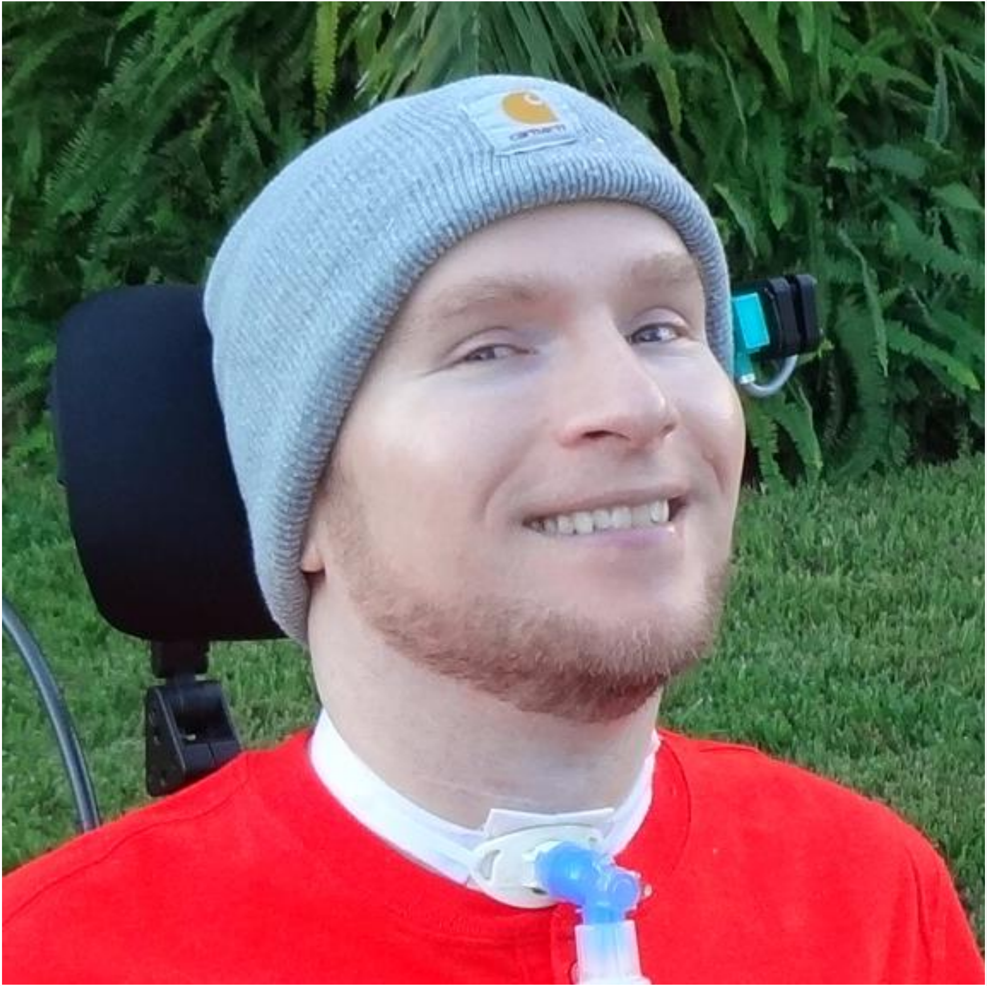
Life Can Still Be Good

– Despite Difficult Challenges –



William A. Miller

A MEMOIR AND MORE

Back cover:

Bill Miller became a C1-2 quadriplegic, paralyzed from his neck down and ventilator dependent more than two decades ago at the age of 20 in 1997.

He shares his story and more to show that life can still be good, despite seemingly or legitimately difficult challenges/circumstances.

Bill wrote this memoir using voice software, beginning in May of 2020 while self-quarantined during the coronavirus pandemic.

TABLE OF CONTENTS – I keep tweaking this, but here is my current outline:

My Story

The "My Story" portion is the first major section of my book.

WHY I AM WRITING THIS BOOK

As I begin to write this in May of 2020, I am in the midst of my 44th trip around the sun, and have been paralyzed from my neck down and ventilator dependent for 22 of my 43 completed years.

The point of writing this book is to share insights I have gained from living and viewing the world from a mostly seated position for more than two decades. Candidly, my primary care physician asked me to share my experiences and write about being a quadriplegic because he did not think an abundance of books existed that could help physicians, and people, understand what they might need or want to know about living with quadriplegia. The fact that my doctor suggested I do this only furthered my own desire to shed light on paralyzed life and show that… *life can still be good*.

From a medical standpoint, I am blessed to be able to report that I have had just four hospitalizations in 22+ years. The first one was preventable, and the last three were related. But still – four hospitalizations in 22+ years as a ventilator user and high-level quadriplegic is a crazy good track record for being healthy (thank you Lord!). I am not a doctor, and nothing I write should be construed as medical advice, but in parts of this book, I will share things we have done successfully as ideas that other quadriplegics and/or ventilator users might consider, to help them live as good a life as possible.

But I also want readers from all walks (and rolls) of life to find reading this book worthwhile, if you are intrigued by the above-stated premise.

A universal human theme is that we all have challenges in life. Learning how I and some others have handled our challenges, hopefully that can be encouraging to people as they face theirs.

The reason I wrote that life can still be good "despite seemingly or legitimately difficult challenges" is because some challenges seem less daunting, when we see what some of our fellow humans face. Even in my situation as a ventilator dependent quadriplegic, I believe plenty of people are dealing with worse circumstances. And yet, I believe that life can still be good.

Regarding everything I have done and everything I do… any and all glory to God!

And now, without further ado… here we go! (Smile.)

PRE-INJURY BILL

Becoming paralyzed a few months before turning 21, I am so thankful to have had what I consider a very normal – and very good – first 20+ years filled with many life experiences typical of many able-bodied American males born in 1976, growing up in the '80s and '90s.

This will give some insight into the person that I was, and still am.

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I was born in the Chicago suburbs, about two and a half years after my brother Andy. Our family of four moved to Central Florida when I was about a year old. That fact allowed me to kind of "claim" both Yankee status and southern roots when I was an 18-year-old server at Olive Garden, wanting to subtly connect with people from the North and people from the South at my tables.

My dad, Jim, and mom, Joanne, divorced when I was about three years old. My dad was awarded primary custody, but thankfully, I was still able to see my mom regularly while growing up. Looking back, I don't feel like I was terribly "adversely affected" by the divorce. I never felt short on love from either of my birth parents, and later, received additional love from stepparents. I also got a little brother out of the deal, as my mom remarried and had Shane when I was about seven and a half years of age.

I was always very observant, and studious. When I was a baby, my mom could put me in one spot and I would just sit and watch her for hours. This trait would translate well when I became a quadriplegic, and I will share some observations in the telling of my story, and later, some life observations as well.

On a side note, I was a pretty serious kid. When I finally turned 30 years of age, my dad said, "Bill, it's about time you actually are 30, because you were going on 30 when you were six."

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From preschool through sixth grade, I attended Montessori school. It was a relatively small, private school with roughly a dozen students per grade, and several grades sharing a fairly large classroom with one teacher. Besides friendships with many quality people, what I remember most is that it was project/assignment based. We would be given a certain number of assignments to do each week, and the freedom to do them as we chose, as long as we completed each satisfactorily and prior to their due date.

I like that form of education, as it seems more "real world" given that real life often entails doing projects and many items on a "to do" list.

That education style also jived well with how our parents raised us. They had some rules and set boundaries, but as long as we stayed within them, we were allowed to play and do what we wanted. As long as we kept acting responsibly, we kept having some freedom of choice.

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At the end of my fourth grade year, when I was nine years old, my stepmom Donna was working at the courthouse as an assistant public defender. I was interested in her job, so she brought me to work and taught me to do legal research. My affinity for the Hardy Boys detective books coupled with the experience of assisting Donna that summer made me want to become a lawyer. Actually, I wanted to become a prosecutor so I could put bad guys behind bars.

I think it was my fifth grade year, Donna helped our Montessori class set up a mock trial – an armed robbery gone wrong – that we treated as real as possible, even getting to do it in a real courtroom. I was the prosecutor (smile) and it was a convenience store robbery, where the owner of the convenience store accidentally shot his wife fatally when attempting to shoot the robber. It was based on a real case, and I was able to convince our jury that the robbery suspect was guilty of the wife's death since she died due to the commission of his felony. So I am 1-0 as a "prosecutor."

After my fifth grade year, when I was 10, my teacher Mrs. Conner "bet" me that I could not read 30 books over the summer. I read 50+ books that summer, mostly more of the Hardy Boys books, and later that year, my reading tested at the high school senior/college freshman level. Unfortunately for me, other interests trumped book reading much of the rest of my formative years, and my reading skills probably did not advance a whole lot more.

One reason why I was able to read so many books that summer was because Donna, who was an English teacher prior to going back to school for her law degree, she wanted to encourage reading and offered to buy any book that I would read. Our family also took a memorable, couple-week road trip around the perimeter of the

United States, hitting most of the major tourist destinations. A lot of driving time afforded reading time. And of course I am also thankful to have traveled to and through so many states and to have seen things like Niagara Falls, Mount Rushmore, Yellowstone, the Grand Canyon, and much more in person.

In sixth grade, our Montessori class took a weeklong field trip to Washington DC… at an age when I was just barely old enough to have a slight grasp of how amazing – truly amazing – it is to be able to spend a week in our nation's capital, and soak up such history. Taking an Amtrak train from Central Florida to DC, and back, made the trip even more memorable.

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Outside of school, my brother and I, and different friends would spend many hours playing outside… climbing trees, building forts, riding bicycles, and playing sports – lots of sports.

I played multiple years of organized team sports – baseball, soccer, and football. I was certainly not the most physically gifted athlete, but I paid attention to my coaches and learned how to play the games well. I thoroughly enjoyed playing each sport (baseball the most) and was good enough to make multiple youth All-Star teams. And whether it was physical education class, or just for fun outside of school, I also played or did at least a little: badminton, basketball, billiards, bowling, flag football, Frisbee, golf, horseshoes, kickball, racquetball, swimming, table tennis, tennis, volleyball, weightlifting, wiffleball, and wrestling.

I am grateful to be able to say that I know what it's like to be able-bodied and… to spend time on a farm as a kid… to climb on hay bales and to ride on a tractor… to whittle sticks with a pocket knife… to ride a dirt bike and a four wheeler… to rollerskate, skateboard and ice skate… to go snow skiing and sledding down a hill… to play pinball and shoot pool (billiards)… to go swimming and snorkeling… to do a front flip and back flip off a diving board, not to mention a belly flop and cannonballs… to dive into a pool, a lake, and through waves in the ocean… to go skim boarding and boogie boarding at the beach… to build sand castles and feel the sand "erode" underneath my feet with the receding of an ocean wave… to go to water parks and amusement parks… to ride roller coasters… to play games and go on rides at carnivals… to throw and catch baseballs and footballs… to hit a homerun and throw a touchdown (funny story about that)… to score a goal and save a goal in soccer… to make 10 three-pointers in a row (practicing basketball in our driveway)… to airball a three pointer and have to hustle down our driveway to keep the ball from going into the street… to ride a 10 speed bicycle 5 miles without touching the handlebars (which was 10 laps around our "block")… to go horseback riding… to go fishing from docs and boats… to shoot a bow and arrow, and a pistol, rifle, and shotgun… to spontaneously go somewhere with several people, and while walking to the vehicle to call "shotgun" in order to get the best passenger seat [does that fit with these other activities?]… to pitch a tent and camp out… to roast marshmallows and hot dogs over a campfire… to have a bonfire… to float on an inner tube down a river… to find sharks teeth in a spring… to go canoeing… to go boating on a pontoon boat, bass boat, and ski boat… to go water skiing, tubing, and knee boarding… to fly a kite, and also fly in a little Cessna and a commercial airliner… to go on a cruise… and to drive quite a few different vehicles – some cars, trucks, and SUVs.

Driving is something I really enjoyed, and miss, but I rarely dwell on things I can no longer do. I was good at driving automatic transmission vehicles, but not-so-good at manual transmission (stick shift) vehicles. In my defense, I didn't have much experience driving a stick shift, before my brother and I drove his stick shift Honda Civic from Florida to Hot Springs Village Arkansas for our grandparents 50th wedding anniversary, when I managed to roll slightly backwards a few times before getting it in gear on some Arkansas hills. (Smile.)

That was at the end of May 1997, a few months before my injury. Something else memorable from that same trip was my brother was suspected of a DUI in a dry county – even though we were both completely sober – because it was late at night and I was sleeping straight up in the passenger seat, but to the police officer who pulled us over, I looked like I was passed out drunk! I was always a good sleeper, able to sleep in less-than-ideal positions and even some noisy environments, which translates well to being a quadriplegic.

A great memory from that trip was Andy and I wanting to "whoop up on" our dad and grandmother at cards. Grandma Willi is really good at playing cards. She and Grandpa Loren played bridge for years, and our dad jokingly says that he majored in playing cards his first year of college at the University of Illinois. So we knew they would make a formidable team, but Spades was a really popular card game with younger people that Andy and I played a lot of, and thought we were good at. Now, there are 13 "tricks" in each hand, and Andy and I said we were going to get five as a team, so that's what we bid.

Grandma said with a smile, "how are you boys going to get five, when I am going to take 10 by myself?"

Andy and I looked at each other with wide eyes like, "oh crap."

Grandma got the 10 she said she would, and Dad got the remaining three. Andy and I got zero that hand, and a lesson in humility.

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Most every summer, and a few winters, Andy and I got to go up to the Chicago suburbs to spend time with our relatives (both our mom and dad still had family living there for years). Our dad's father, Grandpa Loren, he used to go to Wrigley Field with his grandmother when he was a boy to watch the Cubs play. That tradition was passed down to our dad and us boys, making Andy and me fifth-generation Chicago Cubs fans. Going to Wrigley Field in Chicago is special now and it was back then as well, and is one of many experiences for which I remain grateful. I'm thankful to have attended quite a few Chicago Cubs games, including the first official night game at Wrigley Field on August 9, 1988.

Mother nature helped us with that. Knowing that the first official night game would be coveted by Cubs and baseball fans, the exact date was not announced until most of the tickets had been sold. It turns out that August 8, 1988 (or 8-8-88) was selected, but after a couple innings, that game was rained out. We had tickets for the next night, which became the first official night game. [I added this paragraph, but is it necessary or helpful to the telling of "pre-injury Bill"?]

I am grateful for all the aforementioned experiences – and everything I was able to do prior to being injured – and for the people with whom I got to enjoy them. I have learned to value experiences, much more so than material things. Experiences stay with you, and especially now, being paralyzed, I'm glad to know what it's like to do so many things able-bodied.

The quick little story about throwing a touchdown pass… it was Little League football, ages 10-12, and I was a fairly scrawny 10-year-old. But I was smart enough to learn and execute the plays, and Redskins Coach Marcus Lawrence started me out at quarterback. I later read in the newspaper that "Bill Miller threw a touchdown pass to Allen Neiford"… Allen was one of our star players, a 12-year-old running back, and I threw the touchdown pass a whopping 5 yards in the air to Allen, and he did all the work running it in behind the big boys on our offensive line. But it sounded good in the paper without those details! (Smile.)

