

Dear Steve, You're Going Deaf



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New Chapters

Edition 2, 10-3-2019

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Afterword by Chris DiCesare



Day Camp

“Molly Jones? You’re with Tomahawk-12,” yells the camp director.

“Anthony Leoni! Eagle-14.” The director is calling off all the kids’ names and which group they are to report to.

It’s the summer of 1981. I am turning 12 later this summer, and my brother, Chris, is 14. We are sitting in this giant lodge with about 100 other kids we don’t know. This is a weeklong day camp down in the neighboring town on the bay that we didn’t really want to go to, but Mom forced us to. It’s the usual summer camp stuff, sports and swimming with a Native American theme, as is a lot of stuff in the region where we grew up.

Man, why can’t they come up with a better system than this? Calling off individual names? C’mon! Then you have to get up in front of everyone and walk all the way across the hall to your group leader in front of everyone. C’mon, guys! It’s 1981! Can’t we do something with names on color-coded cards or something at the door? It would save, like, 20 minutes, too!

Chris and I are sitting there on the floor with all the other kids, and I am asking him after every name that’s called if it was me. I’m not able to make out names through the noises in the lodge. “Was that me?” He’s telling me to shush. “Was that me?” He’s got a hearing loss too and he’s struggling to hear the guy. “Was that us?” Shush! It’s filtering down to about 15 kids and we are still sitting there. All the groups are gathered along the walls of the room, and individual group leaders are welcoming everyone and bonding their group with high-fives and stuff. It’s getting louder, and we are now sitting there with just eight kids and the director is still calling off names.

We are the last of three as the groups head out to their activities. *Why weren’t we called? Did we miss it, or are we not registered or something?* Chris gets up and motions me to follow

him over to the camp director. There's another kid already there, and the director checks his chart and tells the kid where to go, and she sprints to catch up with her group. Chris is checking in with the guy and I am cursing my mom for making us do this camp. The hall is pretty cleared out now; all the groups have headed out to their various activity areas. My brother spells our names to the guy and he says he called us already; he's been doing it alphabetically. Chris gets his instructions and group name. The guy looks at me and tells me that I'm in Tomahawk-12 and "Looks like they headed out to the softball field for Round 1. So, go out that door, around Shmerkwin Hall, then go *flerpity skoo-napper* and follow that trail to the fields. Have a great day, campers! Go Hawks, Go Eagles!"

I follow my brother to the doors. We are both totally not into this and pretty mad at my mom. He waves and jogs over to meet up with his group. I start looking for Shmerkwin Hall. *What's a Shmerkwin? Is that an Indian name?* There are like three big buildings in front of me and I can't seem to find any identification markings. I walk forward, past a building that says "Algonquin." *What'd he say? Go down a trail to the fields?* There's a bunch of routes to choose from, and I pick one and it turns into a footpath through trees and bushes and then opens up to a big field. There are four or five groups out here, and I walk around a bit but nobody says anything. I head out past the groups, through the field, trying to be cool. I keep walking toward the tree line, trying hard to not start crying. I am planning to hide in the trees.

As I pass the archery range area, someone grabs my shoulder. It's Chris. He knows what's up. He waves me back to the fields and I follow him down. He points to a group and I run down there. I ask if this is Tomahawk-12 and the group leaders say, "Yeah! Can you play third base? Nobody wants to.

Here, use this glove." I run out to third and it seems like everyone is staring at me.

OK. Sports. Cool. My brother and I and the kids on our block play sports and games on our street and in our driveway all summer and after school every day. We've played every single sport, every organized game, as well as made up sports such as "Combat Basketball" and "Over the House Tennis." I am pretty good at sports and games, and the rest of the week at camp goes OK as I get over missing the introductions and everybody's names and just blend in with the activities. I'm still kind of mad at my mom though.

May 18, 2014, 1:26 a.m.

Dear Steve,

Hey man, I know that particular day camp experience started a little rough, but think about all those times your mom got you into those cool camps! The science camps! Remember those? You guys spent a week every summer making rockets and doing science projects. The woodburning and woodcarving workshops? What about all those art camps? Those were great! You consider yourself a bit of an artist, right? You have a degree to teach art, no? Well, your mom started you on that degree program when you were like 6 years old, Steve! All those art workshops in the back of the local hobby shop, the science camps, the music camps and music lessons! Ha ha! Your mom helped make you the artist you are today, man! You had a very caring mom who gave her all and tried to expose you to the best and varied experiences.

Go Hawks!

Steve



Sleepaway Camp

1984. I am turning 15 this summer and it's my last year of three, going to Boy Scout summer camp. I am going to hit Eagle Scout this coming year, and I'll be doing teen stuff and working full-time next summer. This is a two-week sleepaway camp for scouts from all over the state. I attend with my troop, which is very strong and large and has a lot of parent support. My dad has been scoutmaster for the past two years, and other fathers whom I grew up with have been scoutmasters and leaders for our troop. My dad was here this summer for one of the weeks, and my brother was getting paid as a camp counselor.

We spend two weeks working on merit badges during the day for camping, wilderness survival, first aid, swimming and citizenship. Then, nights and weekends were for activities with friends and free time. I loved the free time we had to create our own activities. I used the time to learn and improve sculptural woodcarving, making plaques for our troop's submission for the main wall at the lodge, and practicing the guitar.

I also spent a lot of time putting together various performance groups. We'd perform original written skits, circus-type acts, and songs around our nightly campfires in our troop's social area, inside the circle of 20 or so platform tents. Once a week on Friday evening, the entire camp, about 12 troops, would hike out to the gorge where there would be some sort of scouting ceremony, and then each troop could sign up to perform at the big campfire. Yeah! I signed up every time they allowed me to.

