the great door before it slams shut from above? That was me on my last day at Blind College. I had completed the four week computer Program with success. On the Friday afternoon of that last day, I was on the phone with my sister telling her about how my last week had gone. When I hung up, all of a sudden the vertigo hit like a hammer. My room spun so badly I had to get down on all fours to make sure I wouldn't bang my head into anything. My God, I thought, let me just get out of here without some last minute rush to the hospital. Of course, this time I was an experienced steroid-dizzy vertigo veteran (ESDVV). I had been sensing that my steroid dose might be building up because I could feel myself wanting to go loopy. I had been using sheer will power to subdue the drug and behave how I knew I would if I were not OD'd. The spinning did not stop, but I had to go pee. I knew that some students had already left, so the dorm was only half full. Maybe I could get to the bathroom and back without being detected. So I crawled to my door, pulled myself up, and slithered along the wall to the bathroom. I went pee, and slithered myself along the wall back to my room. I was so relieved when I shut the door behind me. Experience told me the vertigo would be gone in an hour or so, and that I would just skip next morning's steroid pill. It worked. Chloe picked me up, took me back to our home, and I was done. No one but me (and now you Dear Reader) would be the wiser.





## Chapter 15

### *Refurbished-Repackaged-Shipped*

#### A HACK JOB

The repair shop (blind college) was done with me. They did the best job they could with the malfunctioning device (me that had been left at their loading dock (dorm)). (Those of you who are shouting, “What are you saying? Are you saying that blind persons are malfunctioning!” I reply, “Thank you for reading this book. I appreciate all the Readers I can get – even angry ones. And, oh, before I forget, all my comments are about my experiences only. I can definitely say that I was seriously malfunctioning when I was dropped off at the repair shop.) As I said, the school had done the best they could. No factory original parts were available, so they restored as much functional ability as seemed possible. It was done by using a series of hacks, but they always have to modify the hacks to make them work on whatever model of person they are working on. In the end, they got the malfunctioning device (me) working, wrapped me in imaginary shipping shrink wrap, and left me on the loading dock for pick-up. I had been given a set of tools, and instruction booklets for each of them. For many of them, I had recordings on my Victor Reader. I immediately set about making copies on my computer, and organizing them. I listened to them, and practiced, practiced, practiced. I practiced using my cane skills by taking long walks in my neighborhood, using the route taught me by my State-sponsored O&M instructor. My

walks were augmented with my Victor Reader notes and my compass. Here's the thing: If you are totally blind, you cannot just take a walk. You'll kill yourself. First you have to set out with a "Sighted Guide" and together pick a route where the likelihood of you killing yourself is below twenty five percent. For my neighborhood walk, I will tell you how it goes.

#### MANDATORY CANE TRAINING FOR ALL!

Here's how this will work, Dear Reader: You sit still (perhaps on your beach chair), and I'll walk and talk. First, even though you are sitting in the chair, I need to teach you how to use a cane. If I were King, (there's still time) everybody would be taught how to use a cane (or an upside down Swiffer) in elementary school. Suppose you have to rush out of your building in the middle of the night. There's smoke all around. You can't see a thing, every breath makes you cough. It stings to open your eyes, so you keep them clamped shut. You fumble your way from your bedroom to the nearest outside door. You open it, but at the last minute you remember the Swiffer propped next to it. You grab it, go out the door, and fumble with it to make sure you've shut it behind you because you think you remember that being important. Something about fresh air feeding a fire. But you still feel the heat on your back. Are you on fire? Why is it so hot? No, you must not be on fire, yet. If you were on fire, you would know it, you figure. You've got to get away from the building. But now you've got yourself all turned around. Why can't you hear voices? You should hear voices. There is a roar of flames and wind howling in your ears. Now you remember why you insisted that the Swiffer should be kept next to the door, even though you didn't realize it at the time. But instinct takes over. You remember the cane training you had in elementary school so long ago. "Ouch!" You just got stung by a bee on the cheek. Wait, that wasn't a bee – That was a burning ember! Move now! Without even thinking, you turn the Swiffer upside down and push the tip of the handle in front of you. All clear. You sweep it in an arc from left to right, checking the path in front of you. Feels like pavement. All clear. You step ahead, timing your cane sweep instinctively with your

steps. You start with the cane tip at the left side of your arc. While it is there, and all clear, you move your left foot forward into the safe place. You sweep the tip to your right side now, having put your weight on your left foot so you moved forward. All clear on your right side, so you bring your right foot up. Now you sweep your tip back to your left. You repeat this process. This way, each footstep is into a space that you just proved clear. You've gone eight left foot steps when your cane tip hits the soft edge of grass. You realize you have crossed over to the lawn next to your driveway. The heat has lessened on your back. Why? You realize there is a cool wind from your left. You turn left, into the wind, and tap along the grass edge to the front yard. You hear voices. Is that a siren you hear? Someone grabs your shoulders and hugs you ...

That is how it works. That is what we should teach everyone in elementary school. Remember that. It could save your life one day. (That is why I need to be king.) There are many other ways a person might find themselves suddenly blind and alone, (maybe just temporarily) and need to get away from where they are.

#### LET'S TAKE A WALK TOGETHER

So now, relax. Come on this walk with me. First we take a left out my front door and tap along the parking lot curb 44 (left foot) steps. Round about there we will find a crack in the pavement at ninety degrees to the curb. We turn and follow that crack with the tip of our cane until we tap into a curb. While following this crack, we are crossing the entrance from our driveway into our parking lot. Easy prey. We listen carefully before setting off. We know we need about a minute or so of car/truck/tiger free traffic to get across. We, you and I, evolved on the Serengeti Plain, having just recently ventured down from the trees, where we left our brethren (Harold and Edith, if I remember correctly).

Me, "See ya. Been excellent, but we're outa here."

Edith (to Harold), “They’re gonna get eaten.”

Harold, “Was that a folding beach chair the other guy had under his arm?”

Edith, “I think it was Aspen.”