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Growing up, I feel like I always "worked" in some capacity – which is a good thing.

Even at an early age, something like age 4 or 5, I remember learning to do chores like folding laundry with Andy before dinner. As we got a little older, instead of receiving a monetary allowance, my parents put prices on assigned chores. I think that allowed us to learn the value of money, and context for what things cost. If I wanted a three dollar toy, I could buy it knowing that I would have to take out the garbage and clean the bathroom (or something along those lines) in order to earn the money to pay for the toy. So I could think to myself, "is this three dollar toy worth those chores I did, or would I rather save the three dollars?"

Our dad got into coaching baseball (and later soccer) when Andy started Cap League at age 7, and I came along and started to learn the game just from watching. By the time I was finally old enough to play, I was "an advanced student of the game" for my age, and batted .606 for the season as a seven-year-old hitting off the pitching machine.

But our dad has always been civic minded, and due to his involvement, my brother and I also occasionally worked (volunteered) in the concession stands at the ballfields when we weren't playing. (On a side note, our dad is now a young 71 years of age, and up until this coronavirus pandemic, among other things, he still has been coaching youth sports and helping with concession stands off and on for more than 3 decades – all volunteer of course. He is also one of my primary caregivers, and as I dictate this, he is sleeping on a bed near me in my computer room.)

My first real job was working at AMC Lake Square 6 Theatres. Andy had already been working there and knew it was a good fit for me. So as soon as I turned 16 and was able to drive myself, I started working there also almost literally on my 16th birthday. Andy and I both loved movies, and with prior concession experience, my first shift was running a register in concession on a busy Friday night. I actually loved working at the theater. I worked hard and earned accolades and promotions. When I became a concession "team leader" my Grandpa Loren told me that a good leader is not afraid to do the least desirable tasks, to show people you are not above them, and will work just as hard (or harder) as you expect them to, doing whatever needs to be done. Great lesson, Gramps, thanks.

The only problem I had working at the theater was that the paycheck did not seem to match the effort I put forth. [Should I elaborate?]

So, when I turned 18 and was of legal age to serve alcohol, I went to work at Olive Garden as a server with the thought that how well I knew my job and did my job could be rewarded more accordingly with tips. Obviously, a server cannot control what someone may tip, but the quality of your efforts have a better chance of earning more than the flat rate at the movie theater. (But we did get free movies, soda, and popcorn as theater employees… "so we had that going for us, which was nice" – that's a little poetic license with a Bill Murray Caddyshack quote.)

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COLLEGE, CHOICES, CONSEQUENCES

I graduated high school at the age of 17. Even though I had a girlfriend for more than a year, I was still a virgin. Since I know this question will be in some people's minds, I was not a virgin by the time of my injury.

I also did not drink alcohol while I was in high school. That was a choice I made, largely because I knew my parents would not approve – especially while I was living under their roof.

That choice was at least subconsciously influenced by reading a book titled, "Life's Little Instruction Book" by H. Jackson Brown Jr. It's filled with 511 nuggets of advice, and my favorite was: "live like you wish your kids would." That resonated with me, and to this day, I like to share that with people who are raising kids, because it puts the child in the parental role, and is a decision-making framework to help them make better choices.

Later on, I will share more about some of my post-injury speaking engagements, but I spoke with a group of "at risk" ninth-grade students at my high school alma mater, trying to impart useful knowledge, including the above nugget. Ninth graders are roughly 15 years old, and I said to them bluntly, something like, "would you want your 15-year-old child doing drugs, drinking alcohol, or having sex at that age?" Those rambunctious teenagers were still, quiet, and wide-eyed as I asked them to think about that for a moment. "Live like you wish your kids would." Putting choices into context like that can lead to better decisions.

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I was accepted into the University of Florida out of high school, which I was quite happy about because I grew up a Gator fan and always wanted to attend the flagship university of our state. But since the first two years of college were mostly required courses for all students (before declaring a major and focusing on that) I decided I could save money and probably complete them more quickly if I stayed home and attended our local community college, which is now Lake Sumter State College. The plan was to complete my AA degree, and then transfer to the University of Florida, which is ultimately what I did (I also had a semester at Santa Fe Community College in Gainesville in order to take a couple prerequisites that Lake Sumter did not have).

While attending Lake Sumter, since I was still living at home, I still chose to not drink, even though some of my older friends/coworkers at Olive Garden invited me to some parties. I went to one that was supposed to be particularly large, in large part to kind of chaperone a female friend/coworker and keep her out of trouble (years later, she wrote and told me how much that meant to her).

But somehow, one of the guys convinced me to match him "soda for beer" i.e. for every beer he drank, I would drink a soda.

Recalling this story now, makes me think of the movie Forrest Gump, in which Tom Hanks' title character said, "I must've drank me about 15 Dr. Pepper's." (Smile.)

I was drinking Mountain Dew and Cherry Pepsi (not mixed!) and I think I exceeded a dozen in about three hours, as I did not get to the party until after closing at Olive Garden, and my friend/coworker had a head start because he didn't work that evening. I think I finally made it home around 4 AM, all hopped up on caffeine and sugar! Even though I was physically tired, I was WIDE AWAKE and unable to sleep for at least a couple hours.

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A few dual enrollment and advanced placement opportunities became available towards the end of my high school years, and taking those helped me graduate from Lake Sumter with my AA degree in 1.5 years. I then moved to Gainesville with my best friend from high school, Rob, and another good friend of ours, Mark.

Rob went to UF straight out of high school, so he had already gotten acclimated to Gainesville, and the three of us got an off-campus townhouse-style apartment together. That was in January of 1996.

I wanted to keep working a part-time job while I was in school, so I asked Rob what was the best restaurant in Gainesville… "Texas Roadhouse" was his response. So we went there for dinner one night, and I knew that was where I wanted to work.

I spent the previous year working at Olive Garden and discovering what it took to be a really good server. Our Olive Garden restaurant was dynamic, with a great staff, and statistically, I think we were the top-performing Olive Garden in all of Florida at the time (yes, in little ol' Leesburg!). I generally put my all into whatever it was I chose to do; in this case it was becoming the best server I could be as quickly as possible. I learned from top-notch servers who were already experienced, and after about half a year, management made me a server trainer also.

So I felt like I had honed my craft pretty well, and I wanted to be a server at Texas Roadhouse. The food, the atmosphere, the people… I loved everything about it. But so did many other people. I would later come to learn that our general manager would interview roughly 25-30 people once per week, and maybe hire a couple. Considering the talent pool in Gainesville, it wasn't easy to get a job there.

I was thankful to be offered the opportunity to bus tables. It was no secret that the very attractive female waitstaff helped bring in customers, so of course they did not want too many male servers. I took the job, and tried to be the best busboy I could be. I eventually earned a chance to serve, and later became a server trainer there as well. More importantly, I met a lot of quality people, many who I am still in touch with to this day. And we had a lot of fun during and sometimes after work.

Academically, I was a math major at UF. Candidly, I was not the best student.

I worked, worked out, had fun, and definitely was not completely focused on academics. I also did a little tutoring. I enjoyed helping people who claimed to be "not mathematically inclined" who still needed to pass courses like college algebra in order to graduate. That made me think that I wanted to become a math teacher, at the community college level, which was a level of mathematics that I enjoyed and felt like I could explain/teach in multiple ways so that "non-inclined" students would be able to understand. So that was the plan. I wanted to do well enough to graduate with my bachelors degree in mathematics, and earn some type of Masters degree that would allow me to teach at the community college level.

That was the plan.

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The night of August 22, 1997 was a Friday. It was the beginning of the last weekend of the summer before I was to start my senior year at the University of Florida. My roommates (Mark had moved out to live with another friend of ours from Leesburg, and another high school friend, Ernie, had moved in with Rob and me) and I decided to have a small party with some friends at our apartment.

I had way too much to drink.

Sometime after midnight (making it August 23rd) I lost recollection due to being heavily intoxicated, but was told that I managed to make it upstairs to my bedroom under my own power. My roommates checked on me, and found me safely sleeping it off in my own bed. They checked on me again a couple hours later, and found me facedown on my bedroom floor.

It appeared that I had simply tripped over my ab-roller (exercise apparatus) and looked as if I was passed out. So they picked me up and put me back in bed, where I continued to sleep it off.

I woke up probably around 8 AM and tried it to sit up. I was thrusting my arms, shoulders and head upward in a sit up motion, but could not sit up. I called out for some help and Ernie came in. His room was right across from mine.

I said something to the effect of "Ernie, go get Rob, I can't sit up." Rob was a physical therapy student at UF, and we had played football together in high school. We were roommates the entire time that I lived in Gainesville.

When Rob came in, I kind of explained the situation, and said, "maybe it's something like a really bad pinched nerve or something like a shoulder stinger." Playing football, I had what I called shoulder stingers where parts of my neck, shoulder and arm would go numb temporarily.

In the back of my mind, I knew it was more serious than that, but I really wanted to go back to sleep, and was hoping and praying that I would wake up and everything would be fine, and I would be back to normal. I agreed that we could call 9-1-1 later, if I woke up and everything was not fine. And I decided to go back to sleep.

A couple hours later, I woke up again and everything was not fine.

I asked Rob to call 9-1-1.

And my parents.

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A few minutes later, it seemed like there were a dozen EMT type people in my small bedroom, asking me questions, immobilizing my neck and strapping me to a backboard. It was not long before several of the men were carrying me downstairs to the first floor of our apartment, and also downstairs from our second-story apartment to the ambulance. I remember all the stairs clearly because I was in a pretty good amount of pain, which was made worse when they had to turn me sideways and somewhat upright to navigate the turns going down the stairs.

But that pain, and every bit of pain and difficulty that I would endure over the next three months that I would spend in hospitals, it was nothing compared to the embarrassment I felt for stupidly choosing to drink to excess and ultimately becoming paralyzed.

I prided myself on managing my life well, being very independent, and doing most things well or very well. Generally speaking, I tried to be responsible and self-sufficient. I wanted to be someone to help others, not someone who needed help. But I went from being very independent to almost completely dependent in the blink of an eye, arguably from one bad decision.

But it was not my first poor decision. I was not and am not perfect. And I am thankful that I "did this to myself" rather than to another human. There was more than one occasion where I drove at least somewhat impaired. Like I said, I'm not perfect. None of us are. But I am thankful that I mostly harmed myself, rather than someone else.

I say "mostly" because I recognize the fact that my family has also been directly impacted. That actually bothers me more than being paralyzed, yet for the most part, they take it in stride and act like it's no big deal. The fact that they do so IS a big deal. And I could not be more grateful.

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Going back to those "at risk" ninth graders I spoke to, I stressed the importance of trying to make good decisions, because although we cannot necessarily predict outcomes, seemingly good choices are less likely to have bad consequences.

I would eventually learn that if a spinal cord injury is suspected, try to not move the injured person, and call 9-1-1 as quickly as possible. There is a steroid called methylprednisolone that can be administered and has been shown to be more effective at improving physical outcomes if it's administered within the first eight hours. That said, when I finally arrived at the hospital (likely after the eight hour window due to my choice to try to sleep it off) my blood alcohol level was still elevated, and I'm not sure if that would have prevented me from receiving methylprednisolone if I had arrived sooner.

I am not up to date on all the ways in which to treat new spinal cord injury injuries, but calling 9-1-1 and getting to the hospital as quickly as possible is generally good advice. It's also helpful to be transferred to a hospital specializing in SCI rehab as soon as possible.

INITIAL HOSPITALIZATION

The ambulance took me 3 miles to Shands Hospital, a Level I trauma center.

Apparently, most spinal cord injuries that they were used to seeing came from car crashes, and it was somewhat unusual that I had no other injuries. So the examinations were relatively quick. An x-ray showed my C5 and C6 vertebrae in my neck were dislocated, pressing against my spinal cord and thus blocking the signals from my brain to my body, and causing paralysis.

Something called an ASIA exam (American Spinal Injury Association exam) confirmed that I had paralysis beginning at the C5-6 level. That test is based on where a person has the ability to move and has feeling/sensation. At the time, I could breathe on my own, and could move my shoulders and arms, but not my hands or anything else. I'm not exactly sure where my sensation stopped, but it was somewhere on my torso.

My writing in this chapter might be a bit discombobulated.

I was discombobulated at the time.

Besides what I mentioned previously about methylprednisolone (and I may have messed up my opportunity to receive that) I'm not well versed on proper procedures, and all that they may have or could have done, or even what they actually did.

I do know that I was quickly outfitted with a halo, which literally entails drilling screws into a person's skull, and using weights suspended from the halo to try to relieve the pressure on the compressed area of the neck.

Seemingly after several hours, it was determined that the halo was not working to alleviate the pressure or paralysis. I'm not sure if several hours is enough to determine that, and maybe I actually had it for longer. Who am I to question the neurosurgeons and doctors at a Level I trauma center?

Speaking of which, the doctor in charge told my parents, "if Bill were my son, I would go ahead and do the cervical spine fusion" to get me comfortable and on my way to rehab as quickly as possible.

How could they argue with that?

They agreed to the surgery. I would have also, if I had been in the right frame of mind to make such a decision.

Years later, I learned that some people have been in halos for months, while damaged vertebrae slowly heal. I'm not entirely sure I would like to have had a halo for months, but I do know my neck range of motion would be better if my neck was not fused. Now, I can move my head a little, but not a great deal. For me, that's not that big a deal – it is what it is – but it would be nice to be able to have better range of motion and control of my head's position. I mention this because if you have a loved one deciding between a spinal fusion or not, weigh the pros and cons, and pray about it, but if the options are about even, I would try to avoid the spinal fusion.

Late that night, they did the surgery.

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In the next couple of days, things were actually looking up. After I "got over" my initial embarrassment for choosing to drink to excess and winding up paralyzed, I was in surprisingly good spirits. I put "got over" in quotation marks because if I think about that choice and the result, which directly impacted not just me but my family, I still dislike that I made that choice. But we all make mistakes, and in order to move forward and live life, we have to forgive ourselves or at least not dwell on things we cannot change.

I was blessed to have a lot of visitors – family, friends, friends/coworkers, and many people from Leesburg made the 1+ hour trip, to visit me and try to raise my spirits. Many of them felt I raised their spirits as I was excited about getting to rehab, and getting to work on restoring my function (and life). I could still use my arms, and I figured I would just work extremely hard at physical therapy, and eventually recover. That may have been a little naïve, but doctors don't know everything, and that was my mindset. (And, actually, in 2020 as I write this, activity-based therapy is one of the best ways to promote recovery as the search for the elusive "cure" continues.)

But then I started having trouble breathing.

My family members were taking turns staying with me, and my stepmom Donna was with me when I told her, "I can't breathe."

She immediately went to try to get help, but the first couple people she encountered basically said that all new quadriplegics feel like they have trouble breathing.

But Donna knew I was not "crying wolf" or anything like that, so she was frantically trying to get someone to take this seriously, and finally a young doctor did.