Our final performance at the gorge at scout camp consisted of our troop's "rock" band. I went to the mess hall and borrowed white uniforms and a bunch of empty Heinz vinegar bottles. I made the guys wear these uniforms so we would all have the same white clothes on. I always had my guitar at summer camp and campouts. So, I would play guitar, another

boy would play sticks, another on harmonica, another would sing, and one boy played the Heinz bottles filled with water tuned to four or five different tones. I can still remember just about where to fill a Heinz vinegar bottle to get an A, D and C tone. We opened with one of my junky blues originals, which didn't go over too well with the campers. Then we closed with *Stairway to Heaven*, which we'd worked on for two weeks, every night. It got a standing ovation, mostly because of the awesome singing from my scout friend who is also in the school choir.

The daytime merit badge work was organized in classroom format. So, for example, Camping Merit Badge class would be conducted by an older scout counselor like my brother, and there would be about 15 younger scouts working toward earning the merit badge.

These classes, during camp this year, were the first time I grew aware that I was missing "important stuff" because of my hearing loss, and were unfortunately where I developed destructive habits around classrooms and classwork.

I was sitting there, realizing I was missing stuff, but I wouldn't advocate for myself or go to the front of the group to read lips more easily. I wouldn't ask for clarification, ask questions or volunteer. I would stay in the back or on the side with my friends and act cool. I'd get the info later, somehow.

This was denial. A challenge against the hearing loss. Steve versus the slow, creeping forces of evil. A way of fighting back and having some control. *You are taking my hearing. My communication. My music. Fuck You!*

I continued this denial through high school, where I wouldn't even sit in the first three rows of any class, accept any special education assistance, try hearing aids or ask the teacher for notes. You can't lip-read and write notes at the same time. I continued the denial through five years of university classes in giant lecture halls with 300-plus students, and in small

classrooms with 30 students. I continued it through my 20s as we took the band out to do shows and record albums.

I continued this denial, in some respects, right up to the current day, because to accept the fact that I was going deaf would be to accept the fact that I can't make music. Oil and water. They just don't mix. *"Do not go gentle into that good night ... Rage, rage against the dying of the light."* Fuck! You!

May 17, 2014, 3:03 a.m.

Dear Steve,

Acceptance is the only way. You know this. I'm not saying to give up, but does acceptance have to mean letting go? Can you fully accept the situation, any situation, and then channel some of that fight energy to persevere? Acceptance to persevere!

“On my honor I will do my best to do my duty ... to keep myself physically strong, mentally awake and morally straight.” Good stuff! “A scout is trustworthy, loyal, helpful, friendly, courteous, kind, obedient....” Good stuff, man!

They really got it all in there. Kinda “Leave it to Beaver” corny but the foundations of EVERYTHING are in there. You really need to look back over that Scout Law and Oath stuff. Then do it again.

You are lucky to have had the scouting experience with your brother and dad, Steve. You learned a lot of good stuff through that troop. You know what was the most important? Realizing that the parents built that troop and made it great. Realizing that the community offered time and support for you kids and how important that is for any kid. Your dad was a scoutmaster, man! He helped you become the youngest Eagle Scout in the troop! Those were awesome days, and he taught you guys a lot without you even knowing it. Isn't that how you approach your profession as an educator now? Your dad let you guys create and be kids, be idiots and be extraordinary, and he never let any BS through. “Do the right thing,” he always said. You were really lucky to have supportive people around while you were young. Do you recognize that?

Boy Scout Salute,
Steve



Many-Job Man

By senior year, some friends started calling me “Many Job Man.” My first job was probably doing chores in the house, which my mom and I negotiated into a regular weekly moneymaker. There was also the occasional lemonade stand or vegetable stand we ran off the main road at the end of our street. Then my brother and I started a snow-shoveling business on our block. We would get up early, shovel our driveway and walkway, and try to get to all the elderly neighbors’ houses before any other kid-crews would reach our block. After a while, we earned regular customers and they would save the job for us.

When I reached 13, I was old enough to get a “Circulars” route. This is like a newspaper route without tips. You needed to be 14 or 15 for a newspaper route. The Circulars was an advertisement paper. I would pack all these advertisements into individual yellow plastic bags; hang them on my handlebars, bike baskets and other bags that I carried on my body; then Wednesday and Saturday mornings, I would ride around and throw them onto people’s porches.

In the same vein as snow shoveling, I developed trust within the neighborhood and started doing odd jobs such as cleaning gutters, doing dump runs, and landscaping. Regulars would call my mom or come by and ask me if I wanted a certain job, or if I could do a certain job. They never called me directly on the phone.

In high school, I started digging clams. I got my own boat, engine and gear and worked as a bayman or “digger.” I would wake up early, go down to the harbor, row out to my 16 ft. flat-bottom boat and motor out to the bay. The clamming rake is an iron basket-type rake with long teeth that you drag through the mud. It’s connected to a series of aluminum pipes culminating with a T-handle. I would find the right depth, adjust my pipes

so that the teeth angle was optimum, tighten everything, and pull on that T-handle for 5 - 6 hours. Dragging those teeth through the mud, digging up clams and dumping them into bushel baskets in my boat every 10 or so minutes. Best. Job. Ever. Still to this very day. Best job ever.

April 16, 2014, 2:22 a.m.

Dear Steve,

You know what I noticed here? All of these jobs have two things in common. One, they were influenced, encouraged and supported by your parents, and two, they all seem to have you working alone, in a quiet setting, without the need to communicate too much. Interesting.