We evolved to be alert for the low growl of a tiger in the grass. Those who said, “Ah, it’s nothin,” got eaten, and did not reproduce. We have learned to be alert for low growling noises. So as we cross the entrance to the parking lot, we pray that no one is coming with their electric car in self-driving mode. We know it is 14 steps to the other side. Good to know, in case we lose the crack, we need to know when we should have reached it. (This is the same way you navigate your boat in the fog if you have only a compass bearing and time elapsed.) We follow that curb for 5 steps to its end where we find the beginning of a sidewalk which is separated from our driveway by a grass strip. Now we get to relax a bit, because we have to worry only about what might be on the sidewalk. When I first learned the route, I would be startled by the neighbor’s dog, who would lunge at me with the intent of ripping off my face. But I learned that he is separated from the sidewalk by a chain link fence with privacy slats. In fact, all he can do is shove his snout under the fence as best he can to sniff me, and growl his low, rumbling tiger threat to rip my face off. Fortunately, I am a dog lover, so I am fine with this. I have discovered a simple technique that I will use with you now. As we walk along his fence, I hold out my free hand toward him. The fence and his yard are up from the sidewalk with a wall, so his snout is at about hand level. This is enough for him to know who I am, and lets him know that I already acknowledge his right to rip my face off. After 66 steps we reach the handicap ramp at the end of our driveway where it intersects the street. You might say that we should use the HC ramp to cross the street, but I don’t want to do that. (Come back here. I’m leading this walk.) Unfortunately, the HC ramp is dangerous for us, as we are totally blind (for you, temporarily). (Nowadays the ramps are no longer called handicap. They are called an “Accessible “Ramp”, or ACC for short.) The ACC ramp tells us almost nothing. To cross a street we need to know a) where the edge of the street is (the curb line), and b) when we are at ninety degrees to it. We pretty much never want to cross a street at any

angle other than ninety because missing the correct angle by just a few degrees will get us eaten by a tiger. So we avoid ACC Ramps. We go right up to the beginning of the ramp, and then go to our right about 3 steps where we know that the street curb is. We get ourselves all squared to that curb, listen for tigers, and then stride boldly across. We know we will hit the opposite curb in 7-1/2 steps. The good news is that this street has a sidewalk separated with a grass strip on this side. The bad news is that the sidewalk is in such bad condition that we were told to not bother with it. Since the street is low traffic, we will just walk along its gutter line, tapping along the curb. In 15 steps we come to the first driveway. We like this one, because it has a prominent lip at the gutter line. Easy to follow. 7 steps to its end. Then we pick up the street curb again. We started at the top of a hill, and this stretch gets steeper. There are overhanging trees, so the temperature usually drops. The air gets fragrant. We have a long run of 40 steps to where we encounter a catchbasin. There's no missing a catchbasin, with its slotted cast iron grate. 6 steps past the catchbasin is our second driveway. The lip of this one is more poorly defined, so we have to be careful. 13 steps to its end we get the curb again. 17 steps to the third driveway. This driveway has a serviceable lip. Here the hill starts to flatten out, so the lip is prone to getting clogged with leaves.

But I need to take a break from all this counting. Perhaps this is a good time for me to tell a story. My first autumn I was walking this route a day after high winds and rain. It was well above freezing, so I wasn't worried about ice. I generally do not go out after rain or snow if it's below freezing, because I will not detect the smooth ice until I feel my cane tip slide across the surface with no resistance, followed by my feet slipping out from under me, and the back of my head slamming onto the pavement.

EMT #1 (Harold): "Here he is. Looks like his head is split open. Brains should be around here somewhere.

EMT #2 (Edith): "What's that over there?"

Harold: "I thought that was an acorn."

Edith: “No, I think that’s his brain.”

Harold: “Should we try to put it back in?”

Edith: “No point now. It was way too small anyways to be any good.”

Harold: “Well, we better get him out of here. He’s a tripping hazard where he is.”

But this day was calm, with that clean cool air that I seem to only find in New England autumn days just after a rain. Of course, the other thing the pitter-patter of the fall rain does is make the leave piles heavy as wet towels that have fallen off the railing where you spread them out to dry when you came back from the beach. It was in this area, on a fall afternoon, that I encountered a dam of built up damp leaves. It was so dense that I could not sweep my cane into it and find the curb. No problem, I think, I’ll just tap along its firm edge until I get beyond it, and back to the curb. Well, this leaf dam is so long that I lose all count of how many steps I have taken, but I know it is probably more than really makes sense. So I sweep my cane in wide arcs to try and find the curb wherever it is. Ah! Found it. Here on my right side, just as it should be. I head off, but quickly realize that something is wrong. I can tell I’m going uphill. This could only mean that I have completely crossed the street, and am now on the other side. But, the other side of which street? I know I have covered a distance greater than just the width of the street. Did I actually go to the end of the street, and now I am on the other side of the intersecting street? I take out my phone compass. But the problem is that I never have taken a heading on our street. Now, it happens I know the heading to take when crossing the long driveway (driveway from hell) on street #2, and I know our street (#1) is at about a 90 degree angle, so wait – I have only to subtract, what was it? 270 degrees? Ok, this is getting way beyond my acorn-sized brain. I have another app on my phone, “Blind Square.” It is a GPS app specifically designed for walking. Wherever you point it, it tells you what the next intersection is, whether it has a traffic light, and more. If you point it to your side, it tells you what house number you are next to, which includes the street name!

Thus I was able to confirm that I actually was on my street heading back home. I cancelled the rest of my walk, and made a mental note to not go for walks until I had reason to think that the damp piles of leaves that build-up along gutter lines are gone. (And, for good measure, that someone has probably picked up any damp towels by now.)