They connected me to a ventilator, but it went through my mouth, as at that point, there was no reason to do a tracheotomy and have me breathe through my neck.

They also did an MRI – for the first time – and discovered I had a herniated disc in my neck, that was apparently causing these new problems.

That MRI was not fun. I was already having anxiety due to my difficulty breathing, and need for a ventilator. Normally, they give the patient a panic button to push, if they get claustrophobic and start to freak out. That doesn't work with someone who cannot move their body. I also couldn't talk, and had no way to signal if I was in distress. They let my dad accompany me, and told him to "let us know if Bill is in distress."

Good plan (sarcasm). I mean, it was not a good plan, but what could reasonably be done? I don't think there was a good option, except to pray I got through the MRI without panicking.

I managed to get through it by singing (in my head) the beginning of a Garth Brooks song, The Old Stuff, which begins slowly with: "oh I said a little prayer tonight… before I came on stage…" which is how he opened one of the concerts I am thankful to have attended.

I just kept repeating that beginning over and over and over, which helped me remain calm, and I guess was a subtle prayer to God. I'm sure I already said actual prayers.

The result of the MRI showed I needed surgery to fix the herniated disc, and when I came out of that surgery, my functional ASIA level was C1-2.

I lost the ability to move my shoulders and arms, and to breathe independently.

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The official explanation was that my neurologic level "inexplicably ascended" from C5-6 to C1-2 and was attributed to swelling of my spinal cord.

You might be thinking… was that disc herniated prior to the first surgery to fuse my C-spine? Did they miss it? How would a disc herniate after that first surgery, since I was in a hard neck brace the entire time?

Those were questions we had also. Obviously, it is not a good result for my injury level to have ascended while at a Level I trauma center, but was it simply an unavoidable result, or maybe hospital error for not having done an MRI prior to the first surgery? Really, the only way to get that question answered, was months later, we had my medical records reviewed by a law firm specializing in malpractice.

The law firm found that the care I received while at Shands "did not substantially deviate from the acceptable standard of care." Thus, no lawsuit.

And I'm fine with that. I harbor no ill will for Shands or the care I received. I do not believe anyone wanted my injury to ascend, and I would feel badly if a court of law held any medical personnel responsible. That said, there is a part of me that wonders if they had done an MRI prior to the first surgery, would I be a C5-6 still, or would my injury have ascended anyway? But I don't dwell on things like that. A person cannot move forward if they are stuck thinking about the past (which cannot be changed).

* * * * *

I wound up spending a month in Shands. I developed a pressure sore on my ear, and a more significant one on my rear (my sacrum). I also had double pneumonia at one point, and doctors were not sure I would survive. I was on painkillers to keep me comfortable, and a medicine called Versed, which suppressed my memory of those not-so-wonderful days. I believe it was during the double pneumonia when I had a near-death experience that I will share about later in the chapter on my faith.

In addition to the continued support from my family and friends for which I am thankful, one bright spot from my time at Shands that I do remember and would like to recognize was an ICU nurse named Yolanda. When I was unable to talk or signal for help, she taught me to "click" with my cheek, which was and still can be extremely helpful. She also once went to great lengths to get me some fresh air and sunshine, coordinating a team of people to roll my hospital bed and accompanying equipment somewhere outside for a few minutes of respite.

But overall, we learned that even Level I trauma centers like Shands, they generally do not have the experience to properly provide extended care and rehab for quadriplegics. That's why specialty rehab hospitals like Shepherd Center in Atlanta exist, and the sooner an SCI patient can get there, the better the potential outcome and prospects for recovery.

But I had to get stable enough, to at least get over the pneumonias before Shepherd Center would take me. And finally, almost exactly a month after I arrived at Shands in an ambulance, I was flown to Atlanta in a tiny little airplane.

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REHAB

Shepherd Center in Atlanta was and is one of the leading spinal cord injury (and brain injury) rehabilitation hospitals in the world.

To us, it represented hope. For one, they had a good track record for weaning patients off of ventilators. We were hopeful they would be able to wean me also.

So imagine my disappointment when I was fresh off of a pretty scary airplane ride (don't get me wrong, I was grateful to be at Shepherd, and thankful to whatever flight service made that possible, but that was a tiny little airplane and nerve-racking flight for my mom and me, and I think two medical personnel) and almost immediately I encountered a pulmonologist, who promptly disconnected my ventilator circuit from my trach, and commanded me to "breathe!"

I barely knew what he meant. I mean, I had not really tried to breathe on my own for nearly a month, and how exactly was I supposed to "kick it in" now? Not only that, but since birth, breathing is just something the vast majority of us have done naturally, without conscious thought. I had no recollection of what it took to actually breathe.

Not surprisingly, I could not move any air during that extremely brief encounter, which he concluded by saying, "I'm sorry but you will be going home on a ventilator."

Wow. I felt like he/they didn't even give me a chance. Frankly, that sucked.

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I eventually learned that they actually did not give up on trying to get my body to "kick in" and breathe. They purposely kept my ventilator settings at levels in which I was safe, but not comfortable, in order to try to get my body to kick in and supplement what the ventilator was giving me.

But I learned that in hindsight. Nobody told me to try to supplement what the ventilator was giving me. I figured that out months later, reflecting on my time there, and realizing that the same pulmonologist who told me I was going home on a ventilator after I had just gotten off a crazy little flight, that doctor was disappointed when I finally convinced him/them to increase my ventilator settings to where I was comfortable. But again, he did not communicate any of this specifically, and that's what bothered me about that situation.

If they had told me that they were purposely keeping my settings low, trying to get my body to kick in, and maybe even told me to consciously try to breathe… then maybe I could have made some progress at that time, or at least felt more comfortable with what they were doing.

I also learned years later that in order to access the nerves that control breathing, a person usually needs to be C3 or lower. I believe they start at C3, and incorporate C4 and C5 for full access to spontaneous, diaphragmatic breathing in the way that able-bodied people do without thinking from birth.

I should add that there is another aspect to ASIA classifications. I am considered a C1-2 "complete" injury, or "ASIA A" injury. Complete basically means I have no movement or feeling/sensation below the typical level of injury for a classic C1-2. There is actually an ASIA chart that looks like a topographical map of the human body, that shows where feeling/sensation should be for every level injury. For C1 people, it almost looks like the old school hockey goalie mask, like Jason wore in the Friday the 13th horror movies.

The C1 area on the "topographical map" shows a line tracing a person's jawline, up to and going through the middle of the ear, all the way up to the top of the head, and back down around the other side in a mirror image. That is exactly where my feeling is normal, i.e. the feeling in my face is perfectly normal. But below my jawline, the back-half of my ears, and the back-half of my head are all numb, like they were shot with Novocain. I can tell if someone is poking me in those numb areas, but if I am cut shaving, I don't feel that at all (which is nice!).

So, technically, C1 might be more accurate to describe my level of injury, but I would later develop some ability to use my neck muscles to shrug my shoulders and take in air, which a spinal cord injury expert told me was C2 level, and approaching C3 ability. That's why I consider myself C1-2.

On a related note, that same SCI expert asked me if anything happened in the days prior to my intoxicated trip and fall that could have weakened or loosened the vertebrae in my neck. He said with most trip and fall spinal cord injuries, something happens before the paralyzing event that contributes to the injury.

I thought his insight was uncanny, because less than a week before my injury, some friends and I went to a water park in Ocala, and despite warning signs, I chose to make my slide trip more exciting by spinning around as I slid down, and I recall hitting my head on the side of the slide. Driving home later, I recall my neck hurting.

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To follow-up on what I started to explain above, if a person has feeling/sensation or movement below where they should with their level of spinal cord injury, that means some nerve signals are getting through the injury site, and people with those injuries are classified as "incomplete" – which is a good thing. Three classifications of incomplete injuries (known as ASIA B, C, or D) exist and indicate progressively greater sensation and/or function below the level of injury. There are people who have had cervical spine injuries that temporarily caused quadriplegia, but they were fortunate or blessed to fully recover, and be considered "normal" again (it's actually classified as ASIA E since they did experience impairment in their limbs, at least temporarily).

So for example, since I am a C1-2 level injury, I could potentially wean from the ventilator if my injury level was one of the classifications of "incomplete" and allowed access to my C3 level nerves, which are considered below my level of injury.

By the way, spinal cord injuries that occurr at the cervical vertebrae level in the neck, those typically result in some degree of impairment in all four limbs, which is a basic definition for quadriplegia or tetraplegia. Injuries that occur lower on a person's spine, i.e. to the thoracic, lumbar, or sacral areas, those result in impairment from the waist down (generally) and are called paraplegia.

One reason Shepherd Center people did not entirely give up on me trying to wean was that seemingly "complete" injuries can later prove to be incomplete. But of course if initial testing indicates ASIA B, C, or D then that's a better starting point for recovery, rather than hoping and praying a "complete" injury diagnosis proves wrong.

Not that it matters, but the classifications are counterintuitive to me. In this case, it's better to receive a grade of B, C, or D, rather than an A.

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So what did Shepherd Center focus on and help me with during rehab?

The biggest thing they taught me was to "focus on what you can do, not on what you can't." I later amended that to "and try to change some things from the can't do list, into can do."

They have physical, occupational, and speech therapists work with everyone as needed (as well as doctors and counselors, and of course teams of nurses and assistants also). The goal is basically to maximize one's current abilities, and to teach injured people and their families how to live what is in some ways a new life.

Generally speaking, the staff was awesome. I still keep in touch with some of them 22+ years later.

Physically, the staff had to first get my pressure sore on my sacrum to heal before I could do much. So, back in 1997, my actual physical therapy was largely just passive range of motion performed on my arms and legs. As with many new quadriplegics, my blood pressure was quite low, and worse, it was unstable. So once my pressure sore was healed well enough that I was allowed some wheelchair time, they had to work on my sitting tolerance with regard to my blood pressure.

To help stabilize my blood pressure, I wore an abdominal binder, and special compression stockings that went from my feet to above my thighs. They also wrapped my legs with ace bandages on top of the stockings. All of that, just to try to keep me from passing out while transferring to my wheelchair, or shortly thereafter. The wheelchair actually needed to be fully tilted back, so that I would not pass out immediately after the transfer. Then, over the course of therapy time, I would literally sit up about an inch or two every five or 10 minutes.

I wound up spending a total of two months at Shepherd Center, and I think I was not able to sit completely upright until the last week I was there.

That reminds me of a funny story… when I first learned to drive a sip-and-puff controlled wheelchair.

Sip-and-puff controls basically give the user "four buttons to push." Think of drinking a glass of milk with a straw. You can take a sip or blow bubbles. And you can do either one hard or soft, which for sip-and-puff controls, gives you four different inputs to the control box. I thought it was quite intuitive and I learned it quickly.

The problem was my blood pressure was still quite low and I could not sit up (mid 80s over mid 50s is common to this day, even though my sitting tolerance is now generally stable).

So here I am, tilted back far enough that I could not see in front of me, yet wanting to demonstrate that I could drive the sip-and-puff wheelchair under the supervision of my physical therapist, Ainsley.

Before you know it, I was driving down the hallway – still unable to see – much to Ainsley's chagrin!

She urged me to sit up as much as I could. But my theory was that if I looked up at the ceiling, or more specifically where the walls connected to the ceiling, if I just tried to stay in the middle of the hallway, I was unlikely to run into any equipment or people, and frankly, people at Shepherd know to look out for dangerous drivers cruising the hallways… so off I went! (Smile)

And I did not hit anything, or anyone (that I know of!).

That wheelchair was a used loaner. While at Shepherd, I was fit for my first custom wheelchair. It lasted a remarkable 17 years!

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The focus of occupational therapy quickly became showing me how to control a computer with voice software. The problem was, I still did not have much of a voice. Learning to talk again actually involves respiratory therapy as much or more than speech therapy.

I later learned that when medically unstable patients have a tracheotomy to insert a trach tube into a person's trachea (airway or windpipe) the style of tube they choose is one with a little balloon surrounding it called a "cuff," kind of like a little "arm float" you might place around a child's upper arm when they are not yet able to swim safely in a pool. That cuff is actually an inflatable balloon surrounding the trach tube, and when it is inflated, it seals off the persons airway. That allows medical personnel to regulate the amount of air going in and out of the person's lungs, and thus can help stabilize them – but no air passes by the person's vocal cords, and thus, not a sound can be uttered.

So, when the cuff is inflated, we did not have much choice but to communicate through lipreading.

How many people do you know who are good at reading lips?

Probably just as many as me – which was essentially nobody in my family, because they had no reason to learn until I was unable to talk. Thankfully, my family got better at it over time, and some of the staff at Shepherd were pretty good at it also, because they had ventilator patients regularly.

On a side note, if you need to do lipreading with a loved one (hopefully it's just temporary) a way to get started, when you have no idea what the person is trying to communicate, is to ask: vowel or consonant?

It's pretty easy to distinguish the mouthing of "vowel" or "consonant" and then you can simply start going through vowels or consonants until you are stopped. Yes, it's tedious and can be frustrating. But it works. Just make sure you write down the letters and words, because neither one of you wants to start over if you forget! (Nodding or shaking one's head, or even blinking could be used to answer questions about whether it's a vowel or consonant, and to identify the correct letter.)

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Even by the time I would be discharged from Shepherd, I was only able to tolerate having my cuff deflated so that I could talk for about an hour per day.

What's the difference between having it inflated and deflated?

Well, the volume of breath I received when my cuff was inflated was 800 mL (think of a two liter bottle of soda; 800 mL is a little less than half of that bottle).

When a respiratory therapist would deflate my cuff, doctor's orders were to increase my tidal volume on the ventilator to 1100 mL, to compensate for the air that would pass my vocal cords and "leak out my mouth and nose" versus the 800 mL that they could control going into my lungs when my cuff was inflated. The increase in airflow, not to mention the "leaking" out my mouth and nose, that causes dizziness, which is not particularly good for someone with unstable blood pressure to begin with. So it takes a while to learn how to "manage" the additional air and "leaking" not to mention, using it for speech.

Something that people working with ventilator patients need to know is that "leaking" is absolutely the wrong word to use.

When I heard that I was getting an extra 300 mL of air to compensate for what would "leak out my mouth and nose" – that indicated to me that I had no ability to stop it from "leaking" which is absolutely wrong.

Just like I did when I was able bodied, I can hold my breath, and prevent air from escaping my mouth and nose.

That would've been extremely helpful to know, because, remember how I previously said they were keeping my ventilator settings low, to try to get my body to kick in and supplement what the ventilator was giving me?

A lot of times, I was quite uncomfortable. If you think about breathing, there is what I call a "threshold" for achieving a full, satisfying breath. Most of the time (at that time) I felt like my breaths were too shallow, and rarely received a satisfying breath (I could rarely reach and get over the threshold to achieve a comfortable breath). Among other things, that made it difficult to sleep, or do much of anything.

Sometimes I would want to try to get satisfying breaths by switching to the other set up, i.e. I wanted to go back and forth maybe a couple times between having my cuff inflated or deflated (and the ventilator settings changed, accordingly) to see which was more comfortable.