So, shoveling snow. It would be a snow day, right? Your father would probably need to be at work though, and your mother would make you shovel the driveway and walkway. Then that one day, remember? ... As you finished, she yelled out the door, "Christopher! Steven! Go see if Mr. Ray wants his driveway shoveled." Your first shoveling job! Encouraged by your mom, working with Chris, in a quiet setting, without much communication.

The Circulars route. Your mom set this up with the company after you asked for a job like Chris's. She said, "Yeah, you're going to need a regular income now that you're getting older." Encouraged by your mom, working alone in a quiet setting, without the need to communicate.

Odd-job handyman. Remember the day you asked for money for the Fireman's Fair? Your mom said, "Go see if Mrs. Szokoli, across the street, needs anything done at her place. Look, there's a lot of leaves and branches down over there." Your first customer as a handyman! Encouraged by your mom, working alone, and not much communication or hearing needed.

Clamdigger. Your dad practically built the boat, fronted you the money for the engine and taught you how to do it all. Encouraged by your dad, working alone, and no communication needed.

I see a lot of support here from your folks. Remember how often your dad would go out clamming with you until you got comfortable out there alone? Every weekend, and he would take off early some days and go with you in the afternoon. Remember when he would go and get your grandfather from the city, and all three of you would go clamming? They would talk in Italian and broken English and you couldn't understand them with the hearing loss and the wind, but it didn't matter. You just liked being out there with them. Remember how your grandpa would just point to where you should dig. "Dig-ah here-ah!" he'd demand. "No! Dig-ah there-ah!" He would direct you in the broken English he used with you. Trying to get you to dig up the *scungilli*, the conch snail that he liked to cook and eat. "Grandpa! C'mon. I need to get clams. Clams are money! Scungilli—no money!" you said. "More-ay scungilli!" he'd say, smirking. "Dig-ah there-ah!" He taught you something there, huh?

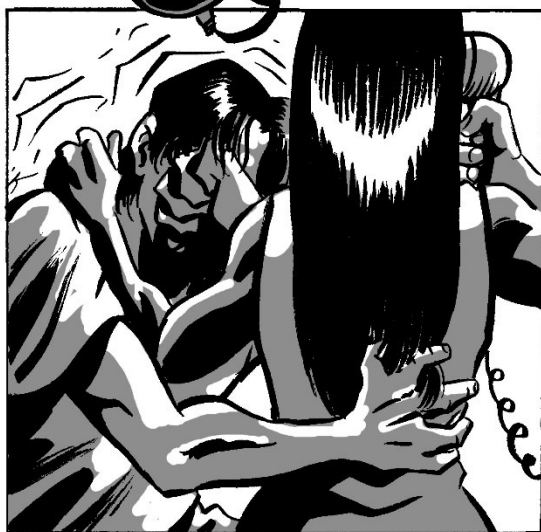
Interesting. Maybe you were dealing with and figuring out how to navigate work with your hearing loss even then, without even knowing it. All your friends had jobs as waiters, clerks, or in sales, and you tended to seek out quiet environments in which you worked alone, without the need to hear or talk to people.

Why was digging clams your "best job ever"? You should look a little closer at that. Did you like the isolation? Was it

just a relief from trying to “hear” everyone everywhere else? An escape? A retreat maybe? Just you and the bay and the rake. A place to chill and work without the constant strain of trying to hear in society.

Well, Steve, they taught you well, and you listened and learned. You used that knowledge and your ingenuity to figure this stuff out and lay the foundation for your careers as a handyman and an educator. You might benefit to revisit some of those lessons.

Good job,
Steve



Phone Allies

I'm pretty sure the last time I put a phone to my ear to try to have an actual conversation was in February, 1997. For the decade leading to that last call, phone use was becoming very uncomfortable.

1987 – TV room in my parent's house.

I'm hanging out after my day job, in the back of our house having lunch and watching MTV. Work this summer consisted of digging clams in the morning and working with Gary the postman in the evening. Gary delivered the mail in our neighborhood and ran a landscaping business in the evenings, pretty much on the same route.

My mom pops her head into the room and swings the old long coiled phone line across her head as she switches the headset to the other side so I can read her lips.

"Steven, I have the Deaf kid on the phone, we are setting up a time for tutoring." She says.

"Huh? You're talking to a Deaf guy right now?"

"Steven, the tutoring. The sign language tutor. He's a kid, a young man, like you. We talked about this. Wednesday at 2:00? OK?" she says.

"How are you talking to them on the phone?"

"Steven! I'm not talking to him directly, I'm talking to an operator person. Steve! Wednesday at 2:00?" she asks again.

"You are talking to an operator? Then they call the Deaf guy?"

"Steven! We are all talking right now!" she yells.

"So this Deaf guy can speak?"

"Steven! He types, the operator speaks to me, there's typing and talking ... Operator please tell Abe that Steven will be there at 2:00 on Wednesday. OK, thanks, please tell Abe goodbye." She goes all the way across the house to the kitchen to hang up

the phone and comes back. "It's some kind of new thing. Deaf people can call not-Deaf people through this special operator that types. Wednesday at 2. Here's the address."

My mom pushed to set up some sign language tutoring that summer when she realized I wasn't using or benefiting from hearing aids. I went once a week or so and became friends with Abe. I started getting into sign language and conceptual imagery that summer and started to see how the ASL language system allows for flexibility around individual creativity in expression. That artistic, creative aspect was a big draw for me.

Later that summer, when I had some vocabulary under my belt, Abe told me about that first conversation he had with my mom. The operator needs to type everything they hear, along with explanation points. Like, "Steven! We are talking right now! (Woman is now yelling at her son)." So we had a few laughs because the operator typed the whole conversation between my mom and me for him. He said my mom was cool and doing a very good and important thing for me. I agreed. He said I was going to be a good signer.