You look restless. Ok let's continue. That was our third driveway where we got waylaid. At this third driveway, we know we should find the curb in 7 steps. Now it is 27 steps to the 4th, and final driveway for this street. 12 steps to cross this driveway. The good news is that when we reach the street curb again, the sidewalk here is in good shape. So we square ourselves to the curb, step up onto it, go across the narrow grass strip, and take a left when we feel ourselves on the paved sidewalk. Now we have an easy run of 56 steps to the end of street #1. We take a 90 degree right turn at street #2 to stay on its sidewalk. It takes a sharp downhill slope (think Black Diamond at Killington). 6 steps to a telephone pole on our left, and then 33 steps to the "driveway from hell." This is a double width driveway, only 11 steps wide, but the sidewalk on the other side is a very small target perhaps only 3 feet wide. To its right is the parking lot of the house. Paved, indistinguishable from the driveway. To the left is the street. The street is indistinguishable from the driveway. So the entire expanse of street-driveway-parking area feels the same to our cane tips. If we miss the target of the sidewalk beyond, there is no way for us to detect whether we are to the right of it - parking lot (angry landowners (actually, they are nice,)), or to the left - street (tigers). So for this, we use my compass (105 degrees.

This is a good time for you to sit down on your beach chair, and I will tell you another story.

One day I was on my return trip (285 degrees) when I was starting to get cocky after several successful trips. I said, "I don't need any stinkin' compass." So I stepped boldly across the driveway. I got to about 25 steps when I had to acknowledge that something was seriously wrong. You will, no doubt, remember that it is supposed to be only 11. Was I in the street? Or was I deep into the parking lot? I was pretty sure I

was in the parking lot because I had detected no crown in the pavement which would indicate a road. I heard a car coming toward me. “Aha,” I will stand still and listen carefully for the car to go by. It should be to my right, and maybe 12 or so feet away. I stood still. The car came closer. It slowed a bit, and then passed right behind me, not more than a foot away. Well, there you go. I now knew where I was: In the middle of the street. Thus armed with that knowledge, I got home without getting eaten.

We have taken just the beginning of our walk. It goes on much longer than this.

“How long is this freakin’ walk? Enough of this book. Into the sea you go!”  
You say.

Ok, I will stop here. “

Wait,” you say, “You can hear me?”

“Yes, of course. I’ve been listening to everything you’ve said so far.”

“But – How ...”

“I’m in your head, right? Don’t you hear me in your head?”

Ok, we can drop this line of thought (as if I actually had one) and move on.

## HOW TO MAKE A BLIND PERSON LOVE YOU

If you want a blind person to love you - and who doesn't? Here are some simple rules:

### *Rule #1: Don't move their stuff.*

Remember, that to a totally blind person, all stuff is invisible. The worst thing a blind person can hear while sitting at their favorite diner is you saying, "I'll just move that water glass for you." If you move it, it's gone, until I whack it over with the back of my hand because I had no idea where you put it. Now, if the blind person is not completely blind, maybe it's ok, because they can still see the glass. Here's a test to see if your friend is blind as a doorbell or not: Move their water glass. Then check later to see if it's upside down in your lap.

Everything is invisible to a totally blind person. That's why the blind people I know don't have cleaners. It's not that blind people are really messy (although I bet some might be), it's because cleaners pick up something, say the little can that has your shaver in it, wipe the bureau, and put the can back in more or less the same place, which is not the same thing as the same place. When I next want my shaver, I will reach for where it is supposed to be, and most assuredly knock the little can onto the floor. The shaver will bounce once and go under the bed (because that's what shavers do).

If you are sitting next to your blind person at a dinner table, it is common practice to locate things by their clock positions, such as, "Your glass is at 10 o'clock. Your mashed potatoes are at 5 o'clock. Your hamburger is in your lap." If you want something moved in your home, it is nice to ask your blind person to move it, and you can approve the new location. If your blind person is recalcitrant, email me.

### *Rule #2: Don't open doors for them.*

*Rule #3: Don't hold doors open for them.*

I used to have a Dodge that would speak aloud its alerts. One of its favorites was, "A door is ajar." I would always respond, "A door is not a jar." This went on for as long as I had the car, neither one of us tiring of it. Another thing a door is not is a doorway. Let's be clear, a door is a solid, potentially painful object. A doorway is a void. Invisible. Air. To say to your blind person, "The door is just ahead," when what you meant to say was, "The open void of the doorway is just ahead," is to invite disaster. First, "Just ahead," could mean 3 feet, or the Canadian border. Don't be surprised when your blind person trips on the threshold, and tries to walk through the open doorway at a 60 degree angle, smashing his shin on your couch side table, with its expensive imitation Ming vase. Don't be surprised when your blind person pulls themselves up and they have an imitation Ming Dynasty vase stuck on their head. If there is some question in your mind about whether you should open the door for them, use your speaking voice. Ask them. If this is a casual walk with me and my seeing guide I will say, "Let me open it." You will then wait patiently, checking your messages, while I find the doorknob and open the door, kindly holding it for you. Imagine, if you will, what I learn from opening a door:

I now know where the hinge side of the door is, so no need to tell me, "The door is on your right (or left)."

In addition, I now know:

- whether the door opens inward or outward.
- about how wide the door is.
- where the threshold is, and I will test that spot gingerly with my foot so I will know for the next time.
- how heavy the door is.

This is even more important to me at car doors. If I approach a car that I did not hear pull up, remember I don't know where the front is from the back. If you open the car door for me:

I don't know where the hinge side is, so I don't know which way the car is facing, and I may very well try to swing my foot up onto the seat, and plant me bum in the footwell (I have done this).

I won't know whether this is a Mazda Miata, or a Ford 350 dual cab monster truck. Remember, I need to have some idea of what I'm aiming for.

When I'm in the car/truck, don't shut the door for me. Despite what I may have told you in the past, I am not British Royalty.

*Rule #4: Tell me about stairs before I get there.*

If you're a sighted guide, tell your blind person about upcoming changes in terrain. Simple things like, "There's a piece of sidewalk sticking up in about 3 feet," or, "We're going to walk across a grassy area. It may be a bit bumpy, but it's not too bad," or, "There's a high curb, step up in about 3 feet," or, "There's an open manhole coming up in about 3 feet, we're going to leap across."

Stairs require special attention, because they are potentially lethal, both to your favorite blind person and you. Your blind person might hold onto you as they tumble down the stairs. Tell your blind person that stairs are coming. Say whether they are up or down. If it's just two or three, tell the number. If it's a bunch, say, "A Crapload." Unless you already know otherwise, assume your blind person wants to use the railing, and will do the stairs on their own. Tell them if there's a railing on their side, and wait at the beginning of the stairs until they have found it and have a firm grip on it.