I understand it could be frustrating for a respiratory therapist to keep helping me go back and forth, but imagine my frustration, when I was simply trying to get a comfortable breath. (And if I had known that I could prevent the "leaking" then I most likely would have wanted my cuff deflated more often, to receive the bigger breath.)

One respiratory therapist lied to me. I asked (or my mom asked on my behalf) him to change it back, and he mentioned that we could not keep going back and forth "all night." I knew that I was not his only patient, and I knew we could not keep doing it, but I asked him to please switch it back (I think to cuffed, most likely because I was dizzy). He pretended to do it, then flat out lied to me, and said he did it.

I knew he did not, and I quickly got ANGRY – and began to call him out on his lie.

Then my heart stopped.

Code blue.

That was actually the first of four times that my heart would stop, before my medical team decided I needed a pacemaker.

I'm sure it is scary to witness, and might be not-so-fun to read, but it's not that big a deal (seemingly) to the patient, because all I remember was pleading with the respiratory therapist, getting angry about him lying to me, and then all of a sudden, it's like I woke up to a dozen different people staring at me, asking me questions (after they revived me). What is all the fuss? What did I do? Oh, okay, I coded. Got it.

By the way, that respiratory therapist never worked with me again. My myopic perspective was that he should be fired for outright lying to a patient, but hopefully me coding on him made enough of an impression that he won't lie to other patients.

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Until they increased my ventilator settings, about the only time I felt like I was getting a comfortable breath was when I was being "bagged" with an ambu bag, which is a handheld plastic apparatus that can connect to my trach and allow someone to manually fill my lungs with air, in lieu of the ventilator. A full squeeze of the ambu bag would result in a comfortable breath.

If I had congestion, i.e. secretions in my lungs, then full, fairly rapid and rhythmic squeezes of the ambu bag (for maybe 30 seconds) also seemed to help draw the secretions up into the inner cannula of my trach, which allowed for relatively easy removal with suctioning. That was the only time when I felt like suctioning was successful at clearing my secretions.

Both Shands and Shepherd respiratory staff used what used to be called a mechanical insufflator-exsufflator, or "in-exsufflator" for short, which I describe as a medical shop vac machine, and today it's called a CoughAssist machine. Press a switch in one direction, and it fills the patient with a big breath of air (insufflate) and then quickly flip the switch the other way to pull air and secretions out (exsufflate). It's noninvasive, and I felt it was much more effective and efficient at removing secretions compared to suctioning, not to mention comfortable. I hated suctioning.

To suction me, a nurse or respiratory therapist would disconnect my vent circuit (meaning I could not breathe) and stick a plastic suction catheter down into my trach, and often beyond my trach into my lungs, and hope that the catheter "found" the problem and could suck it up into and through the small catheter tube. If that does not sound like fun, I can assure you it's not.

The interesting thing to note here is that suctioning is an invasive procedure, whereas in-exsufflating is not – yet only the respiratory therapists were allowed to in-exsufflate. Registered Nurses, even ones trained at Shepherd, were not allowed to perform what I consider an easier, safer procedure, but they were allowed to stick a plastic tube into my lungs.

Further, my family was trained to suction at Shepherd Center, not to in-exsufflate, because insurance typically did not approve the purchase of in-exsufflators for home use. My dad saw the idiocy of that, and said "we are not going home without an in exsufflator" and thankfully, our insurance approved one.

Months after being home, I contacted the in-exsufflator manufacturer directly, and eventually realized that their machines were essentially "blackballed" (my term, not theirs) by the industry, who hid behind the claim that there was not sufficient data to prove the worth of the in-exsufflator. I read between the lines and realized that sterile suction catheters were the alternative, which was something insurance companies could not refuse to cover, and thus was a gold mine for their manufacturers. Conversely, the in-exsufflator was essentially a one time purchase (support materials for it comparatively cost very little compared to years of sterile suction catheter orders).

Thankfully, the CoughAssist machine is now approved by insurance/Medicare/Medicaid in many long-term situations.

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Having clear lungs is somewhat of a prerequisite for speaking as well as possible on a ventilator.

And learning to talk again was a sizable challenge. You have to learn to work with the ventilator.

In the beginning, they had me try to go through as much of the alphabet as I could. "ABC" was about as far as I could get, before my voice would trail off with the "C" as I ran out of air from the ventilator breath, and had to wait for the next one.

That makes it difficult to use a voice software controlled computer, but the occupational therapists were able to show me enough to know that I wanted a Multimedia Max set up once I got home (more on that in the chapter on Home).

My speech therapist actually worked with me on swallowing.

Think about laying in hospital beds for three months. The main source of entertainment available is a TV. What is on TV roughly every 15 minutes?

Yep, commercials – and the food commercials are pretty brutal when you cannot eat, but did so for the first 20+ years of your life. Man, they can make pizza look GOOD on commercials.

Obviously I wanted to eat again. I asked my speech therapist, Susan, what were the chances that I would be able to eat a normal diet by mouth again?

She was teary-eyed when she told me "not good" and I asked why. She explained that because I was on a ventilator, they typically did not do swallow therapy exercises with vent patients.

I asked, "why not?" And she said she had the same question for the expert who taught her about swallow therapy. That "expert" said because "it makes them gag, so we don't do it with ventilator patients."

Wait a second. I'm breathing through my neck, why would I care if I gag? Besides that, the main point of doing swallow therapy exercises was to develop or reestablish the person's gag reflex, so that they will be able to cough up food if they begin to choke.

So Susan and I decided to do swallow therapy exercises. And four months after my injury, I was a groomsman in a friend's wedding, and decided I was going to make wedding cake my first food by mouth in four months. And I did.

And I've been eating a normal diet basically ever since.

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I celebrated my 21st birthday at Shepherd Center. My friends at the Texas Roadhouse ordered the most audacious and ludicrous singing "birthday gram" – some crazy guy dressed head to toe in a bear outfit. He looked like a mascot for a football team. That guy was absolutely nuts, but his performance was hysterical. And appreciated. I still remember him practically bouncing off the walls, and weirdly but enthusiastically inflecting his voice and singing, "Happy Birthday, Wild Bill!" (I really wasn't that wild, but when your name is Bill and you work at a place called Texas Roadhouse, that becomes your nickname – so I embraced it in a good-natured way.)

I have to express additional gratitude to my family and friends for their continued support while I was at Shepherd.

I had a ton of "get well" cards.

Immediate family members made the six hour drive numerous times.

Some friends even made the trip – some more than once.

Grandma Willi and Grandpa Loren got a small apartment across from Shepherd so that I would always have family with me or available.

I wasn't always up for company, but I still appreciated all of their efforts.

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Generally speaking, I was fine during the days, which were filled with activities, but I was often terrified of the nights. I was scared to go to sleep. I still did not trust that the ventilator would always work, or at least always alarm quickly enough for staff that I trusted to hear it and come fix it. I got to know the day staff better, because that was when there was "more action" typically, so I was more comfortable with their ability to take care of me than I was with some of the night staff.

I still had to wear a hard neck brace for a good bit of my time at Shepherd. The only thing I could feel was my face, and of course I could not move anything. But there were nights when I felt like my body was freezing up, that if I closed my eyes, it would be almost like rigor mortis would set in. I was too scared to shut my eyes. My mom and grandmother spent lots of time stroking my forehead in an attempt to alleviate my fear. They would both tell you that neither of them had much of a singing voice, but there were times when I wanted them to sing literally anything.

I recently went back and read the visitor logs (which we scanned) that my family made available for friends to write in while I was at Shands. Many friends, and friends/coworkers praised me for my positive attitude and mental strength, which was evident both before and after my injury.

But at Shepherd Center, while I was trying to get better, I was also depressed – seriously depressed.

I could not wrap my brain around what I could still do, or what life could be like, or actually would be like.

I needed four different antidepressants – three concurrently and one as needed (PRN) – just to allow me to "step back" and get a handle on my situation.

I was also still in a lot of pain. I had a lot of neck pain, and neuropathic pain that is like a burning sensation on parts of your body.

I had to learn to accept the fact that after incurring such an injury, life is not going to be exactly the same as it was before. You actually grieve the life you lost, because some aspects of it are reduced to memories. You have to learn new ways to do things, and learn what you can still do.

Grandpa Loren was talking with me one afternoon at Shepherd; he knew I was still struggling. He told me "we can do this" but that I had to decide that I could do this. He was right, on both accounts.

With one of my many prayers, I basically cried out to God, wanting to make a deal with Him. I prayed and said, "God, if you take away my pain, then, yes, I can do this." I could live as a ventilator dependent quadriplegic, even if I did not get any functional recovery.

Right around the three month point post-injury, my pain essentially disappeared. I humbly thank you Lord for answering that prayer.

To illustrate what an incredible blessing that is, I met a low level quadriplegic (C6 area) who could use his arms and hands well enough to light his own cigarettes and smoke.

Of course he was not on a ventilator either, but he was in so much pain that he told me he would trade the ability to use his arms and hands, and even take my ventilator, if he did not have pain. WARNING – the rest of this sentence is graphic: he later broke four teeth from clenching them so hard, and eventually took his own life.

Thankfully, not every paralyzed person experiences pain to that extreme, but some level of pain is fairly common. For anyone with chronic pain, I pray that it's at least manageable, or that it disappears completely.

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I am pausing to reflect on what I just wrote.

As I literally sit here and think about it, yes, my neck pain disappeared, but right now, my arms are tingling which could be considered a burning sensation, or pain. Except I don't think of it as pain. I think my arms, especially my forearms, pretty much constantly tingle. I cannot recall exactly what it felt like 22+ years ago when I was in rehab, but perhaps I just started to think about the neuropathic "burning" differently. That said, I do know that some people who have been injured for years report having significant neuropathic pain, and I do not want to ridicule them or trivialize what they legitimately feel. I'm only mentioning this because the brain might be able to be conditioned to think about that sensation differently, almost like learning to ignore it.

There is something to the brain's ability to learn to ignore certain things.

A late friend of mine, David Jayne, he lived more than half of his 5+ decades with ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease) and was essentially a quadriplegic on a ventilator for most of that time. He realized early on that it simply was not practical to ask someone to scratch his nose every time it itched. So he basically taught himself to ignore all nose itches.

That gave me the idea that I could do the same thing. My nose used to itch frequently, and I would often ask people to scratch it. But thanks to David, I got the idea that I can learn to ignore nose itches, and candidly, I might ask someone to scratch my nose once a month or so nowadays. I rarely think about it and it rarely bothers me anymore.

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My time was winding down at Shepherd Center. I knew I could not stay forever, but I had anxiety about going home – even though people kept telling me that things would get better at home, and life would be better at home.

One thing the respiratory staff was able to help me with was successfully getting me comfortable on just "room air" delivered by the ventilator, i.e. I was able to wean off of supplemental oxygen. That meant that I did not need to have an oxygen tank or canister with me wherever I went, which obviously is a plus for quality of life. The simpler my care requirements, the better.

Shepherd Center was a comfort zone; a safe haven filled with experts who knew how to provide the care I needed. Who was going to take care of me at home? That was on my mind a lot.

Thankfully, my immediate family members all took classes at Shepherd to learn how to provide my care. But still, they were new to all of this, like I was, and I didn't want to leave the experts.

But the good Lord sent a nurse named Pandora, who had extensive experience working in home healthcare with special needs patients, including vent patients. She even volunteered to go up with my dad to Shepherd Center and learn about my care, and to help bring me home.

In late November, I "graduated" from Shepherd Center, and my mom and Pandora rode with me in an ambulance for the six-hour trip from Atlanta to Leesburg.

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HOME

While I was still at Shepherd, back home, my parents had some doorways widened and concrete poured to make the house we had built in 1986 more accessible for me. I believe a state of Florida Vocational Rehabilitation (Voc Rehab) counselor advised my family on the necessary home modifications, and Voc Rehab even paid for them. My parents paid for an aluminum overhang to cover our back door, and for some additional concrete to make a little path into our wooded backyard, to give me a little retreat.

Donna's parents, my step grandparents, generously purchased a brand-new full size Ford van, which Voc Rehab paid to have modified to meet my needs. (Voc Rehab is a government program designed to help injured people ultimately return to the workforce.) The combination of that van and my wheelchair gave me the ability to go just about anywhere, which was a huge step towards restoring life. That van enabled my first post-injury job, reviewing movies, and the big Ford lasted a good 19 years, taking me lots of places all over Florida and parts of the US.

My dad's parents, Grandma Willi and Grandpa Loren, they generously paid for a ceiling lift to be installed in what was now my bedroom. They also sold their dream home that they had retired to in Hot Springs Village, Arkansas, to relocate to our neighborhood, so that they could help out with me.

Growing up in this house, my brother Andy and I had our own bedrooms with a bathroom in between. The bathroom became a nurse's station. Being on a ventilator, I had no desire to have a roll-in shower, so we actually put a countertop over the bathtub to make the space more usable (although I know a couple of quadriplegics – with trachs – who love having roll-in showers; whereas I'm fine with sleeping through a bed bath). Andy's room became my bedroom, and my old bedroom eventually became my computer room, where I am sitting in my wheelchair dictating this to my computer.

Those three rooms became "my suite" which has worked well for us for the last couple decades. My stepfather at the time, Eddie, he had an air conditioning business, and he generously installed my own HVAC system, so that I could keep my three rooms at the temperature I needed.

Those are all blessings for which I remain grateful, as is being home.

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One reason it's nice to have thermostat control over my three rooms is that when I was at Shands and Shepherd, my body would spike some crazy high temperatures, and seemingly just hours later, I would be "freezing" with a body temperature as low as 95-something degrees. High-level quadriplegics like me lose the ability to regulate our own temperatures, or basically, our body's internal thermostat is broken. One reason is that most quadriplegics don't sweat, unless there is a serious problem. I cannot believe I have not mentioned autonomic dysreflexia yet.

Autonomic dysreflexia (AD) is a brilliant design by God for people who cannot feel a pain stimulus below the level of their injury, people with T6 injuries and above (so that includes all quadriplegics, and some paraplegics).

In response to a pain that we cannot feel, our autonomic nervous system alerts us that there is a problem by producing symptoms that we should notice, like raising our blood pressure. For example, if my bladder needs emptying and the catheter is crimped, or maybe the catheter bag is completely full, my blood pressure will spike and I will notice "head rushes" with blood rapidly going to my face. I may look flushed, and sometimes red splotches can appear on a person's torso as a symptom of AD, and in more severe cases, sweating and intense headaches can be symptoms.

Not to scare anyone, but if left untreated, autonomic dysreflexia can be life-threatening since elevated blood pressures can lead to a stroke for example. The Christopher and Dana Reeve Foundation offers free "wallet cards" that explain AD and how to treat it, since many medical professionals are unfamiliar with it (they should be found easily with a quick Internet search). The majority of AD issues are bladder related, but I have heard of people not realizing that bathwater is way too hot, and they incurred burns which caused AD.

Technically, a 20-40 point rise in systolic blood pressure (the top number) can indicate AD. People with SCI need to know their baseline blood pressure. My baseline is roughly 88/55 or something close to that, so for me, 120/80 generally means I need to pee. Obviously that does not sound like a dangerous BP, and it's not (it's often considered perfect for able-bodied people) but it can indicate a pain for me. I call that "mild dysreflexia" but I recently had a blocked catheter and my BP got up to 170/110 briefly (more on that in the "my care" portion of this book).