1989 – College dorm.

I'm sitting in my suite room with my suitemate Harley, whom I met a year ago, and we're debating the merits, demerits, techniques, and pros and cons of the "prog rock" genre vs. "jam band" genre, using Rush and the Grateful Dead as a basis for our discussion points.

I'm lounging with my guitar on the old Salvation Army couch by the windows, which at this point in the year smells permanently like hot wing sauce and stale beer from the Old Milwaukee beer balls we tapped weekly. Harley is sitting on the Old Salvation Army sometimes-reclining-recliner. Our friend Beverly from down the hall enters without knocking and quietly takes a seat in the other corner near Harley. Beverly wears a permanent smile.

Harley and I are conversing, debating, almost arguing. Beverly is grinning. The phone rings. It's closest to me. They both look at it. I missed the first ring, but as the room goes silent, I understand on the second ring. Harley looks at me with eyebrows raised and I look back with a scrounged up face and shrug my shoulders and take a breath.

I pick it up and put it to my better, left ear, instinctively. "Hello?"

"Hi. Shufta cin Day effa Shnuble? This is forgdum effys," the voice says really fast.

"Hi, yeah, this is Steve. Who's this?"

"FORGUDMN WHYFYS. Shuffa kejdma? Hufta Day shaka-laka!" says the voice. I am sensing agitation, but I give it one more try.

"Sorry, can't hear ya. This is Steve. Who are you asking for?"

"I am ASKING for day vah! KNOTTEN FORSHEKTO KRAPPEN SHLOCK! FORNATO KUMBLE!"

Whoa. I bring the phone over to Harley.

"It's definitely a guy." I say with the handoff.

Harley takes it. "Hi, this is Harley."

The guy is talking on the other end.

"Dude, the guy is hearing-impaired," Harley says in his matter-of-fact manner.

Pause.

"No man, the guy can't hear well! What's your deal? He is hearing-impaired."

Another pause and now I can see Harley is turning up the heat in his facial expression and volume.

"Dude! Man! STEVE CAN'T HEAR WELL! HE'S HARD OF HEARING! He's got a HEARING PROBLEM! What's YOUR problem?"

Pause.

"Yes! That's Dave's roommate! Dude. Chill. I'll get him!"

Harley gets up slowly and bangs forcefully with the soft side of his fist on my roommate Dave's door, three times, then a pause and breath, and adds a fourth, final, "let-it-all-out-fucking-A" pound. Dave comes out smiling with headphones on and Harley hands him the phone. I look at Beverly. She is smiling and I smile back. It felt pretty good to have an ally.

1995 – Cathy's House.

"OK, let's call 'Sh-Sh-Shh-Chavaaaaaaaaaun' now!" Chavaun is a rich ritzy-glitzy 30-something divorced single mom who wants me to move into her garage apartment and become the multi-tasking handyman-do-whatever-needs-doing, glorified houseboy. We usually recite each of my client funny name jingles before we put on serious voices and call them. We just called "Mr. Stanford!" which we scream in military fashion with a salute. He was in the air force. Before that we called "Mrs. Meyers," which we do in a very loving grandmotherly voice because she was my first client in this new business, and she is awesome. Mrs. Meyers thinks I was sent to her by her recently deceased husband, who went deaf from an illness a few years before passing.

"Hi Chavaun! It's Cathy calling back for Steve."

"I'm great, how are you and the kids?"

"OK, I'll ask him."

She covers the mouthpiece with her hand.

Cathy looks to me, smiling. In a soft chuckling voice, she tells me, "She needs you 2 - 4 hours on Friday morning this week, to uh-hmm ... wrap Christmas presents while her kids are at school!"

"Um ... OK. Hell yeah! Sure. Tell her I'm a great wrapper! It's my specialty." I'm psyched, thinking about getting paid \$25 an hour for wrapping presents.

Cathy returns the phone to her head. "Steve says he'll be there at 9. He says wrapping is his specialty. A master wrapper—perfect at corners." They are both laughing.

I have about 20 regular clients, and my friend and next-door neighbor, Cathy, makes all the phone calls for me. I go over to her house each evening and we spend 10 or 15 minutes joking around while she calls and talks to my clients and sets up appointments for me for the week.

January 1997—Kitchen in my rental house.

My friend Frank goes over to pick up the phone. He is talking and looking at me. I come over and lip-whisper, "Who is it?" Frank talks a bit more, but I can't see his lips. He stops and covers the mouthpiece with his hand, looks directly at me, and says, "It's your brother and he wants to talk to Kim." Kim is a great girl I've been dating for about two years. She is in the living room.

Dread. *Uh-oh*. My mind immediately starts racing to bad thoughts. My dad has been fighting cancer for almost six years at this point and, living in another state, I call once or twice a week to check in but mostly ask yes-and-no questions and try to hear their answers.

I ask Frank to give me the phone and he does.

"Chris, it's Steve. What's going on?" I make extra effort at pronunciation when I talk to my brother because of his hearing loss and my failing speech clarity. He probably does the same. He wears a hearing aid and probably has his on high for phone calls.

"Steve, I have—um ew abao Dad. I called -is doctor and finkel shronto dalking. Can you uner stan? Put Kim on." He says slowly.

"What? Can you say that again?"

"Put Kim on," he says.

"Tell me."

“Put Kim on, I wan to make ur oo uner stan,” Chris repeats.

I’m crying now. So is Kim. And Frank.

Kim takes the phone. “Hi Chris, it’s Kim.”