*Your Question: "How do I lead them?"*

(Sorry, Dear Reader, for stating this question on your behalf, but I wasn't sure when you would speak up, and I have to keep this narrative moving along at a brisk pace. ("Too late for that," you say. "I heard that," I say.) You lead your blind person by offering your elbow. Either one will work, but your blind person will probably be holding their cane in their dominant hand, so if they're right handed, your right elbow works best. Then you just walk along, with your blind person beside, and slightly behind you. Remember that you are now double-wide. Pay attention to signs mounted at head level. Important to not just avoid the pole, but also the head-smack sign.

## SET FREE

On October seventeenth, almost one year to the date of deciding to go blind, I was finally set free from my steroid. I remembered that I had been told that I might be on it for life. I know a woman, much younger than me who successfully beat GCA, but has stayed on a small steroid dose out of fear of it returning. My rheumatologist told me that if it didn't re-appear by now, my risk was reduced back to "normal." Since the steroid obviously caused trouble for me, even on a small dose, he felt that it was best to get off it. I can tell you that I am now fully sensitized to The Monster's early symptoms, and that Monster is not going to sneak up on me to place his icy clamp on me again unnoticed if it tries to come back. (Tigers, on the other hand ...)

Thus, I was fully equipped to begin my beta-testing phase. I had these new systems and training in place, but I was not quite ready to spring forth back into the world of the living.





## STICKS AND STONES

In November, just before Thanksgiving, and just over a year from going blind as a doorjamb, I have a meeting with the Director of the local office of the company that has stood by me all this time. I had worked in the home office, but since being forced to give up my home on the water (something about certain drowning being against the rules) I had moved to a city where commuting to the home office was not an option. How fortuitous, then, that they should have a branch office about fifteen minutes from my new apartment. Bob, my good friend who also works at the company, drove me over, and sits in. It is strange to be having a meeting in the middle of the night, because it is pitch black in the glass walled conference room. I have to keep reminding myself that it is only 5pm. I have to assume they have turned on the lights, or Justin, the Office Director has instituted a new office policy which states that there will be no lights used in the office, since we must all do something positive about global warming. I know that it is at least one of those things. Still, I can't get used to being in a business conference room in the pitch black. I set that aside. We discuss what functions I could still do, and there were just two. I could be a Buddha of engineering wisdom, drawing on my decades of experience. The company already has many senior engineers who fill that role, so this is not a dire need, but hell, always nice to have an extra expert in the closet. The other thing I can still do is be the person managers could turn to for their construction specifications. Everyone is familiar with engineers and architects walking around with a roll of plans under their arm. They spread them out on a table, and a bunch of good looking people lean over the table with serious (but not distressed) expressions on their faces. Someone is pointing with a

finger. They are pointing at the “plans.” But every construction contract also includes two big bound books, called generally, “The Specs (for Specifications).” Of course, now all of this is in digital format, and is read on tablets and computers, but many times bound paper copies are still made. Unfortunately, I cannot see the plans anymore, as I cannot read plans on a computer screen or piece of paper. But, now with my screen reader, the specs are right up my alley. Let me explain:

After I graduated from engineering college, all baby-faced and under a full, bushy brown beard, my first full-time job was with the New York, New Haven, and Hartford Railroad. I worked on the 4<sup>th</sup> floor of South Station in an office that I am sure had not changed since 1920. Next I was with a prominent old Boston engineering firm. I was miserable. Here’s the thing: Engineering is fascinating in school, when you are learning about how molecules interact, and how force vectors accumulate, and where they go after accumulating. (They are a feisty bunch, those force vectors.) But when you are entry-level in a large, stodgy engineering firm, it is boring as hell. There were piles of calculations to be done (all pencil on paper (with a sliderule!)), and no creativity needed or wanted. All the required information was in one thick green hardbound book. I looked up sines, cosines, tangents, and so much more, and cranked my numbers until it was time to join my carpool for the long ride down the Southeast Expressway home. To be clear, engineering as a practice becomes fascinating, and yes, even fun, after a few years when you rise to a level where you are helping to solve problems (oops – opportunities (problems)). This company was large enough to have its own Specs Department; a group of about 4 engineers. When I heard there was an opening I asked if I could fill it. I have always loved writing. Numbers give me a problem. I love letters. There was an additional advantage: Most reasonable engineers and architects hate specs. Saying you like specs is like saying you like reading legal briefs. (I like reading legal briefs.) Now, to be clear, given a choice between reading a well written mystery novel and a badly written earthwork spec, I will choose the mystery novel. But, I do like to get into a badly written spec. I might gob-smack my forehead and say, “Are you kidding me sometimes?” But then I enjoy tearing into it and re-sorting the words, paragraphs, letters, commas, periods, and other magical symbols until I have a document that is clear and concise. Now, there’s something to consider: “Clear and Concise.” Is it possible to be Clear, and not Concise? I would say,

“Yes, but it is a bitch to do.” The more unnecessary words there are, the harder it is going to be to keep it clear. Here’s something to do when you want to take a break from this book, Dear Reader, read a book by Hemingway. Simple declarative sentences. Now it is true you can find an entire paragraph that is only one sentence, but go into that sentence and try and find a word that isn’t needed. Every word, in a book, a play, or movie should be tested. If this word is taken out, does the meaning of the sentence change? If you can take the word out, and it doesn’t make a difference, pick out the word with your fingertips, hold it up in your hand, and fling it into the sea. (Don’t worry, you can get it back if you need it later (unless it has been grabbed by a crab (in which case it may have a letter missing – best to check))). Now, Dear Reader, I hear you saying, “But what about richness? What about the adjectives? What about the tinge of the light on her cheek from the morning sun just breaking over the wheat field beyond the old back porch wood railing, so long in need of paint?” To that I say, that may be critical to describing a state of mind, and therefore each word may qualify as necessary. (Also, Dear Reader, very nicely spoken. I myself have been trying to get that sentence into a concrete spec for ages and haven’t yet found just the right place for it.) (But, just a thought, if he had such tender feelings for her, that fateful morning, why did he do the thing he did later on, when the sun was not yet casting afternoon shadows over the dusty dirt driveway?)