That was a needed "aside" on a potential medical emergency that all quadriplegics (and our caregivers) need to be familiar with. Now back to my return home.

* * * * *

Besides the respiratory equipment I needed, my now bedroom had not much more than a hospital bed and the ceiling lift when I came home.

Pandora immediately took charge, thankfully. She helped us get organized, and set up cleaning routines for all of my equipment. More than that, she helped us modify some of the care routines we learned at Shepherd to better suit life at home. Her experience and help getting us set up was invaluable, which is the right word to use because it means extremely useful (which is obviously valuable) but I don't like it because "insane" means the opposite of "sane" (and I can only imagine how insane these usage quirks must be for people learning English as a second language, but I am getting off point!). Later I will share details about my routines, equipment and setups, some of which still trace back to Pandora.

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Being a student at the time of my injury, I was still on my parents insurance, actually Donna's insurance as she was a county judge with good benefits. But even with good insurance, those first three months in hospitals probably spent roughly half of the one million-dollar insurance cap. So we were a little leery about how to use the insurance coverage we had, knowing this was a long term situation. But in the beginning, you pretty much take all the help you can get (the insurance cap on catastrophic injuries eventually was removed, but over time, our nursing coverage also went away as I will explain later).

Insurance initially covered 24/7 around-the-clock nursing care via a local home health agency, which employed Pandora and her good friend Bobbie. They were the two shining lights providing my care for the first couple of years.

Frankly, Pandora did not put up with any subpar nurses or subpar care, and candidly, it is difficult to staff a 24/7 case like mine with well-trained nurses around-the-clock. Part of the problem is in the urgency to fill the shifts, not much time was afforded to training. My care is highly specialized. Even Pandora needed to learn things about my care. Every quadriplegic is different, and has different needs (although some commonalities exist, of course).

But in the beginning, it was a revolving door of nurses, some who Pandora called warm bodies, people who made us wonder why they chose to work in home healthcare. One guy needed to go home in the middle of his eight hour shift to walk his dog. We asked him not to come back. One woman went out to her car to get a jacket because she was cold in my room. Yet, when my dad came in, I was in bed covered with just a sheet from the waist down, and had a body temperature around 95°F. I'm pretty sure we asked her not to come back either.

* * * * *

The approved 24/7 coverage did not last long (about a month). Insurance dropped us down to 16 hours a day, which was actually a good thing, because my family had to stay with me anyway to help train and also supervise nurses, and Pandora and Bobbie combined to cover many of the shifts.

Pandora liked the night shift, which was great for me, because she was comfortable trying to help me learn to breathe on my own.

Remember how I said that when I left Shepherd, I was still only able to tolerate having my cuff deflated for about an hour a day?

Within a week of being home, my cuff was deflated 24/7, because I was no longer at Shepherd where I trusted that the nurse who came in knew what to do. I needed talk, because I needed to train people. So pretty quickly, I kind of forced myself to get used to having my cuff deflated all the time. No more lipreading – that wasn't going to cut it at home.

I still could not talk super well, but at least I could talk, and help to train people. My family learned my care at Shepherd, but so did I. Now, whenever we have somebody new, I do most of the training.

* * * * *

Before I left Shepherd, the head of respiratory therapy, Dwayne gave me a speaking valve, which is designed to increase the amount of time that I have to speak with (which in effect shortens the pause in between ventilator breaths). But my primary day nurse at Shepherd, a guy named Big Jim, he told me that my lungs would get stronger if I learned to talk more without using the speaking valve.

I still had aspirations of weaning off the ventilator, so what Big Jim said basically convinced me to keep the speaking valve in a Ziploc bag on the shelf, and we basically forgot about it for the first year that I was home.

Early on, I used to panic when the ventilator circuit would "pop off" if nobody noticed it within five seconds (and came quickly to reattach it).

But over time, I gradually got more and more comfortable with brief, intentional disconnections like when putting my shirt on. So Pandora helped me conduct a little experiment. I wanted to know how quickly my oxygen saturation level (commonly referred to as O2 sats) would drop, if the ventilator circuit was disconnected, and I did not panic, but also did not try to breathe.

So she placed the pulse oximeter (O2 sat monitor, or "pulse ox" for short) on my finger, and disconnected the vent circuit from my trach.

My O2 sats remained in the 90s for about 45 seconds. That was without me panicking, or trying to breathe. (And my O2 sats also came back up pretty quickly, once reconnected to the ventilator.)

When I was at Shepherd, they told me that any oxygen reading in the 90s was acceptable, but obviously the higher the better. With that knowledge, we considered O2 sats in the 90s to be safe.

Then I wondered if I tried to breathe, if I could get my chest to rise up a little, if that could keep my O2 sats in the 90s longer than 45 seconds. Laying in bed, I started to work on "pushing my chest up" while still connected to the ventilator.

About six months after my injury, we disconnected the ventilator circuit and I tried to breathe. I managed to keep my O2 sats in the 90s for one minute and nine seconds.

That might not sound like much, but it was roughly 24 seconds longer than my time when I did not try to breathe. Considering I used to panic, if the ventilator popped off and nobody noticed within five seconds, that one minute and nine seconds felt like a long time – and it also proved to me that I was able to move some air. Not much, but some. That encouraged me to keep trying to get my chest to rise – push, pull, whatever.

I was eager to try again, but Pandora convinced me to keep working on trying to develop the ability to move/take in air, and suggested we do tests weekly.

So a week after the first test, I kept my O2 sats in the 90s for two minutes and 26 seconds – a little more than doubling my original effort. After another week, I went for five minutes and two seconds.

Another week, 10 minutes and 31 seconds. That was three straight weeks of more than doubling my previous best.

Then 14 minutes 34 seconds. Then 20 minutes 43 seconds.

This continued until I reached my goal of going two hours off of the ventilator by the one-year anniversary of my injury.

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In my mind, being able to go two hours without the ventilator was proof that I could move significant air, and was a good start on weaning from the ventilator. So, I wanted to go somewhere like Shepherd and finish the job.

But that was before I knew that a person needs to have access to their C3 level nerves in order to begin accessing their diaphragm for spontaneous breathing (as I explained previously).

So I had to "settle" for my breathing being a nice safety net, and something to make transfers easier.

* * * * *

For anyone with an injury like mine who might want to develop the ability to breathe some, basically I use my neck muscles to pull my chin down and chest up in kind of a mini "sit up" motion. When the ventilator circuit is not connected to my trach, that motion causes my chest to rise enough to take in air effectively enough to keep my O2 sats in the 90s. You can practice or develop the ability to do the mini "sit up" with the ventilator attached, and use it when the ventilator is not attached.

I continued to develop my ability to breathe in that manner until I could go for three hours under Pandora's supervision. One problem with my breathing tests is that we were doing it simply by disconnecting the vent circuit from my trach, and letting me breathe through my open trach (actually the inner cannula). It wasn't actually a problem, but it was awfully quiet, because breathing in that manner did not allow me to talk at all, since there was no air going by my vocal cords.

Plus, Pandora wanted me to concentrate on my breathing, so we sat in silence as she monitored my O2 sats and also routinely checked my blood pressure, just to see if it might indicate that my body was experiencing some type of issue, and thus we should stop the breathing test and put me back on the ventilator.

For basically all of my breathing tests, my blood pressure remained relatively normal for me, and the determining factor for ending the test was my O2 sats. Once I got fatigued, and could no longer keep my oxygen level in the 90s, then Pandora would quickly put me back on the ventilator.

She also visually monitored the color in my face.

You might be thinking that she was looking to see if my lips might be turning blue, which indicates that someone is not getting enough oxygen, but the pulse ox had that covered. She was actually looking to see if I was more red in the face than normal. That could indicate that I was not eliminating enough carbon dioxide. Thankfully, gravity pulling my chest down as I relaxed my neck muscles was enough to exhale sufficiently, so I would later learn.

Three hours is a long time to sit in silence at night. So we stopped doing the marathon sessions. But I did partake in an inspiratory muscle training study at UF.

Some researchers at the University of Florida wanted to see if inspiratory muscle training might help spinal cord injured ventilator patients like me. They previously used inspiratory muscle trainers (little spring-loaded devices designed to exercise one's breathing intake muscles) to help lung transplant patients recover and wean from their temporary need for mechanical ventilation.

To establish a baseline from which to compare later results, I went up to Gainesville for a breathing test and went for three hours pretty comfortably, despite not having done any breathing sessions longer than one hour in many months (a couple years). Then after several weeks of exercising with the spring-loaded device by placing it over my trach and using my neck and inspiratory muscles to pull air through it, I went back up to Gainesville for them to measure my progress.

They knew I would improve upon the three-hour initial test, and also wanted me to try to relax and not necessarily focus on my breathing, to breathe a little more naturally. So they suggested I bring some of my favorite movies to watch. I brought three and we watched two of them over a duration of 4.5 hours. They recognized that I probably could've gone quite a bit longer, but for the purposes of their study, 4.5 was enough. So we ended it there.

When I first started using the inspiratory muscle trainer, we had the tension/spring set to where it was easy. I could not do it on the hardest level. But during the weeks that I was told to exercise with it, I eventually got to where I could do the hardest level pretty easily. And several years after the research study, I wanted to see if I could still do it on the hardest level, or if my ability had weakened. I was quite pleased that I was still able to do the hardest level, and I believe I could breathe for more than 4.5 hours right now if I had to. (I think both breathing and holding my head up during transfers helps to keep my neck muscles strong.)

* * * * *

My quest to eat a normal diet by mouth again continued upon coming home. We found a speech therapist who continued the swallow therapy exercises with me.

While I was at Shepherd, I had a barium swallow test to see if I could swallow safely without aspirating food or drink into my lungs. That test was described to me as a "live video x-ray" watching me eat and swallow. The food is coated with barium so that it can be seen on the x-ray.

The food itself probably would have been pretty good without the barium, but the barium was like adding chalk – not exactly tasty. Not only that, but I had not had food in my mouth in roughly 2.5 months (at the time of the test at Shepherd).

Right now, can you describe how to take a bite of food, chew it and manipulate it, and swallow it? How much saliva do you need? How finely does it need to be chewed before ushering it to the back of your mouth and attempting to swallow it? Think about that for a moment.

That's an innate process we do from birth without conscious thought. I had no recollection of what to do with the barium-coated food in my mouth. Yet I did the best I could with some chicken, green beans, and a dry cookie. One of the nurses assigned to me watched the live video, and she thought I passed the test. But it had to be reviewed more closely to make sure I did not trace aspirate some food particles.

Upon further review, I did trace aspirate. So I had to continue doing swallow therapy exercises.

But my doctor did allow me to start drinking small sips of water with food coloring in it (so they should be able to see the color in my respiratory secretions if I were to aspirate it) and also to chew sugar-free gum. My interpretation of that was that apparently it would be less harmful to potentially aspirate saliva with the "juice" from sugar-free gum, than it would from sugary gum. I was also told that water is one of the more difficult things to swallow because it is completely liquid without any substance or density to it, meaning it's difficult to control.

Given the above paragraph, in hindsight, I think if I had asked if I could eat sugar-free Jell-O, I bet my doctor at Shepherd would have approved it. It is colored, it is sugar-free, and what in the world is easier to swallow than Jell-O? You don't even have to chew it. (Smile.) So I contend that anyone working their way towards eating again, that sugar-free Jell-O should be a confidence builder that can help us learn how to manipulate and swallow food again.

And it would be nice to be able to eat something instead of nothing.

* * * * *

In the first month that I was home, I did a couple more weeks of swallow therapy exercises (which I had continued until discharge at Shepherd) so now it was more than a month since I nearly passed the barium swallow test, and I wanted to try again. My speech therapist thought I was ready. So we set up a live x-ray barium swallow test at our local hospital.

But my large wheelchair with the ventilator on the back could not fit in the space required for the live x-ray. So I did not get to take the test.

A few days later, I was a groomsman in a friend's wedding. I decided I was going to eat wedding cake for my first non-test food by mouth in four months.

And I did. And I have been eating a pretty normal diet ever since – even though I've never passed a barium swallow test (I never tried to set one up again).

And I know I still trace aspirate, probably often. You read that right. And my voice software heard me correctly.

I believe I trace aspirate, probably daily, and probably with the majority of my meals. And I have for more than 22 YEARS – and I am still alive and able to dictate this!

* * * * *

I am not trying to "flaunt" the fact that I eat a normal diet by mouth, despite knowing that I trace aspirate regularly. I am grateful that I am able to, because being able to eat and taste food is a HUGE PLUS for a person's quality of life, or at least it is to me. But how am I able to do so safely, without getting frequent pneumonias from aspiration?

I've learned firsthand that the body's response to something foreign in the lungs is to coat it with mucus, so that it can be more easily expelled by coughing. Except I cannot cough hardly at all. That's why the CoughAssist machine is essential equipment for me.

I know I do not swallow particularly well. It is not a coincidence that after meals, I usually feel secretions in my chest. But with the CoughAssist, the secretions do not stay in my chest long enough to become problematic (i.e. pneumonia). For me, that's the key. And I thank the Lord that this works for me.

The proof that this method works for me is in the lack of hospitalizations for respiratory issues. I've actually had zero hospitalizations where pneumonia was the reason I was admitted. We do twice daily breathing treatments with several rounds of the CoughAssist, and after doing so, my O2 sats are usually 98 or 99. And my doctors have not treated me for pneumonia at home either (certainly not in the last 15 or so years; maybe once or twice earlier on when I was less aware, but I don't recall any instances).

IMPORTANT: I need to emphasize that aspiration can be dangerous – and even fatal – if not dealt with. If something foreign stays in the lungs long enough, it will lead to pneumonia, and pneumonia is one of the leading causes of death in quadriplegics. I lost a friend to aspirational pneumonia, so I'm not downplaying the potential seriousness of aspirating.

But in my case, thankfully, we have been able to manage my secretions well, such that we get them out before they become pneumonia.

I will write about secretion management in the section on My Care, as well as more about the CoughAssist. (In 2014, I posted a video on YouTube demonstrating how we use it (an Internet search for "Bill Miller how we CoughAssist" should locate it quickly; it has 60,000 views as of this writing in June 2020!).

* * * * *

So let's check the scoreboard to see if the people at Shepherd were correct, that life would get better for me upon coming home.

In the first year that I was home, the following progress was made:

1. I went from only being able to tolerate having my cuff down for about an hour per day when I left Shepherd, to having it deflated 24/7 in less than a week, giving me the ability to talk whenever I wanted or needed.

2. I could not move any air whatsoever upon arriving and departing Shepherd, but I went for two hours off the ventilator by the one-year anniversary of my injury, and increased that to three hours by the time I had been home one year. Developing some ability to breathe gave me tremendous peace of mind, and I'm sure it helped my family be a little more comfortable as well, as neither of us needed to panic after five seconds if the ventilator circuit popped off.