They talk for a minute and she stops to tell me my dad is OK right now and at home and comfortable. Kim is crying and I’m a mess. They talk a bit more and she hangs up. She explains to me that Chris was able to get the information and prognosis directly from our Dad’s doctors. He called to let me know that the doctors all confirm that there isn’t anything more they can do and he has a few more months to live.

I can’t stop crying, and between sobs I ask Kim to walk with me up to Mark’s house, a couple of blocks away. We get there and I still can’t breathe enough to talk. Kim explains what’s going on and we all spend some time together walking around in circles in Mark’s living room.

February 1997 – Kitchen in my rental house.

“OK, Mom, can you put Dad on?” I had just talked to my mom for a minute or two about how things were going. They never told us the prognosis, and if my brother hadn’t called the doctors, I am not sure if I would have known. I guess my dad didn’t want to burden us. Shortly after this phone call, I decided to take off the rest of the semester of graduate school and spend it at home with my parents.

“Hi Dad. How’s it going?”

“Oh, I’m all right.” His classic response, never transferring his stuff onto anyone. “How are you? Kim?” he says. He knows I can’t hear him well and keeps it all short, loud and clear. I have the phone jammed hard against my left ear.

I’m trying to not start crying.

“We are all good. Listen Dad, I just wanted to tell you that I love you.”

Pause.

“Thanks Steve, thanks a lot. I love you too, very much.”

This is the only time I told my father I loved him. It is the only time I remember him telling me. We just didn't speak openly about emotions in our family. There was no doubt that we loved each other, and I never needed to hear it from him. Every single day, he showed me through his actions how much he cared and loved me. That's the way he raised me. Never a doubt.

May 19, 2014, 3:11 a.m.

Dear Steve,

I'm proud of you for having the courage to call and say the words to your dad from the heart, knowing that you might not be able to hear his reply. I'm proud that you consistently offered your support to your dad and family throughout his illness.

I'm also proud of you for opening up. I'm proud of you for accepting help from others. I know it's not an easy thing for you to do. Don't forget, like the support you got from your mom, dad and brother, you have a lot of friends and family that care about you and want to help you through the stages of hearing loss. You have many allies and a lot of patient and understanding friends. So many supportive people in your life that are helping you communicate, making phone calls, learning sign language, and writing things down for you.

Remember your allies and people that care about you and support you, Steve. Be open and accepting.

With gratitude,
Steve



Concert Fails

I've attended a lot of concerts. Hundreds? A thousand? Everything from bluegrass to jazz, classical, rock, pop and metal. From local singer-songwriters to international sensations. I've spent a lot of money on tickets and actually walked out of close to 50 paid-for concerts ... so far. Why do I keep trying?

The Grateful Dead, RFK Stadium, Washington, D.C., 1990.

I am alone, on the field, in general admission seating. I paid extra in a trade to get on the field this show because about a week ago, I snuck down into the field at the Pittsburgh show and really enjoyed it. Somehow, all contributing factors led to really good sound for me on the field there in Pittsburgh. Whether it was the weather, the humidity, the sound system, my earplugs and earmuffs setup or venue, I was really connecting to the music. It's been off and on at concerts for me for the past year or two. So I got a field ticket for this show and went in really early to get up close to the stage. Mark and the crew have tickets in the stands. Of course no one has cell phones back at this time, so before splitting up, we make plans in the parking lot to meet inside.

Mark says, "Meet at the back of Level 2, Phil's side, at set break."

"Yep. I might go take a break up top, by that orange cone with the construction flag during Drums/Space," I reply. Then we reply in unison, "If all falls through, meet at the van after the show."

Usually either someone in our party is at these predetermined meeting spots or all of us are, and occasionally, no one makes it there. All fine. We always get back to the van. If someone isn't at the van by midnight, we send out the search and rescue. Everyone goes out and looks for the missing person,

but I usually go with a partner to make sure I'm hearing the right info from any venue personnel.

Eddie Brickell opens the show and the sound is weird, but that's common for opening acts. I just focus on resting physically and mentally for the Dead, coming up later. After checking out a song or two, I plug up with my highest-decibel earplugs and put the muffs on over them, close my eyes and just try to relax and deal with the heat and humidity. It's close to 100 degrees.

A couple of songs in, I get totally sloshed with water. I open my eyes and realize that they got the hoses out and are hosing off the crowd in the field. This is feeling good and I'm glad I plastic-bagged my backup earplugs in my pocket. Wet earplugs do not function well. The moisture changes them, and even if you squeeze them out, usually with moist clothing or even dryer underwear, they still alter the sound negatively compared to a dry pair.

I often get funny looks from the guys checking the bags at the gate as they open my shoulder bag to find a pair or two of earmuffs and various plastic baggies, glasses cases and film containers containing a multitude of fluorescent-colored earplugs. Then there's an empty water bottle that I fill up inside the venue, and a bag of peanuts. I am sober and hydrated and here for the music.

We are waiting for the Dead to start. It's so hot, humid and hazy — people are sweating, lying down in mud and sitting in little puddles. But the energy is high, everyone is smiling and happy and getting psyched for the show. I have three different decibel levels of earplugs with me and a pair of muffs. I figure I will start with my high-grade earplugs that seemed to work in Pittsburgh and see how it goes. The band comes on and it starts raining. The rain feels good, but Jerry isn't looking too good.

I am not really understanding what the opener is. I usually get my cues from the bass because that's my go-to instrument

at this stage in my hearing loss. I know most every Dead song and can play most of them but don't know the lyrics and some of the song names. Sometimes I watch people in the crowd singing along to try to get a line on what song it is. Sometimes I'm amazed at the real lyrics to the songs after I read them or am told what they are. I tend to hear the singing as a melody line, not as individual words or sentences.