Here’s the thing: as I said, words and letters are magical. They are symbols that allow access into the mind. (Ok, fine, so do numbers, but we’re not talking about them here.) The idea that, just by placing little squiggly figures in a particular order an author can enter your mind and make you laugh or cry is just mind blowing. I don’t know if I will ever get used to that.

So it was that I gladly took the position of spec writer in this prominent old firm. I had found a home. But soon, I wanted more. I was, after all, just a few years out of college. I had a beautiful and talented recent wife, an even more recent house that needed a lot of work on a magical pond, and an even more recent magical baby daughter. Of course I wanted more. I saw an ad for a Landscape Architecture / Planning / Architecture firm that needed a site civil engineer. I did not have any experience as a

site civil engineer. But I wanted to work at this firm because it was chocka-full of creative people. I managed to get an interview. First thing, I told the chief engineer I was not who they were looking for, but I asked the question to which I hoped the answer would be no: “Do you have someone who is your specs expert?” The answer was, “No, these are creative people. No one has much interest in specs. All the managers pull together their specs from past jobs they’ve worked on, pretty much.” I then spent the rest of my interview explaining why they, especially given their size, scope of work, and reputation, needed an in-house specs department. A week or so later, I got the answer: They agreed. I got one of the best jobs of my life. Sure, the work was interesting, but it was really the people. After just a year or so, I decided I wanted to be one of the site civil engineers. So I developed a plan. I explained that there was so much specs work that I needed an assistant. They hired a very talented and beautiful woman to be my assistant, and she quickly learned so much that I said, “Hey, she should be your specs department. You should make me a site engineer.” So they did. I then spent decades as a site engineer, who just happened to know a thing or two about specs.

So, here I was full circle, finding myself blind, hanging onto the thread that was my expertise in specs. (Aren’t you glad, Dear Reader, that you stuck around for the full story? Glad to hear it. (Actually, that is not even close to being the whole story, but as I said, got to keep the pace..))

Thus I started back to work, using both my newly learned skills and my decades old expertise to carve open a little sliver of my former life. Then, just when things were starting to fall into place ...

#### A PERFECT TIME FOR A PANDEMIC

To be clear, there is never a perfect time for a pandemic, nor is there anything good at all about a pandemic, but this is how it worked for me:

God said to me, “Sorry dude, for smacking you so hard on the backside of your head that your eyes popped out onto the pavement, but at the time, I thought you deserved it. Gotta admit, right now I don’t even remember what the issue was, but you know, I’m old. Don’t remember things quite the way I used to.”

Me, “Well, yeah. I tried to put them back in, but I think I got them in backwards or something, ‘cause they don’t work anymore.”

God, “Well, I have an idea of how I’m going to make it up to you.”

“You’re going to give my sight back ?!”

God, “Actually, in spite of what you may have heard, I don’t know how to do that. But I can make it so that everyone else is just as restricted as you are. So I’ll see ya. Got a lot of work to do to make that happen.”

Me, “Wait – wait.”

God hesitates.

Me, “You’re not going to make everyone blind, are you?”

God, “Well, that’s what I kind of had in mind.”

Me, “No – Don’t do that.”

God, “Well, there is something else that might work, so that everyone else is stuck at home, and, even if they still can drive, there’s nowhere to go.”

Me, “Well, wait ...”

God, “Gotta go.”

So it was, that just a month after starting back at my job, a disastrous virus swept the world (repeatedly). Everyone in my peer group, and way beyond, was forced to stay at home, going out rarely just for essentials. I was fortunate that I could do my job perfectly well from home. I was already shutdown, and now the world was too. A hell of a price to pay. Sorry, but it wasn't really my fault. Not my decision is all I know for sure. But it did provide a nice environment for a continued rehab.



## Chapter 17

### *Dawn On The Horizon*

#### THE LOSS

I know how it feels to lose a loved one. In my case, the loved one was me. Does that mean I feel bad for myself? You bet. Does that mean that I have it better than so many others? You bet it does. No contest that my blindness came onto me far easier than it did for countless others. Many of the people I met in the dorm told stories that were so distressing they made my toes curl. But the fact is that in so many measureable ways my life ended. I miss my eyes. I need to deal with the loss. Big deal. Welcome to the club. "I'd offer you a seat, bro, but it's so freakin' crowded in here, I don't think there are any." In my case, there was an extra little ingredient: My vision teasing me that it was still floating around there somewhere. The fantasy that my vision could come back if I just willed it hard enough was based on a few bread crumbs of truth. My MRIs showed no damage from the GCA. I was told that was quite unusual for a case where the GCA had progressed so far. In addition, I had no side effects from the GCA (plenty from the steroid, but none from the GCA. Again, I was told that this was unusual. Then, after a couple of months, my vision began flirting with me. I had the Polaroids that I previously described, but beyond those wonderful flashes of vision, I

started to have other visions. While at Blind College, I once had a full vision look at a classroom of which I otherwise had no previous knowledge. In this classroom, I had never done anything more than be led to a chair near the entrance where I sat for a lecture. It echoed in that room, and I assumed it was quite large. Then, one time, I had a vision that must have lasted 10 seconds or more. I saw the room, and saw that it was actually quite shallow. More significantly, I was able to slowly scan left to right before the vision faded. Later on, I asked my O&M Instructor to lead me on a tour of that room, which he did. The tour confirmed what I saw. I hear a skeptic saying, “Dude, you did that through echolocation;” but I will say that I don’t think my echolocation abilities were even close to being up to that level. (Also, Dear Reader, if there’s someone else with you making comments, please tell them to be quiet. Unless it is a beautiful brunette. If that is the case, tell her to say her phone number out loud.)

These bread crumbs left me with the, almost cruel, belief that my vision was going to come back one day. You have heard the heart rending stories of the mother and father who have had a daughter disappear, without a trace. They are interviewed in their kitchen fifteen years later, cigarettes and cold coffee mugs in front of them. They haven’t moved a thing in their daughter’s room since the day she didn’t come home. They haven’t taken any long vacations. They are convinced that she’s coming back, and they want to be there when she gets there. This loss has consumed their lives. They can’t move on. That is how I felt. My vision was going to come back. Not because any doctor ever even hinted at that (quite the contrary), but because I could not accept what had happened. I needed to believe it wasn’t true. Then more things started to happen.