3. I was not able to eat anything by mouth when I left Shepherd, but one month after being home, and four months after my injury, I was eating wedding cake. And I commenced eating a normal diet from that day forward.

I would say the quality of my life improved significantly over the first year being home.

And I have not even mentioned getting a Multimedia Max computer system yet.

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The wake-up command was: "Max, I need your help" which would turn my sleeping microphone into the ready or on state.

"Multimedia Max at your service!" was the programmed audio response to the aforementioned wake-up command.

A former math teacher turned entrepreneur named Dan, he put together computer systems to help quadriplegics like me. At the time, they were the best option available, from what the occupational therapists at Shepherd Center were able to show me. Thankfully, Voc Rehab agreed, and even paid for me to have one.

Dan configured some of the best available PCs with voice software called DragonDictate Classic Edition, which was the predecessor to the Dragon NaturallySpeaking line of products that are popular today (I am dictating this with what is essentially Dragon NaturallySpeaking Professional Version 15). Dan also taught me to write custom voice commands called "macros" with DragonDictate, that enabled me to automate certain processes, and combine multiple voice commands into a single command.

For example, instead of needing multiple voice commands to change the font size to 14, I could write a macro to allow me to do it with one voice command. I could also use pixel coordinates to program "Max" to click certain areas on the screen. There was not much limit to how commands could be combined. I had fun writing macros, and it made using voice software much more efficient.

Some programs like Microsoft Word had built-in voice commands that came with DragonDictate, but quite a few programs did not. So I would write commands to access menus and whatever else I needed in order to make using the program more efficient. Using the mouse by voice was the most tedious aspect of using DragonDictate, which is why I put so much time into writing commands (many of which were simple and quick to write, yet helpful). I literally wrote about 10,000 voice commands (I did not count, but that was a calculated estimation) in roughly a dozen years of using Max.

Dan also incorporated a suite of Environmental Control Units (ECUs) that would allow users to do things like turn on lights, control a thermostat, or ring a chime to signal a caregiver. Those are things that many people do themselves today, using Amazon's Alexa devices, or Google Home devices. But back in 1998, Dan's "Multimedia Max" package was top-of-the-line.

Because I wrote so many custom macros, I kept using DragonDictate until it was more than a decade past its prime. It was copyrighted 1993-1997, which means it was primarily written for Windows 95 (released in 1995) but I had it working on all subsequent versions of Windows, up to and including Windows 7, which was released in 2009.

While I was customizing my voice software, I changed the wake-up command response from "Multimedia Max at your service!" to a movie quote, of course.

When I woke up Max, I programmed it to play an audio clip of Bill Murray in Space Jam, saying: "Perhaps I could be of some assistance" (smile).

With the Internet, Max became my primary means of accessing the world and enabled me to get back to work, while awaiting the right opportunity to return to school also.

* * * * *

Before I wrap up this chapter on HOME, and write about getting back to work, I have one more improvement to share.

Just a few days after being home one year, we rediscovered the speaking valve that had been on hiatus in a Ziploc bag while I worked on strengthening my lungs.

Big Jim had told me my lungs would get stronger if I learned to talk without using the speaking valve, but I had been doing so for essentially a year, and had also worked my way up to three hours off the ventilator by that point. I had also learned that the same breathing technique I used, i.e. using my neck muscles to pull my chest up (or, more specifically, my chin down and chest up with the miniature sit-up motion) that doing so could trigger the ventilator to give me another breath before the next scheduled breath (on SIMV mode).

I was receiving 13 breaths per minute from the LP-10 ventilator, with a tidal volume of 1000 mL (we had decreased it from the original 1100 mL set at Shepherd). My inspiratory time was 1.5 seconds, followed by a three second pause in-between breaths. I could only talk during the 1.5 seconds of inspiratory time, when the ventilator was actually giving me a breath (and thus air was going by my vocal cords). That three second pause is a long time if you are trying to talk on the phone, especially to someone who doesn't know you are on a ventilator.

But with my ventilator set on SIMV (Synchronized Intermittent Mandatory Ventilation) mode, I could shorten that three second pause by triggering another breath. Once I discovered that ability, I "played" with it to learn more about it. You might be thinking that I could hyperventilate myself if I kept shortening the pause, and thus receive way more than 13 breaths per minute. But the LP-10's SIMV mode was cleverly programmed. It would only allow me to shorten the pause five straight breaths – and then brilliantly – the ventilator would pause for something like eight or nine seconds!

I was impressed by the ventilator's SIMV programming when I discovered that.

But I felt like I had essentially maxed out the benefits possible from going the entire year without using a speaking valve, and it was time to give it – what is formally called a PassyMuir® Valve (or PMV) – another chance.

And guess what? The PMV is also designed to "shorten the pause" in between ventilator breaths – so when I started using it, I could speak almost without any pause at all!

The PMV is actually a one-way valve, that allows air to flow in easily in the inhale direction, but seals off the exhale direction completely, which effectively allows air to remain by my vocal cords longer, which gives me a little more breath and time with which to speak. When I do not have the PMV on, almost all of the exhale goes out the ventilator circuit's exhale valve, and makes the pause in between breaths basically silent (I say basically because my voice can trail off a bit with the exhale, but the duration of exhale is surprisingly quick, which makes my speaking time essentially match the inspiratory time).

So with my ability to initiate breaths and shorten the pause, PLUS the PMV – that combination allowed me to talk quite well. I was no longer concerned with whether the person on the other end of the phone knew that I was a ventilator user or not.

Since I could now talk nearly continuously, I jokingly said that I tripled the speed of my voice-controlled computer with a relatively inexpensive, reusable valve. The PMV was actually invented in the mid-1980s by David Muir, a man with muscular dystrophy who was frustrated by his inability to talk on a ventilator. Thank you, David! RIP brother.

GETTING BACK TO WORK

Now having the ability to talk well with the ventilator, and the ability to use a computer by voice, that combination gave me the ability to work in some capacity.

* * * * *

My first post-injury job was reviewing movies as a freelancer for our local newspaper.

Donna wanted to help me keep my mind active, and she knew I was still capable of accomplishing things – but movie reviews?

True, I loved watching movies, even before I spent a couple years working at our local theater. But I was a math major. I had never written a movie review before in my life.

But that didn't stop Donna from asking Jim Perry, then publisher of the Daily Commercial to consider giving me an opportunity to write movie reviews – and that conversation happened while I was still in rehab at Shepherd 400 miles away! Jim Perry had never even met me, and yet, he gave me an opportunity. He even offered $10 per movie review just to make it an official job. I'm sure he knew he could quickly pull the plug on publishing my reviews if they stunk.

I wound up writing 67 review columns, and they published them all. I don't think they "stunk" but, you know how you might go back and read something you wrote years ago, and you kind of cringe, because at the time, you thought it was good?

That's my reaction to reading them now (smile). Maybe I am being too critical, but before I share a few of them, please remember I was in my early 20s, and they were written sporadically from parts of 1998-2000.

With that disclaimer, my first review was The Truman Show.

* * * * *

I had no idea what I was doing, but this is what I sent to the newspaper:

"THE TRUMAN SHOW" IS TRULY SUPERB

By Bill Miller

Worthy of NBC's Must See TV, "The Truman Show" is both entertaining and original. A refreshing break from the current Hollywood trend of natural disasters and space odysseys, "The Truman Show" receives my personal rating of FOUR STARS. Have you seen it? Yes? Then you know what I'm talking about.

Rated PG, "The Truman Show" stars Jim Carrey ("Ace Ventura," "Dumb & Dumber," "Liar, Liar"), Laura Linney ("Absolute Power," "Primal Fear") and one of my favorites, Ed Harris ("Apollo 13," "The Rock"). Appropriate for all ages, "The Truman Show" should make most moviegoers' top 10 list for 1998. Probably near the top.

"The Truman Show" is Australian director Peter Weir's best effort since "Dead Poets Society" in 1989.

Andrew Niccol is the mastermind behind this charming, original script. He does an excellent job portraying the high demands of the media's microscope on a 'famous' individual.

The premier role of Truman Burbank is easily the best performance of Jim Carrey's career. Yes, I'm a fan of Carrey's comic talents usually typified by his body contorting, slap-schtick behavior and outrageous antics. "Dumb & Dumber" is a Carrey classic, but the dumb character of Lloyd Christmas is quite sophomoric. "The Truman show," however, presents more of a challenge for Carrey and he shines with the overall humor being subtle and more sophisticated.

Truman Burbank (Jim Carrey) is an unassuming insurance salesman from the tiny island community of Seahaven. He often has a suspicious feeling, as if he's being watched…

He has no idea how right he is.

Tired of fake emotions offered by actors, the OmniCam Corporation adopted baby Truman and raised him on live television. His entire life, handcrafted and carefully manipulated, had become the most popular documentary/soap opera in history. Christof (pronounced Kris-toff, Ed Harris) is the God-like puppetmaster controlling Truman's life and directing the intricate network of over 5,000 hidden cameras. The people of Seahaven, Truman's wife (Laura Linney), his best friend, even his mother – all are paid actors.

What would happen if he figured it out? Hmmm…

Yes, Truman, we're all watching your superb show.

* * * * *

Okay, I guess that was not too cheesy. But wait there's more! (Smile.)

My second review was ARMAGEDDON:

ARMAGEDDON: End of the World – Or Best of the Summer?

By Bill Miller

If Mother Nature's evil twin, El Nino, sends you to the theater to escape these torrid temperatures, put Armageddon on your list. Love it or hate it, this PG-13 thriller is a must-see. The intense emotion, created by Jerry Bruckheimer, grabbed me from the opening scene and carried me throughout. I loved it.

Doesn't it seem like many veteran movie critics never give five stars? To me, a rookie reviewer, if you would tell your friends it's an excellent movie, why not tell your readers? Armageddon is excellent and deserves a five star rating.

A movie is meant to entertain and provide a two-hour escape from everyday life. Thanks to the imagination and creativity of producer Jerry Bruckheimer and director Michael Bay, this one does. A similar movie, Deep Impact focused primarily on the emotions and preparation associated with the possible end. Armageddon is an all out, action flick with camaraderie, guts, and worldly patriotism surrounding the actions of a courageous crew.

WARNING: If you have a heart condition, or sensitive ears – enter at your own risk! This movie contains explosive special effects and a booming soundtrack, an adrenaline lover's delight. Armageddon is one of the most intense PG-13 movies since Days of Thunder (1990), which is not-so-coincidentally also a Jerry Bruckheimer production. Bruckheimer and Bay are the dynamic duo responsible for The Rock, a summer smash of 1996.

A dire situation presents itself as a 'global killer' threatens mankind. No, it's not MTV, it's an asteroid the size of Texas streaking towards earth at 22,500 miles per hour. Impact would equal the power of 10,000 nuclear warheads – nothing would survive, not even bacteria.

NASA officials determine the only way to neutralize the threat is to bore a hole into the mass and explode it from the inside. Under orders from the president, NASA executive director Dan Truman (Billy Bob Thornton), calls upon Harry Stamper (Bruce Willis). A 3rd generation oil-driller, Stamper is regarded as the best in the business. The battle to save mankind, becomes a race against time as there are only twelve days to get Harry, A.J., Rockhound, Chick, (Willis, Ben Affleck, Steve Buscemi, Will Patton) and company trained, outfitted, and launched into space. This motley crew of roughnecks-turned-astronauts are the world's only hope to prevent Armageddon.

The character of Grace Stamper (Liv Tyler) adds an emotional sincerity to the film. Grace, daughter of Harry and fiancee to crewman A.J. Frost (Affleck), tugs at the heart strings of audience members as she watches her family and future journey into the unknown.

Will this be "Earth's darkest day or man's finest hour?" Find out and enjoy the journey.

* * * * *

I think this next review, Saving Private Ryan, was one of my best, even though it was just my fourth:

SAVING PRIVATE RYAN

By Bill Miller

The Ryan family has already lost three sons to WWII and the U.S. Army does not want to present Mrs. Ryan with a fourth, folded flag. Powerful. Graphic. Emotional. Realistic. Take your pick. They all apply to Saving Private Ryan. This Steven Spielberg movie is a hard-core look at war, unadulterated, unfiltered, and unnerving. The saving of Pvt. Ryan involves and navigates the audience through the harsh realities endured by Americans during WWII. This is not a happily-ever-after Hollywood hoax, but rather a film offering the truth about a devastating period of history. Viewer discretion is advised.

The action begins on the beaches of Normandy as viewers experience the horrors of D-DAY. Amidst the bodies and bullets, the focus is on a squad of eight led by Captain John Miller (Tom Hanks). Upon surviving the invasion, Captain Miller and company are presented with a new mission: save Pvt. James Ryan (Matt Damon).

The question naturally arises: is the life of one man more valuable than that of the eight? Is it more difficult for a family to mourn the loss of their fourth and final son or for a mother to cope without her only child? Pondering this and questioning their orders, the men try to prevent either scenario from becoming a reality. Captain Miller justifies the mission with patriotism and the hope that saving Private Ryan will put him one step closer to returning to the States and his wife.

Oscar nominations are inevitable for this powerful picture and its talented creators. Saving Private Ryan is blunt and brutal, yet Steven Spielberg manages the atrocities of war with a certain artistic elegance.

I had the distinct honor and privilege of watching the movie alongside two veterans. Their emotional reaction emphasized the film's authenticity. Images of Saving Private Ryan will help cement a deep respect and appreciation for the men who so admirably served our country. The final credits may compel you to give a standing ovation – not for Tom Hanks and Matt Damon – but for the men they represent.

Five stars.

* * * * *

Naturally, my writing style evolved a little bit. I eventually realized that I should try to give readers a little flavor of the movie, and to make it clear who the target audience was. I wanted people to enjoy reading my reviews, but also to be able to determine whether they would like to see the movie or not.

Here is my review of a critically acclaimed dark comedy, American Beauty:

American Beauty
By Bill Miller

Ponder the words "American Beauty" for a moment, what comes to mind? Now, forget any classic images that you may have mustered, except the red rose, and keep an open mind – this is one unique perspective. In the movie, "American Beauty," we look on through the directorial eyes of Englishman Sam Mendes as he sets his easel inside Alan Ball's dark comedy script and paints a thought-provoking picture of "American Beauty." An accomplished theatre director ("Cabaret" on Broadway), this is Mendes' first work behind a movie camera. His talents, along with sensational acting in a daring screenplay, are drawing Oscar attention to "American Beauty."

Academy Award winner Kevin Spacey heads the handpicked cast, and provides the introduction with a voice-over narration saying… "My name is Lester Burnham. This is my neighborhood. This is my street. This is my life. In less than a year, I'll be dead. Of course, I don't know that yet. In a way I'm dead already."

Lester is the focal point of the movie and a man caught in the doldrums of a mundane routine that has become his life at age 42. Since long ago has the passion been gone from his job, marriage, parenting – and life. But to the credit of the filmmakers, he's not the only well-developed character with problems and issues that need to be addressed.