The first song isn't going well for me, but I decide to leave my protection system as is. The band flows the first song into what I think is *Feel Like A Stranger*, a tune I know pretty well. *Yep! Stranger! Yay!* But I'm feeling a bit like a stranger right now. I have so much bass going on, I can't get past it to even lock in on the snare drum as I watch Mickey hitting it. Can't pick out any of the guitar, and the keyboards are pretty much nonexistent.

This goes on for another song or two as I move to various positions in the field, trying different spots and different earplugs, and then finally just earmuffs. Nothing is working, and the bass down here on the field is just overbearing. It's vibrating my body and making me sick. I need to try the stands. I'm feeling pretty sick now as I work back to the exit at the far end of the field and start looking for something to throw up in. There's a big, open-top yellow garbage pail, and I hang out there for a few minutes, waiting. Luckily, most of the field crowd is jammed toward the front. There are scattered groups of dancers, twirlers and hoopers back here, which is not making my situation better. Circular motion makes me sick even when I'm standing alone in my room. *What is that even about?* Something about the balance mechanisms and vertigo that I get with the "going deaf" package, I guess. I go over to the pail and vomit a few times, and head up into the stands. People throwing up at Dead shows seems a common occurrence, so I don't think twice about it.

I go on up to a second-level row and shimmy into a free space and check in for a song. *Still sucks*. Still too much bass. I'm not receiving anything from stage right, guitars and keyboard. *Keep moving, man*. I do a circle around the stadium, checking sound and earplug configurations at various spots on the second level with no luck. Still a lot of bass for me and nothing else. Behind the stage is a little better, and I climb up to the highest level of the stadium in hopes for a little more clarity. *Still kinda sucks*. I can't even really tell what song is being played. I am bumming pretty hard. I hang out for a bit and decide to head out to the parking lot before the hallways and stairs get crowded at the set break. *Bummer*. I find a good spot on Shakedown Street, a vending area in the parking lot, and set up our van's grilled cheese stand and get ready to sell some sandwiches after the show.



Rush, MGM Grand Las Vegas, 2004.

This place! Although I've had countless fun moments here, this place really freaks me out. Its overbearing lights, activity and energy rob me of all my senses like an anti-gravity, isolation floatation tank situation. I don't last too long on the Las Vegas Strip, and each visit gets shorter and shorter. Living out West brings us through Vegas once or twice a year as we tour the national parks in the area, go rock climbing at Red Rock Canyon, or go specifically for a certain concert or show.

Mark and I leave the hotel room for the long-awaited, much-appreciated visit with our all-time favorite band, Rush! Even before we get out of the hotel's halls, my senses are depleted as I plug up with medium-grade earplugs at 30 decibels. Auditory communication is out. Getting to the casino level, I'm assaulted by the flashing lights from the machines and neon signs, crowds of people moving in all kinds of random directions or dead-stopping right in front of me. Then there's the multitude of visual oddities that I can't look at for fear of burning out my brain processors trying to understand it all. Visual communication is out.

And people still smoke cigarettes. Even after all the gigs and concerts and everything I've been exposed to through the music industry, I'm still surprised at all the smoke in these places. There's a giant cloud of smoke, and even if I were to get down on my knees and crawl, I couldn't escape it. It dries my eyes out. Visual communication is *totally* out. This smell is not something I am used to, living in the mountains, and my ability to distinguish any smells – or tastes, for that matter, other than cigarette smoke – is destroyed. Olfactory and gustatory support is out. That leaves me with touch, and I am not touching anything on the germ-ridden Las Vegas Strip.

I walk two paces directly behind Mark, with my eyes down, and just follow his feet through the casino to the street. This is even worse. Higher-intensity flashing lights, noises, screaming,

laughing, car engines, crowds, some beggars and solicitors, with a side order of drunkards. *Just follow Mark. Watch his feet. Don't look up. Ugh! This place!* I can handle this stuff and have navigated through this alone many times, but I'm trying to conserve brain-processing energy for the show.

We get to the MGM arena, where the search crew lady smiles at me and shows me that her earplugs are already in after she inspects my bag and finds all my earplug canisters.

We are pretty pumped up for this show. It's been a while since I went to a concert with Mark, and I finally agreed to come along on this one. We grew up listening to Rush. Like most Rush fans, I could air-drum, air-guitar, bass and keys through every Rush song from the first album until *Presto*, their 14th studio album, when my hearing got too bad to access new material. Mark could air-play the entire Rush collection and *play* it on bass as well.

Our seats are on the first level off the floor, directly opposite the stage. We are hanging out writing notes back and forth on my pad as we wait for the show to start. We realize we are veterans here now and are glad to see a bunch of teens and 20-year-olds in attendance.

It's time. The lights dim and Alex and Geddy come out waving while Neil gets behind the drum set. They kick off into what I'm guessing is a song, but from my experiences up to this point, I'm sensing that this is an Ultra Extreme Volume Situation, which to me sounds like a crunching, rhythmic jet engine. I am not able to even distinguish a rhythm. I see that Geddy is on the keyboards and I'm hoping it's something from the recent years, one of the songs that I am not too familiar with. I was expecting problems, but not so severe. I look at Mark, who's smiling.

"What song is this?" I lip and sign to him.

"Subdivisions," he lips back.

Damn. I know this. I know every note of this. I've played this. I listened to this on a radio beneath my pillow late at night for a week when they put it out as a single before they released the album in 1982. A friend of mine made me a cassette tape of just Subdivisions playing over and over for 60 minutes. *Damn.*

I try to focus but can't get to any point of recognition. The second song starts, and it's the same. I look at Mark and shake my head a little. He nods apologetically and signs "large amount" and "money" for the song The Big Money. He knows what's going on. I try to add the muffs over the plugs for the next couple of songs, but it's just a mess. I don't want to bum him out, so I decide to split. I give him a high-five and sign "noise" and "me-up." He knows I'm going to try to check out sound situations in the upper levels and around the arena before leaving.