#### ARMS IN THE MICROWAVE

Using what I had learned at Blind College, Chloe and I affixed three little “bump-dots” to the control panel of our microwave. Bump-dots are just what they sound like: Little rubber self-stick bumps. The blind (clever devils they are) put a bump-dot on the “5” of any conventional number pad. The 5 is dead center, and once

you know where the 5 is, you now know where each of the other numbers are. Then we put one on the “set time” button, and a third on the “start” button. That is all I need in order to run the microwave.

One evening, I am very carefully lifting my plate of food up into the microwave. It is over the stove, so I have to reach up to eye level. As I do this, I see two dark, burly, arms come up from behind my head and reach into the microwave going for my plate. I jumped back and said, “Holy Shit!” I was genuinely scared. I turned, still holding my plate. No one there, as far as I could see (remembering that I couldn’t see). Then a realization hit me. So this time I reached up and put the plate in more slowly. Sure enough, as I reached, the arms from each side of my head reached in also. So I slowly withdrew the plate. The arms withdrew in sync. As I had suspected, those were my arms, illuminated by the microwave’s eerie glow. Even knowing that, it was still scary. (Now I am aware, Dear Reader, that this is the first time I have used the “S” swear in this book, but you have to imagine not seeing your arms for about a year, and then seeing them all of a sudden reaching from behind you into your own microwave. It gives you a start, it does.) I then had to give this incident the test of time: would the arms be there the next evening? They were. (I am used to them now.) There were many other incidents, but too small to mention, lest, Dear Reader, I bore you. (What’s that I hear? “Never stopped you so far?” Oh, I see, that was not you Dear Reader, that was your beautiful companion. Ok then.)

But not all improvements were consistent. Another, maybe cruel, twist was that some improvements in vision came in fits. I would have a bunch of micro-improvements over a period of a month or so, such that I could convince myself that at this pace I will be walking about using my eyesight more than my cane in perhaps six months. Then the improvements would stall. Dead in the water like a boat that has sucked its gas down to some water that was sitting at the bottom of the tank since last winter. Months would go by. My improvements would stall so long that I would finally have to have that talk with myself at night where I lay awake and say, “Richard, that’s it. You’re done. This is what you’re left with. Your vision is fried, and it’s not coming back.” Then it would start up again.

In the colorful rainbow that is blindness, the bottom, where I was dropped to, is blind as a deadbolt. (This is not the term the doctors use. They say "Totally Blind;" but we know what they mean.) Above that is called "Low Vision." My current goal is to get to low vision. I am now pretty good at seeing soft light reflected off surfaces, if I stare a bit and let the photons accumulate. The bummer is that I am no good at direct light. The doctor's assistant shines the penlight into each eye and says, "Can you see that?" "Nope. Not a thing." I know I am not going to get any credit until I can see the damn penlight. Maybe that day will come. Someday, maybe my daughter, "Vision," will, if not come home, at least move close enough that my eyes and I have a richer relationship.

#### MISSION TO THE PLANET LOQUACIOUS

As I mentioned earlier, my middle name should have been "Loquacious." That is a lovely name. Sadly, it is not my middle name. I cannot fault my father for this oversight, as he was a true born and bred Yankee. I blame my mother. Growing up in Winnipeg, she had a very clear understanding of class distinctions. Her family was not in the upper class, and, if I read into her many stories correctly, they were probably just occasionally bobbing their heads above the lowest class. (Maybe they had snorkels, she never actually said one way or the other.) So she was infused with the tea tannin that you should at least demonstrate your refinement at all times. This led us offspring siblings to have the unique Canadian / English sense of humor wherein we delighted in mocking the very standards our mother was trying to maintain. One of the favorite times my brother and I remember is when we went to our mother's, long after our father had passed, for someone's birthday (don't remember whose). Mind you, we were both adults. My mother had (foolishly) set out those party noise makers that you blow into and a rolled-up paper tube extends as the horn blows. Here's an interesting fact I discovered: If you put a green pea into the center of the rolled-up tube, it will shoot out like a vegan cannonball when you blow the horn. They are surprisingly easy to aim. My brother and I promptly engaged in an epic battle. My mother was forced to

try and deal with this decidedly non-elite insurrection. This, of course, made it all the more fun.

But, you see, I have digressed, or gone off on a tangent, or probably, digressed off from a tangent again. The point is: I have always had a distinct tendency towards loquaciousness.

Lieutenant I-hearya, “Captain Cork, 5 minutes to the outside limits of the Loquacious Earshot boundary.

Captain Cork, “Alert the boarding party. Tell them to report to the Bridge.

The Boarding Party enters the Bridge Deck. Cork, “Checkmark, Doctor MyBoy, Nurse Synagogue, Guards, you have all been briefed, but let’s go through it one more time.

Checkmark (anxious to get going), “But Captain, we’ve been through it, shouldn’t we be donning and adjusting our Conversation Cancelling Headsets?”

Doctor MyBoy, “Captain, the Conversation Cancelling Headsets, CCH’s, have not been tested in the presence of a full Earshot Force Field. I don’t know if they can take it. The Loquacians’ endless chatter may be overpowering.

Cork, “We don’t have time for debate. Those CCH’s HAVE to work. Do I need to re-state it? No one who has ventured into the Earshot Force Field has ever returned. The Federation analysis is that they were sucked into never-ending conversations. Those Headsets are our only hope. The Federation has sent this Ship to deliver a message to the Loquacians, and I will not fail that mission.”

Red Shirt Guard #1, “But Captain, what if something were to happen to you?”

Cork suppresses his anger as he turns on him. “What is your name?” He demands.

The Red Shirt Guard looks for his name tag. He is alarmed to find that there is none. “I – I don’t know.” He stammers.

But Cork ponders the observation. He turns to the crew, “The fact is that we don’t know whom of us will get to their leader, or if indeed, any of us will survive.”