Lester's workaholic wife, Carolyn (Annette Benning), virtually ignores him while being obsessed with the image of success and forging her identity by having the right car, the right house, and the "right" family. As long as her rose gardens remain immaculate, the image is preserved, problems don't exist, and all is right with the world. Further beneath the Cleaver-household façade, neither parent is attune to the needs of their teenage daughter, Jane (Thora Birch). She puts forth an angry exterior, feeling failed by her indifferent father and oblivious mother. Ok, so they're not the Waltons. But if you think their family defines dysfunctional, wait until you meet the neighbors.

The supporting cast of characters impact the film greatly, and they themselves are supported by a script featuring no small parts or insignificant roles. Of particular note is the Fitts family that moves in next door. They consist of an enigmatic high school senior son, Ricky (Wes Bentley in a breakthrough performance), with an ex-Marine father who is struggling as a civilian, and an estranged mother who has seemingly withdrawn from every aspect of life. And then there's Jane's friend Angela (Mena Suvari). Her cheerleading charm has profound effects on Lester and his ensuing rose-petal delusions are his personal catalyst for change and serve as the early turning point in the movie.

Re-energized to once again actively live life with the zest and zeal of his youth, Lester sparks a chain reaction of characters addressing their own plaguing issues.

Assumptions… illusions… pre-drawn conclusions… individuals with exterior behaviors masking secret insecurities… this film takes an unadulterated look at the underbelly of life in Anytown, USA. All topics are fair game including: sex, drugs, violence, nudity, adultery, homosexuality, homophobia, child abuse, murder and just about every possible type of potentially offensive subject matter. Which begs the question… is this really "American Beauty?"

With a bold look that dances the envelope across conventional lines, ideas of wholesome beauty are semi-corrupted and may not sit well with viewers. Though I'm a young, red-blooded American male, I found a scene or two of sexuality in poor taste, which black-flags this dark comedy. True, these incidents do add depth to the problems and vulnerability to the characters. But in a movie with Oscar-caliber everything (else), a little more tact could have been taken in achieving the desired effects. [That said, my biggest problem is with the title. We Americans are going to glorify a movie called "American Beauty" by nominating it for and probably giving it the Oscar/Academy Award for Best Picture. Yes, it's a satire and as such the movie has merit and some undeniable elements of truth. But, as an American, these are not the images that I want to associate with and be representative of the words "American Beauty."]

Three stars.

Review Trailers:

Title: "American Beauty"
Starring: Kevin Spacey, Annette Benning, Thora Birch, Wes Bentley, and Mena Suvari
Director: Sam Mendes
Distributor: Dreamworks Pictures
MPAA Rating: R
Genre: Dark Comedy
Target Audience: Mature, open-minded adults

The Miller-meter: THREE STARS
– FIVE STARS: Excellent... in every way.
– FOUR STARS: Good... a memorable film.
– THREE STARS: Average... hits and misses.
– TWO STARS: Sub-par... in many ways.
– ONE STAR: Just plain bad.

* * * * *

If you read the four above movie reviews… did you find yourself thinking more about the movies, or that you are reading a book written by a 43-year-old quadriplegic in the year 2020?

I hope the movies garnered more of your attention. I'd like to share one more.

The 67th movie review I wrote was about how the life someone was planning to lead was "interrupted" after high school. It does not perfectly parallel my story, but I can relate to the interruption.

Girl, Interrupted
By Bill Miller

I must say that I wasn't looking forward to seeing this movie. And as I sit down to write this, I'm still scratching my head because I'm not sure why I really enjoyed experiencing a year in the life of acclaimed author Susanna Kaysen. Maybe because it was different, i.e. not the usual fare found at mainstream movie theaters. It's certainly not going to be everyone's cup of tea, but if you're looking for a refreshing change of pace, consider "Girl, Interrupted." Based on her "coming of age" true story and best seller, "Girl, Interrupted," is about Susanna's stay at a mental health facility in the mid '60s, shortly after she graduated from a private high school.

Coming from a well-to-do family, Susanna (Winona Ryder) was expected to go on to college and make something of herself. But to the chagrin of her parents and at the expense of her social standing, she was the only member of her graduating class electing not to pursue a higher education. It wasn't enough for her be a bright girl with aspirations to become a writer. With mixed messages of disappointment from some adults, and sexual advances from others – not to mention disapproval from her own parents – it's no wonder the black sheep had skewed perceptions of reality. She was confused, struggling to find her identity, liked to party, and had no real direction or positive influence in her life.

After chasing a bottle of aspirin with a bottle of vodka for what Susanna called "a headache," her family had her unceremoniously sent off to Claymoore, a private psychiatric hospital for upscale types. Whether or not her psyche warranted the psychiatric ward, she's labeled "Borderline Personality Disorder" and institutionalized. That's the pill she's forced to swallow.

This is where the story really gets interesting. Susanna's new roommate, Georgina (Clea DuVall), offers introductory information about the dozen, or so, residents who call the second floor ward at Claymoore their home. Georgina is outgoing and seems normal enough, so Susanna asks, "why are you here?" As if awakened from a trance, Georgina's warm demeanor disappears as she eerily replies, "I'm a pathological liar."

Georgina was one of a handful of girls who had spent extensive time at Claymoore, getting treatment for a severe disorder. Susanna, whose mental illness was seemingly marginal at best/worst, now joined the group of Georgina, Polly, Daisy, Cynthia, and their intensely charismatic, sociopathic rebel leader Lisa (Angelina Jolie) – who stole the show. When we first meet Lisa, an 8-year veteran of Claymoore, she's being dragged in by the police after an apparent two-week hiatus from camp Hell-more, I mean Claymoore.

Lisa is a "button pusher," willing to do or say anything just to see your reaction. On the positive side, at Lisa's direction, the group bends the rules and rallies together with a supportive camaraderie to find ways to *keep each other sane*.

The acting was truly superb. Angelina Jolie has award nominations coming her way. Winona Ryder was excellent also and the story seemed so very real. For this, credit Kaysen who helped produce the film and Ryder, who, like Kaysen, also checked herself into a mental health facility during a rough time in her life. Sure there are disturbing behaviors and very sensitive, sad, and turbulent issues lived and discussed here that make the movie an emotional event, but I found it to be more of an enlightening experience than an engrossing hardship.

Make no mistake, "Girl, Interrupted" will not leave you with the warm fuzzies. But it asks you to think about the thin line between supposed mental health and real mental illness. We all experience various levels of sanity as we wade through some of life's deep waters, facing sizable challenges. Some days it takes all you've got to keep your head above the water.

Susanna was a girl interrupted from living her life – but maybe it was an interruption she needed.

Four and a half stars.

* * * * *

Reading it now, I am not terribly fond of the above review I wrote. Of course I'm older now, and have more life experience and perspective, but mental health is a relatively sensitive subject in society at large.

I was in a fog of depression after my injury. It took four antidepressants to lift the fog and allow me to figure out life post-injury. Thankfully, over time, I was able to figure out how to live a life, what I consider a good life, and I eventually weaned off of the antidepressants.

But there should be no shame in needing some help. And sometimes it seems there is a stigma attached with "mental illness" but "Girl, Interrupted" does a pretty good job of showing what a fine line that can be.

Anyway, I also tried to inject a little figurative humor into my reviews, occasionally, for readers who knew I was paralyzed.

You may have noticed that I wrote: "And as I sit down to write this, I'm still scratching my head because…" of course I am sitting down, I am paralyzed, and no, I'm not literally scratching my head! (Smile.)

That was my last movie review, but I wrote one additional column to explain why I was moving on – and that was the first time that I disclosed to my readers that I was/am a quadriplegic. I hope that doesn't sound like I was being disingenuous, but my physical disability should have no bearing on my ability to review a movie. But it was a good bit more challenging for me to go to the movie theater and watch each one, than it was for people who only wish to be accompanied by a bag of popcorn when they watch a movie.

At the very least, I roll in with a big wheelchair, a ventilator, and am accompanied by a caregiver… and maybe a bag of popcorn (smile). We would usually bring in the in-exsufflator machine, if I was planning to have some popcorn or a snack, because remember, I don't swallow well, and can trace aspirate and get congested pretty easily. Thankfully, we never needed to leave in the middle of a movie to eliminate secretions. Even when I do feel secretions "brewing" in my chest, oftentimes it can wait a little while, even several hours.

I enjoyed doing movie reviews, but decided to move on so that I could work on four specific things: breathing, website design, speaking engagements, and going back to school.

* * * * *

Discussing breathing here might look out of place for a chapter titled "getting back to work" but when you are a quadriplegic on a ventilator, one way or another, it's always a relevant topic.

I wanted to learn to talk while I breathe, so that my time off of the ventilator could be productive. I had recently learned that the same speaking valve (PMV) that I use in-line with my ventilator circuit, it could also fit over my trach. That allowed me to take in air through the PMV (when breathing without the ventilator) but forced the entire exhale out of my mouth and nose, which allowed me to speak a little.

My goal was to try to get off the ventilator during the day, and only use it when I sleep (since the manner in which I breathe requires conscious, awake effort).

But it felt significantly harder to take in air with the PMV on, as compared to breathing through the open trach. I was never able to get comfortable breathing and talking with the PMV on. I don't think I exhaled sufficiently, which seemingly made it difficult to tell if I pulled in enough air with my next breath (I know that sounds confusing).

Conversely, with the open trach and the silence, I could hear air going in and out, when I did not have the PMV on. But with it on, I think my face would get a little red, possibly from overexertion, but also possibly from CO2 retention. I believe we had my arterial blood gases drawn by a phlebotomist at the end of one such test, and the results confirmed that it was not a good idea for me to continue. So we abandoned that pursuit.

And that's okay. Not every ambition results in success, but it was not for lack of effort. (And of course, if you don't try, you surely cannot succeed.)

Not to sound like sour grapes, but even if I was successful at it, the effort that I would have to put into each breath (the mini sit up motion) that may have tired me out, especially if I was trying to go all day. So "in the big picture" having the ventilator breathe for me saves my energy, which I can put towards being productive.

There are always silver linings, right? (Smile.)

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When I was at Shepherd, we had trouble finding resources that could shed light on life as a ventilator-dependent quadriplegic. So once I gained some experience, I wanted to begin sharing some of the things I had learned, to help pave the way for others who might follow in my wheel tracks. I thought a website would be an excellent way to share my story and things I have learned. (That's also largely why I am writing this book.)

My dad actually came up with the name "Look Mom, No Hands!" for my website.

It was perfect, because I was sharing some of what could be done sans hands – working by voice because I had no choice – including doing the whole website from start to publish.

A former work colleague of my dad's gave me a few pointers on how to create a website, and I also bought a program for building websites called Microsoft FrontPage (it was eventually replaced by Microsoft Expression Web, which I still use for occasional updates). But thankfully, FrontPage was pretty intuitive, and it allowed me to build my website, and 11 other websites, six of which are still live.

As I write this in July 2020, my website is in dire need of a complete overhaul. I originally optimized it for viewing on computers with screens displaying 800x600 resolution, which was still common in the year 2000. On my full HD widescreen monitor that is 1920x1080, my website looks funny and out of date, with most of the content occupying roughly the middle third of the screen.

Thankfully, though, I do believe some of the content is still relevant and can be helpful for high-level quadriplegics and/or ventilator users. After writing this book, I will probably design an entirely new website for myself on a WordPress platform (which is what I use for my blog) rather than building the entire site from scratch as I originally did with Microsoft FrontPage.

Over the years, quite a few people have emailed me with questions about spinal cord injuries, or ventilator use, after finding my website. Some just wrote to say thank you for sharing.

I'm thankful that my website has helped some people, and I also like having done websites for my family and for community initiatives (as a volunteer). Doing websites for my family was a tangible way that I could do something for them, since they do so much for me. And doing some civic-minded websites as a volunteer helped/helps me feel like I was contributing to the community also.

I don't know when it will be updated, but I plan to keep the same domain for my website, which you can check out at: lookmomnohands.net.

[Should I list the other five that are still live, or a couple?]

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My positive attitude led to speaking engagements.

Apparently some people think it's impressive that a young man who was paralyzed and on a ventilator was/is still happy to be living life.

I observed some universal truths, one of which is that we all have challenges. Some people's challenges are just more visible than others. I roll in – literally – using my mouth to drive a big wheelchair with a ventilator on back, and people can readily identify that I have some physical challenges, and likely some perspectives that may differ from theirs. That gives me a bit of a unique platform with which to possibly reach people.

My dad and stepmom were both civic-minded and plugged-in to the community, and they helped me get lots of opportunities to speak at local chambers of commerce, churches, service clubs, and schools, and to audiences big and small of all ages. For the vast majority of my speaking engagements, I would tailor a PowerPoint presentation to the audience, built off the themes of having healthy perspectives and overcoming challenges.

Naturally, people were curious as to why I needed the big wheelchair with the ventilator on back, so I would start off with a little about my story and of course mention the three big challenges to my quality of life that I faced after becoming paralyzed.

Reading this book, you can probably guess that I talked about… learning to talk again… learning to eat again… and learning to breathe well enough on my own that the ventilator is not much of an issue. After briefly talking about those big challenges, I surmised that a problem becomes a challenge when you accept the challenge that the problem presents.

Someone once told me that if we all hung our problems outside on clotheslines for the world to see… and then we saw what other people are dealing with… we might be pretty quick to claim our problems.

That was one of the messages I shared regularly at Anthony House, a homeless shelter and self-help program for people in our county. When you think of a homeless person – what image comes to mind?

I think the natural inclination is to envision a disheveled person with a cardboard sign on a street corner seeking help.

I learned that homeless people – are just people – people with problems to overcome. Many of them even have jobs and families, but at that time, they could not make ends meet and thus did not have a place to call home.

My job was to help change their perspective, and to eliminate the "woe is me" attitude some had. They were all dealing with some type of legitimate problem or problems, but when they saw this twentysomething-year-old guy paralyzed from the neck down and using a machine to breathe, they put their problems into perspective. Just like the clothesline anecdote above, all of a sudden their challenges did not seem so bad, or so insurmountable.

And that is why I loved speaking there as a volunteer for several years, until funding issues closed it down (it was reopened later with a similar mission, but with a different name and some different methods).

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I did more than 150 presentations altogether. I don't know if they were motivational or inspirational, or something else, I just wanted to share about my story and perspectives to help people.

I'm writing this in the past tense not only because I'm recalling past events, but also because most of my speaking engagements I believe are in the past.

The primary reason why I have only done a few in the last five-or-so years is because I am not able to talk as well on my current ventilators, as I did on my original machines (I will elaborate when I talk about my equipment). But that is yet another reason for me to write this book – you can read it at any speed you like, and how many words I can dictate with each breath has no bearing! (Smile.)

My dad says that because I have to pause more now than I used to, that I am more dramatic as a speaker. That is a nice, positive spin, but I dislike that I cannot talk as well as I did on my first ventilators.

Yet, I remain grateful that I can talk, as I know three adults who have essentially been nonverbal quadriplegics since birth. I can only imagine how frustrating it is for them to not be able to vocalize words from their mouths, but all three graduated high school and at least attended college. I think they would tell you that with the right assistive technology, and especially family support, life can still be good.

See? We all have to keep things in perspective.

* * * * *

I mentioned that my final newspaper column stated that I was moving on to pursue four specific things: breathing, website design, speaking engagements, and going back to school.