Some other notable concerts I walked out of: Peter Gabriel, King Crimson, Phish, Bela Fleck and the Flecktones, George Benson and my son's middle school band performance. Why do I keep trying?

June 26, 2014, 1:14 a.m.

Dear Steve,

Yeah, that sucks, maybe you can get some money back from Ticketmaster! Ha ha. Dude! You left a Halloween Phish show!? Hey man, bummer, but you did get to experience a lot of music and concerts and watch some of the masters, you know? Some people never get any of that. You've been extraordinarily lucky, man! How about thinking about and remembering all the concerts you DID see and experience? You're sounding a little negative here. Stay positive, man. Those were some good times. Not to mention, once you stopped going to concerts, didn't you discover another type of artistic performance in Vegas? Those Cirque du Soleil shows you started going to when you couldn't hear the music anymore. Right?! Those are awesome! There's little to no talking, they are a visually communicated concept show, and international, so specific language isn't used! What a discovery! From Cirque to dance, magic shows to Blue Man Group type stuff. Didn't this trigger a lot of creation for you with your black-light videos, and art lessons in school?

Dude. One door closes, another opens.

Stay positive,
Steve



Movie Fails

I've gone to a lot of movies as well. Maybe more movies than concerts! In the past decade, since they started providing captioning devices, I have walked out of exactly 19 of 34 movies, as of this publish date. I've kept track on a little note in my wallet. That's more walkouts than stay-ins. Why do I keep trying?

Through middle school, I would probably go once a week. I would save my chores money for tickets or at least to pay for popcorn. I always hold the popcorn.

In high school, I had a good amount of cash on hand from working a few different jobs. I averaged probably twice a week. Once a week at the multiplex for the new arrivals, and once at the dollar cinema as a social event with all my friends. My friends usually got, or snuck in, candy and soda, but I always got popcorn for the crunching effect.

Through college and my early 20s, I averaged a few times a month, maybe less. Money was tighter because I was on my own, ticket prices increased, and hearing and comprehension decreased drastically. I was experiencing movies at a different level than the director intended. I was making up my own stories while watching their visuals. I usually just attended for the social aspect, hanging out with friend groups. I felt loss, missing my cinema experiences, but I was playing a lot of music at this time, and my focus and attention were elsewhere.

Then I stopped going to the movies for about 10 years as DVDs and captioned movies became more available at home. This worked out pretty well until I exhausted the library of captioned videos. Captioning wasn't easy to come by. When I was younger, I would get really angry because not all movie rentals had captions! I would write letters to studios and production companies and sometimes send them and sometimes not.

It's cool talking about this with Deaf and hard-of-hearing friends now because we all had this experience as the industry adapted and transitioned to trying to caption its media. Things got a lot better and FCC laws were put into effect to caption all TV and produced media by 20-whatever, and updates were made to the Communications Act. Everything was getting better for the Deaf and hard-of-hearing community around captioning until ... YouTube. No captions, automatic captioning, self-made captions, joke captioning, and a lot of confusion for me around YouTube. I missed a lot of good stuff, for sure, but that's the way it goes sometimes.

I remember the day Mark said, "Dude, this movie theater in Springfield has some sort of captioning glasses. You can wear these glasses at the big screen and it captions them somehow!"

"Really, like Geordi on Star Trek or something? Hell yeah! Let's go!" In 2013, Regal Cinema developed a captioning device that allows the viewer to see captions as they would be accessed at home, through these special glasses that can be worn over regular glasses, and they even have a 3-D adaptation. We actually went to Star Trek Into Darkness for my first captioned big-screen movie! It worked! I watched the movie and read the captions right in front of me through these glasses that no one else could see. It was very liberating.

I'm back!... and I'm holding the popcorn! Tracey thinks I like crunching because it's some type of tactile, sensory deaf thing. I can't hear the crunching, so I very dramatically crunch and munch popcorn so that I can *feel* it, and apparently, so can the people sitting near me.

Soon after the glasses, another theater in my area introduced a captioning device that fits into the cup holder on your seat. Whoa! Two choices to choose from. Soon most theaters had most movies listed as closed-captioning accessible and I started to attend movies almost as often as I used to when I was a kid.

As with any new technology, there are going to be issues to overcome. With the glasses, there's the pain and piercing sting

into the side of your head for two-plus hours. There's the need to get there early and sit in the middle of the theater, so the glasses don't project the captions onto the side wall. With both, there's what we call the occasional "tech failure." Where it just isn't f-ing working.

Then, with the cup-holder device, there's the "screw's not tight" issue and the unit is floating around for two hours where I have to have one hand holding it while I jam the popcorn bucket between my leg and the seat so I can eat it all with my other hand. I've started to bring a small monkey wrench to movies to tighten the bottom nut on that sucker!

There's the "if you want to go in, get a seat, and then go get popcorn, you're out of luck" issue. You can't really go anywhere near your specific theater or else the device registers your presence and clicks "ON." Then if you exit the vicinity, the device gets confused and shuts off or picks up another movie's captions. So I go to the bathroom and fill my water bottle on the other side of the building before the movie begins and then go to my specific theater. You have to go in and sit down, send your wife to get popcorn, and stay there and hope it works after the previews, which aren't captioned. Occasionally, there's also the aforementioned tech failure, when it just isn't f-ing working.