Nurse Synagogue sidles close to him, “Captain, don’t even think such a thing,” she says, trying to find a lapel on his tunic to fondle.

Cork, with determination, “No, it is true. Perhaps it would be best if all of you knew the contents of the message.

Checkmark, “What is the message?”

Cork, “The message is,” But he pauses to be sure he should use his Ship’s Commander discretion to reveal the message. He decides he must. “The message is - Shut the Fuck Up!”

Spot, “There is stunned silence. But First Officer Spot remains composed. Captain, if I may speak freely.”

Cork, “Go ahead.”

Spot, “Let me go through Earshot and onto the planet alone.”

Cork, “Out of the question. It’s much too dangerous. I can’t risk the Ship’s First Officer on such a dangerous mission. Additionally, we don’t know how well the CCH’s will fit over your ears.”

Spot, “Captain, I don’t need a CCH. I will use my forces of reason and logic to avoid being sucked into their conversations.”

MyBoy, “Captain, it just might work!”

Cork, “I’ll permit it. But 10 minutes max on the surface. If you have not delivered the message in that time, I’m sending in the full Boarding Party.”

## FROM MOURNING TO MORNING

One of the most thrilling things that happened was in July at a Boothbay Harbor summer house. I was awoken in a guest bedroom by the bright morning sun. On the face of it, that sounds simple, but you must remember that there is no sun for me. I had long ago skipped pulling down shades or closing venetian blinds to keep the early morning sun out, so you can imagine my surprise when, one morning, I found myself saying to myself, “Self, why is it so freakin’ bright in this room?” It’s not that I saw sun coming in the window (I didn’t), it was that the sunlight hitting the wall opposite my bed was so bright it woke me up. I had to say, “WTF! I was just awoken because it was too bright in my room! WTF!” (I didn’t actually say “WTF”. When speaking, I freely speak in non-abbreviated swears. It’s just for this book that I am letting you, Dear Reader, participate by filling in words where needed. Yes, I hear you saying, “Hell, I could do that for the whole freakin’ book.”)

I decided that I needed to get on with life. I decided to write a book. (Oh, you know that.) I am writing this in the middle of a pandemic, so like so many others, I’ve thrown myself into activities that don’t require going out into the world. I exercise in my apartment. I’ve got an audio book teaching me how to play the guitar. I keep on going. And I keep a faith that someday I will dance again.

## YOU ARE A GOOD LISTENER

Well, Dear Reader, this is about as far as I can take us for now. I thank you for keeping me company on this journey. And one more thing: Remember when you were sitting in your beach chair (where you may be right now, except much later in the day) and, frustrated with this book, flung it at the seagull who was inching up to the lunch bag of the person dozing in the beach chair a bit in front of you? That seagull had gotten so close that (if he could drool) he would have been drooling. You flung this book right into the lunch bag, and the poor seagull had to expend a huge amount of energy to escape. Well, that seagull never forgot what you did. Now you have finished this wonderful book, closed it, and set it on your lap. You have set your straw hat atop it so you can warm your face in the glow of the late afternoon sun. You are thinking, "That was a pretty damn good book." (Sorry, I have to make my best guess of what your conclusion is since I did not hear you nor your beautiful companion (if they are still there) actually say it.) But above you, right now, gliding in a circle, is that very same seagull from earlier. She seems focused on your straw hat. Oh-oh ...

END





## EPILOGUE

I wrote this book because what happened to me could happen to anyone. At the earliest signs of your eyes doing weird things, see an Ophthalmologist. If it is GCA, They will say they don't know what is wrong. If THIS happens to you, what you need to do is review this book. Then do not do any of the things I did. If things get worse, go back and tell them it's worse. Let them take it from there. The important thing to remember is that, if the GCA affects you as it did me, and if you are naturally a fool, your inclination may be to not go back. But don't wait for it to get better.

A word about The Madhouse. Madhouse and Blind College are my nicknames for the Carroll Center for the Blind. While I was there, The GCA had been banished, but I was still tapering down from the killer steroid dose. In order to be true to my story, I had to describe my adventures there as I experienced them, but that did not make for flattering prose. It actually is a wonderful place. It taught me all I know about how to function in the world as a blind person. I learned so much.

People often ask me how going blind has changed me. I have to take a deep breath before saying it, but it has made me a better person. Perhaps I should expand upon that statement. Am I not worse off for having gone blind? Yes, undoubtedly. I still wish, nearly every moment of every day that I had my sight, back. But other changes were not negative.

let me explain by breaking this person into his two major components: Physical and Mental, while acknowledging that they are intertwined.

I'll start with the physical changes since they can be measured. A big change was my sudden weight loss. After my "blind date" (the term means something different to me) I lost twenty pounds, and kept it off. The reason is my appetite took the exit with my vision. Many times I wondered Why this should be, when my taste and smell are fine. The answer came to me one beautiful day when some friends took me out to an expensive seafood restaurant and as I was eating, I realized my appetite took a hike because now I can't see the food. We all know how important the food's presentation is. You are drawn to admire the different textures, the wonderful colors, some bright, some saturated, some subtle. The food is resplendent. It is as anxious to get into your mouth as you are to get it there. If this is not a restaurant your food is at; and you are at home your food has just been pulled out from the fridge, but as you handle it you see the rich red tomatoes, and the juiciness of the steak, all waiting for you. Next you see your plate on your table, next to your beer mug, foamed to the rim. You pull your chair in and wiggle. You make sure everything is just right, so there will be no distractions once you load your fork for your first bite. Anticipation is a big part of appetite. But I have learned that I am still too hung-up on needing to see these things. When I was in the Carroll Center, I learned that blindness, even total blindness need not stop someone from being a great cook. It's just that food was never a big deal to me, so I am not motivated to learn the skills to go beyond just simple prepared foods.

After getting settled in front of your plate, there's the process of bringing your food from your plate to your ready-to-drool waiting mouth. If I make my own dinner, I know what's on my plate, and have a general idea of where it is. But if I'm at a restaurant, I have only the waiter's description to guess what's on my plate. When I dive in to eat, I am just happy when my fork stabs something well enough that I can lift it up to my face. Is it a chunk of scrambled eggs? Is it a home fry? Did I impale my piece of toast? I will not know until it is getting masticated. There is no anticipation, only mild surprise.