It's the tech failures that screw me up the most. As I said, 19 out of 34 times, according to my records, there have been tech failures, where the movie starts but the captions don't. So, I sit with my friends or family for five or so minutes after the movie starts, messing with the buttons on the unit because no captions are being produced, get pissed, then take a bunch of deep breaths and go to acceptance, and let my wife or child or friend know that "Shit's fucked up, I'll catch the next one." I leave the popcorn and go to the service desk to let them know in niceties that "Shit's fucked up," and they give me redeemable tickets for future presentations. I go and meditate out front, or get a beer, or walk around, or drive around, or go home.

It can be disappointing, but overall, I'm so grateful for technology right now and for this advancement in accessibility for us at the cinema. I know it's going to get better and better. I'm psyched!

June 12, 2014, 4:02 a.m.

Dear Steve,

I love your positive attitude here, man! Awesome. You should get involved in developing better technology for the Deaf and hard of hearing. You have a lot of ideas, man! You have that list of really cool stuff for movie theaters, concerts, social situations, restaurants ... while you're at it, you should get involved with advocating for captioning and access to media in your school district. Set a meeting with the district offices to talk to them about captioning the district's Professional Development courses, because remember that one last year? It sucked! It was so boring because their videos weren't captioned. You were left out. Baloney! Set that shit straight, Steve. It's an awareness thing, man! They're not oppressing you on purpose. They just don't *know* yet. They don't understand. They have a lot of stuff to deal with, man. You've got to let them know!

Dude ... thanks,
Steve

Afterword

My younger brother, Steve, recently wrote this book chronicling his hearing journey; specifically his journey becoming deaf and working with that challenge over the past 40 years. The book surprised me in so many ways because it taught me so much about Steve as a person – as my brother and as a man – and his perseverance inspired me. It also helped me see myself a bit differently and will likely do the same for other readers, which is why I want to articulate what I've learned and gained through reading it.

The book describes how my brother experienced situations throughout his life and how his hearing situation posed challenges (in some cases *small* and in some cases *huge*). At the end of each chapter, he wrote a letter to himself (“Dear Steve....”) to take responsibility for his experience so that he fully owned it; being a *victor* and not a *victim*.

The book also brought back a lot of good memories of growing up, of family, friends and what life was like in high school and college. It was a fun read ... that's important. It was *fun*! I relished every chance to curl up somewhere and just spend some time with myself and Steve's book.

How do I see my brother in a different light? How did I get to know him as another person?

To start with, I got to see Steve as someone who works on himself and does his best to improve and grow. I can see that he works on himself on an internal level, and what is really special is the fact that he's doing it on his own. He doesn't have a group, teacher, tour guide or school that he's part of or where he draws guidance. He is self-driven.

Much of what he shares is very vulnerable and raw. He can open up his heart and shine a light on the hard stuff and bring it into the public eye – exposing a lot of his fears, anxieties, frustration, self-doubt and perceived shortcomings. Hence I

see my brother as vulnerable, and I never really saw this aspect of him before.

I got to see Steve as a man—not as a kid, not a younger brother, not a lesser person (which usually goes along with being the younger brother). I got to see him as a man who takes responsibility for himself: his emotions, his choices, the cards he was dealt, the seed he was given. I am proud to see he is not a victim to his hearing challenges and works through each one in the best way he knows or discovers. I can see he is a leader of his own life. He is raising the type of family he wants as a committed husband and father, living where he wants. He's steering his teaching career as he sees fit while enjoying a very active social life. He is living his dream, not anyone else's, and to top it off, he is going for it, pushing his boundaries and not holding back when there is something he wants.

I see Steve as a success. He takes healthy risks and they are paying off for him.

I see Steve as a writer, as someone who can articulate, draw out from within, and use humor and storytelling to get thoughts and ideas out there that people can relate to and draw inspiration and strength from.

I see Steve as fun. Why? Because he is working at putting "fun" into his life. He is befriending himself in a positive way. He's rock climbing, running, building a wood-fired pizza oven, pursuing music, writing ... all this and more, on top of having a family. He handles the negative stuff that comes up so it doesn't keep him down. In the book, he describes instances when he struggles with the concept of life not being fun and can slow himself down and recognize it and make choices to fix it.

The book also reminded me just how creative and talented my brother is. He has been a musician and recording artist all his life, despite the deafness, and has written and recorded at

least 10 albums of original material, one of which is all children's songs. He wrote and produced a series of sign language movies, and I remembered his talent as a self-taught woodcarver crafting beautiful sculptures as well.

Steve can adapt and overcome. I got to see how through his hearing challenge. He chose to be creative, research, uncover solutions and sometimes just work around stuff. But the most important thing is he chose not to give up on himself.

I see how much Steve and I have in common. We both share a lot of the same challenges, workarounds and a similar underlying emotional matrix. As a person who has gone deaf, it was really interesting to see someone close to me experience some of the same issues, emotions, scars, healing and growth. I don't feel alone in what I've been experiencing. I am reminded too of how we all have our challenges, and we all must grow, change, let go, adapt.

I realize that all these positive qualities I discovered in my brother are a reflection of me and what I have inside. I must be able to see these things in myself first if I'm going to be able to see them in him. I'm reminded of how creative, successful, adaptable, articulate and fun I am. I am a leader of my own life and all that comes with it. I am living my dream and working hard to push it forward. I give my best and try to take responsibility for who I am.

Again, I am all these things I see in Steve, but for some reason, it's easier to see them in others sometimes ... because often we're unwilling to recognize all the positive qualities in ourselves. But that's just how most people are – and I'm learning every day to further appreciate my gifts and just go for it.

Chris DiCesare