But that's just the eating part of appetite. There is the shopping part. Since I can't wander through the super market, diligently fulfilling my carefully prepared shopping list, grabbing lots of impulse items (extra-salty pretzels, chips (might as well try this new flavor), forgot about the dulce till I saw it) Along the way. I have only a simple list of the same things I always buy each week. I don't want to experiment with new things anyways, because then I won't know where to put them in the kitchen. My things have assigned places. Cans of soup go in the second shelf of the cabinet left of the microwave. When I want a can of soup, I know just where to go. I don't know what kind of soup I grabbed. Sure I could use my magnetic labels, smart -phone apps, and so forth, but I won't be bothered. I'll find out soon enough when I pour it out and smell it, but heck, close enough. There are no accommodations in my kitchen for exciting food options. But, I am not complaining (although it sure sounds like complaining to me).

Now for the physical/mental crossover changes.

In my mid-life years, I discovered mindfulness. I went to a guru for group training weekends on a Vermont hilltop. I soaked it up. I readily told anybody who was patient enough to listen that it changed my life. I used to have an incredible amount of upper body tension. I new I was naturally pretty tense, but I never appreciated how much until Robert worked out enough tension to hold up a moderate suspension bridge. Still, I was so envious when I would watch someone let Robert raise their arm, support the full weight of it, and then unexpectedly let go. It would just flop against their side. I was amazed at such relaxation. Now, after going through blindness, I can do that! You might reasonably ask, "Where the heck did all that tension come from?" I clearly remember where. I was building a deck for my first house. I was 27. I had so much constant fatigue, that I could work only an hour before I needed a nap. I had daily fevers, and cold night sweats. Fortunately, I did not live alone back then. My wife at the time took me to the doctor. He thought I had tuberculosis, and told me to go straight to the hospital. Turns out, I didn't have tuberculosis, but I did have a lung tumor. They took out the bottom lobe of my right lung. While I was still in the hospital recovering from the operation, I grabbed a Reader's Digest, and was surprised to find an article

about the very operation I just had. I was even more surprised to read that it was a fairly new operation, and It had a fifty-fifty survival rate. As I recovered at home, I was aware that I had the feeling that someone had forced a too-tight leather vest over my head. A vest with no buttons. No way to open it. Over time, I became used to that vest. After going blind, the vest finally floated free.

Then there are the purely mental changes. When in my forties, My wife at the time and I were watching our three year old bouncing off the walls. When I say bouncing off the walls, I mean running across the living room with arms extended, bouncing off the wall, turning, and doing it again into the next wall, until they were exhausted. That kind of bouncing off the walls. We went to a child psychiatrist. At the first visit she gave us charts of symptoms and told us to check all that apply. I went down my copy of the list and said to myself, Wait, all of these apply to me. I got my own psychiatrist. She gave me my own Ritalin. It was a miracle. After just a few days, I was at my office and looked at my big worktable where I usually worked and said, "What the hell?" The entire table was covered in messy piles of documents and folded plans, with just a small clearing for working. I went through all the piles, and filled several waste baskets. I was surprised to find at the bottom of some piles meaningless letters that were ten years old. When I was done the desk was clear except for two neat files. I was flabbergasted. After a few years, I was able to drop the Ritalin and just continue, having ingrained my new behavior. But I knew I was still ADHD. I was just a more functional and reasonable ADHD person.

Now after my blindness I am normally calm, and less likely to stress-out about whatever issue is trying to become top-of-the-heap thought champion of the day. I am not a psychiatrist or neurologist, but I am convinced I can explain the change that settled upon me. When I had my first panic attack (Chapter Seven) it broke holes through some kind of cellophane mind safety wrapper. The holes allow the mind to float free of the boundaries of reality. Depending on which direction you are pointed (up or down) you become terrified or euphoric. (Do not take notes on this analysis.)

My mind found this new freedom to be like wonderful new playgrounds that it could explore. I believe that once the cellophane -wrap reality seal is broken, it stays broken, but I have learned that this is not actually a problem. When I am having wonderful daydreams or quite depressing thoughts, I just allow myself to enjoy or wallow in them, then at some point say, ok, that's enough, time to get back to whatever I was doing. No effort. No problem.

All this has been life-changing, and I am grateful for it. I couldn't have had them without you, blindness. I won't say I am glad I met you, but I will say I am a better person for it.







First and foremost, I express my thanks to my sister Gwen and her husband Steve, without whom I don't know how I would have survived my attack in one piece.

I express my thanks to vhb, the company that stood by me, and without complaint made accommodations to keep me working.

I would also like to thank my close friend David Grotian who designed the Cover for this book, functioned as my editor, and always made special efforts to make sure I was kept in the loop of the living.

Finally, I thank my daughter Chloe, for being my roomie, and helping me make adjustments to my new life.





## ABOUT THE AUTHOR

Richard Westcott loves words and what can be done with them. While he was sighted he wrote a series of 10-minute plays. His favorites are assembled into *The Comedy Collection*, also available at [westcottpress.net](http://westcottpress.net).

This is his first book. (He was waiting for something interesting to write about.)

Most recently he was invited to be a Moth Mainstage Storyteller, leading to his appearance in four cities.



## RESOURCES

If you (or someone you know) are concerned about how to adjust your life to vision loss, you are not alone. Places you can go for information and guidance are:

In the United States:

The National Federation of the Blind

<https://nfb.org/>

In Canada:

The Canadian Organization of the Blind and Deafblind

<https://cobd.ca/>

## **Back Cover Synopsis**

One day Richard Westcott had fine vision, the next day he was blind as a doorknob.

There was no accident. But there was a catastrophe, one the experts at Mass. Eye and Ear said could happen to anyone.

It took courage and stamina to write his story. He never thought he would have to apply his humorous writing style to his own story, but in truth, it was the only way he could write it. So, strap yourself in and be prepared to cry and laugh — at the same time.

Richard Westcott lives in central Massachusetts