So I will conclude this chapter by saying that when I stopped doing movie reviews, not only did I start working on the other three items, but I was awaiting the right opportunity for me to go back to school.

That was in the year 2000, when online college options were few and still developing. The right opportunity would become available and, much to my delight, it allowed me to return to the University of Florida in 2005.

But before that happened, a recreational pursuit became a passion of mine.

* * * * *

DEVELOPING A WAY TO BOWL

Calling it a recreational pursuit does not do it justice, but that's what it started out as.

Basically, I have three items I can physically control – independently: my wheelchair, my computer, and Amazon's Alexa (some quadriplegics have and love smartphones, but for my situation, I have yet to see the need – although I know I might regret not getting one sooner, if I finally decide I need one.)

Frankly, there weren't any real feasible recreational pursuits, sporting opportunities, or ways in which I might physically have fun and compete in a fair manner with able-bodied people.

My stepmom saw how well I could drive my wheelchair (by not marking up the walls in our house, except for a few minor "oopses" over the years) and insisted that there must be a way that I could bowl using my chair. The closest possibility was a stationary ramp, but without any physical ability to interact with the ramp and the bowling ball, that would not feel like real bowling to me.

Donna met a lot of negativity when she would ask someone about developing a way for me (and potentially others) to bowl, until she asked a man named Claude Giguere, who was working as a volunteer bailiff in her courtroom.

Claude is a retired engineer with a big heart, and he said, "I can make Bill bowl" (of course he meant make a way for me to be able to bowl) and that was the spark that launched something that became much more than a recreational pursuit of mine.

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Claude and I brainstormed ideas. We quickly agreed that the most feasible option would be an attached ramp concept. I cannot interact with a stationary ramp that sits on the floor, but if you attach a ramp to my chair… then I could be in control of the speed, timing, angle, and location of the bowling ball's release. So that's what Claude set out to build.

Claude custom-built a wooden prototype for my wheelchair, to prove we had a feasible concept.

And it worked.

Before continuing, I should rewind a bit, back to driveway bowling.

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In the interim between Donna searching for a way I could bowl and Claude agreeing, we "invented" what we called "driveway bowling."

Quite simply, we put a basketball on top of a large plastic cup, and put some plastic bottles about 30 feet away, down our driveway. My dad put a small board underneath my shoes and on top of my wheelchair's footrests to allow me to roll up to the basketball and knock it off the cup with a straight edge, rather than with my shoes (where it would be difficult to bump the ball with the tip of my shoe in order to send it in the direction I wanted).

After trying it out, I competed at driveway bowling with my dear friend Rhonda, who was paralyzed about six years before me in 1991 when she was 25. She is also considered a high-level quadriplegic (a C4-5 complete; she successfully weaned from ventilator use, can shrug her shoulders, and has a little bit of bicep, but she says it's not enough to accomplish any tasks; she cannot use her hands at all, and also uses a sip-and-puff controlled wheelchair like me).

Driveway bowling was a fun little game (although it was labor-intensive, since there was no automated ball return or pin setter) but Donna wanted to get us in an actual bowling alley, somehow, someway. So my dad took some more scrap wood from our garage, and made a device that would fit over the footrests of my wheelchair and allow me to push a bowling ball. It wasn't exactly high-tech, or high-speed, but it allowed me to push a bowling ball down a real bowling lane. He made several of those "pusher" devices.

Rhonda introduced me to several other local quadriplegics and about five of us used the pusher devices in a real bowling alley. That was the inception of our Quad Squad, a name that Rhonda coined to describe our group of wheelchair users.

But the speed of the ball was limited to the speed of the chair. Power wheelchairs like mine generally top out at about 6 mph – but the short approach to the foul line does not give much room for getting up to speed, and stopping without fouling. So the ball speed was probably 2-3 miles per hour. Some little kids might be able to propel a ball faster than we could… but I was not going to use the bumpers no matter what! (Smile.)

So when Claude built a nice, wooden ramp that could attach to my chair, it felt like my ball speed tripled. It certainly doubled.

The only problem was that what Claude built was custom fit to my chair, and could not be shared. But at least we knew we had a feasible concept. And we had visions of wheelchair users everywhere being able to bowl with attached ramps.

* * * * *

Claude was friends with an experienced entrepreneur named Vincent Tifer, who retired early due to multiple sclerosis. Even though Vincent does not use a wheelchair, he could empathize with those of us who do.

The three of us wound up co-founding a company together to try to make bowling available to as many wheelchair users as possible. That was in 2002.

We actually formed a business plan around the idea of being able to capture 1% of the wheelchair user market. Doing the math, if we could capture 1% of the wheelchair user population, our company could be financially successful. So we asked family and friends to buy stock in our company to give us the capital needed to develop a manufacturable, shareable, and hopefully affordable attached ramp that would enable wheelchair users to bowl.

We went through several designs and iterations. Today, that attached ramp concept we developed is known as the IKAN Bowler®. IKAN? Yes you can! (Smile.)

The name actually came from a Greek word, ikanos, meaning enable.

The IKAN Bowler® was honored as a 2004 da Vinci Award winning invention by the Engineering Society of Detroit and National Multiple Sclerosis Society Michigan Chapter. Technically, Claude invented it, and I was generously listed as co-inventor.

We also got the IKAN Bowler® approved (sanctioned) for league and tournament play by the American Bowling Congress (ABC) and the Women's International Bowling Congress (WIBC) which later merged to form the United States Bowling Congress (USBC). That means wheelchair users can legitimately compete against able-bodied bowlers.

Our company is Manufacturing Genuine Thrills, Inc. because if you are a quadriplegic, who either lost or never had the ability to participate in a fun, physical activity like bowling, that first spare or strike in particular is truly a genuine thrill. We've seen tears of joy on the faces of first-time users who never thought they would do something like bowling a strike.

When I was at Shepherd Center, the therapeutic recreation experts did not have much to show me that I could do. We eventually showed them the IKAN Bowler®. They loved it and told us that having an outlet like bowling can build self-confidence and self-esteem which can carryover into other areas of the person's life. As such, the IKAN Bowler® is an empowerment device. That's why I titled my blog "empowering wheelchair users" as my blog was/is designed to spread awareness about people using the IKAN Bowler® and how it can help to improve one's quality of life.

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In 2004, our local Quad Squad members were able to try out the first iteration of the IKAN Bowler®. The same people who pushed or scooted a bowling ball with one of the pusher devices my dad made, now they were using adaptive technology that allowed for significantly greater ball speed and accuracy.

We also made the IKAN Bowler® available-for-sale to anyone anywhere in the world.

Let the games begin.

* * * * *

I maintain that the goal of bowling should be to have fun, and it generally is – but it's extra fun to bowl particularly well. Starting out, I always wanted to keep setting personal bests, but I also had my eyes on the 200 Club. I wanted to be the first person to bowl 200 using an IKAN Bowler®. Since I was Claude's primary test pilot, I probably had more experience than anyone else at that point, so I felt like I should be the first one to break 200 (not necessarily that I deserved to do so, but competitively, I would have been a little disappointed in myself if someone else beat me to it).

It turns out that I was the first IKAN Bowler® user to break 200, and it happened under the most unlikely circumstances on November 6, 2005 (the day before my 29th birthday).

Athletes and sports enthusiasts are often routine oriented, and generally perform best in familiar surroundings under ideal circumstances. For example, golfers should have a better chance of shooting their best round ever on a golf course that they have played many times, using their favorite clubs, and when the weather and course conditions are considered perfect. The way I broke 200 would be like a golfer shooting their best ever score on a course they had never played, using brand-new golf clubs they had not tested – during a torrential downpour.

That kind of reminds me of the classic comedy, Caddyshack, where Bill Murray's character (Carl Spackler) says, "I'd keep playing. I don't think the heavy stuff is going to come down for quite a while," when it's already a torrential downpour, and yet the Bishop for whom he is caddying is having the best round of his life.

Thankfully I wrote about this in detail shortly after it happened.

Here's what I wrote:

We were at a Rotary Club "Bowling Ball" (ball as in party) fundraiser in Tampa at a bowling alley I'd never seen before. I was also trying out a new model of IKAN Bowler® (once setup, it should function identically to previous models, but still, it wasn't the one I've been using for about two years). Also, at our two local bowling alleys where we bowl regularly, we Quad Squad Bowlers generally get our own lanes (although it's possible for us to backup farther to let able-bodied bowlers bowl with us on the same lane). This bowling alley was nice, but it had a drop-off by the ball return, which meant we couldn't backup too far or we would blindly back off the step.

I had the pleasure of bowling with another wheelchair user, a Veteran named Jerry. He is a quad from the Tampa area who drives his chair with chin controls. He is pretty darn skilled with it. He's bowled a total of 4 games with the IKAN, and has broken 100 in all but his first game, a 99, and he has a high of 135! (On a side note, breaking 100 is a good score for someone without much experience; heck, when I am off my game, sometimes I struggle to break 100.)

Jerry and I shared a lane. This meant, after each frame, we had to drive off to the side out of the way so the other person could bowl (two big wheelchairs with ramps attached don't fit well on the same lane). That's really no big deal, as we were on the end lane, but still, it wasn't ideal for the concentration and continuity that one might think is required to break 200.

Anyway, that doesn't sound too bad, new alley, new IKAN Bowler®, rotating turns. Well, let's try black-light bowling (turn off the regular lights), add loud up-tempo music, and put a large projection screen TV right over the pins on lanes 49 and 50 – and Jerry and I were on 50! They were showing the Bucs game, and alternating that with music videos – that's right, football action, not to mention – have you ever seen pro cheerleaders at a football game or the female dancers in music videos? Not distracting to a nearly 29-year-old male AT ALL! (Smile.)

I'm not done! More to "deal" with... Jackie is my primary caddy. She has the most experience caddying for me. Granted, it isn't that big of a deal, as long as the person volunteering to caddy for me has the patience to load the ball right where I think it needs to be, rotated precisely so I can control the shape of my shot (and some of y'all know I can be picky). Anyway, I had two brand new caddies alternating shots with me, two Tampa-area college students caddying for me, Joe and Jessica. Jessica was/is quite attractive, and was dancing to the music. Another distraction. Put all this together... now LET'S BREAK 200? Right! (Smile.)

With the black lights, I could barely see the arrows on the lanes. And, because of the drop-off by the ball return, I couldn't backup as far as I'm used to, so my approach was shorter than normal. All this together, and I still don't know how my score added up to a barrier breaking... 201! I call it "the magic of falling pins" and give thanks to God, because I didn't do it entirely by myself. Maybe our dearly departed Quad Squad friend, Wendell was kicking over some pins for me. But it was exciting! (Smile.)

I'm most proud of the last shot. I started with a lucky turkey (I told both caddies I couldn't see what I was doing) but still managed three straight strikes, but I had an open frame in the 9th, on a spare that I should've picked up. I thought that probably was going to prevent me from breaking 200... BUT, I was sitting at 181 with one frame left. I knew I could still do it, but one of my fellow co-founders, Vincent, made sure I knew what I needed and said "Bill, you need a mark (a spare or strike in bowling lingo) and 9 pins for 200."

No worries.

Music blaring, TV going, lack of light, short approach, new IKAN Bowler®, first game on these lanes, Jessica dancing, sure... let's bowl a strike when I REALLY need it – my 10th frame.

The magic of falling pins… it was a Brooklyn strike, which I followed with a pocket 9 to break 200, and left me with one little 10-pin to pickup for a better sounding 201 (two oh one sounds better than "just" two hundred). The 10-pin is my bowling nemesis, but I converted the spare for a 201.

There are several points to this lengthy explanation. One is to show my fellow IKAN users that if you have an idea of what you're doing (how you want to make shots) and you bowl enough, eventually, with the magic of falling pins you CAN join me in what I hope will eventually be a relatively large group of IKAN users in the... 200 CLUB! (Smile.)

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To my knowledge, 13 different wheelchair users have bowled games of 200 or better in dynamic fashion. "Dynamic" wheelchair bowling simply means that it incorporates the movement of the wheelchair (i.e. it's not stationary ramp bowling, although an IKAN Bowler® can be used as a stationary ramp). That's why the IKAN Bowler® was sanctioned for league and tournament play, because when used in dynamic fashion, it mimics what able-bodied bowlers do: set up, then physically approach and release the ball prior to crossing the foul line.

Every time I learn of an IKAN Bowler® user breaking 200, I highlight their achievement with a post on my blog. You can read about them at Powerwheelchairusers.Wordpress.com (once there, search "200 club" to see entries).

I have bowled 28 games of 200 or better, my best of which is 255. That sounds good, and candidly, it is, but I know a few guys who have broken 200 much more than that. And the overall world record is currently 269 by a young man in Finland!

Those website development skills I learned previously allowed me to make a website for tracking various wheelchair bowling records. To spotlight the achievements of multiple people, I created different categories: reason for wheelchair use, wheelchair driving method, and male and female categories for both of those. You can check it out at WheelchairBowlingRecords.com. My 255 game has an interesting write up on the records website. I'm still in disbelief when I look at my scoresheet for that day (which is included with the write up).

* * * * *

Once our Quad Squad group started bowling together, we kept doing so roughly twice a month right up until the coronavirus pandemic shut down our local bowling alleys. Of course, quadriplegics are generally considered immunocompromised, so we will probably not resume bowling as a group until it is safe to do so. I should also add that we have welcomed anyone who has wanted to join our local Central Florida Quad Squad, and have encouraged people in other parts of the country to form their own Quad Squads.

I think the most we have ever had bowl together at one time was nine wheelchair users.

And five of our friends who were frequent Quad Squad bowlers have passed over the years, which underscores the importance of living life and enjoying a fun activity like bowling with family and friends. RIP Wendell, Jeff, Alex, Aaron, and Ben – though you are gone, you are not forgotten.

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The pandemic has also put our company, and thus the availability of the IKAN Bowler® in jeopardy.

We currently have a list of people interested in buying IKAN Bowlers, but we are essentially out of inventory, and our local manufacturer's new cost estimates are frankly, much too high for us to replenish the inventory – AND keep the cost as low as possible so that more wheelchair users can afford it (I'm largely referring to power wheelchair users, as most people who use manual wheelchairs have not been greatly interested in using an IKAN Bowler®, instead preferring to bowl with the arms they can still use).

Truth be told, after all these years in business, we have not been able to show any significant financial profits, which part of me regrets because I sold family and friends stock on the notion that we should be financially successful (thankfully, I did not ask anyone to put money where we wouldn't, as my parents also invested significantly, which in the big picture was money that could have been used to help provide my future care). Despite marketing in many different ways (albeit always on a small scale, due to our limited resources) and streamlining our operations (today, everything is run by two of us co-founders, Vincent and me) the market has proven to be tougher than we expected. I'm not judging anyone, but it seems that even people who are interested in bowling and can afford an IKAN Bowler® usually take a while before clicking the purchase button.

One guy who wanted to purchase immediately, was one of our original Quad Squad members, Jeff (one of our aforementioned departed friends). He got to try out the first version, which technically was still a prototype that we could not legally sell him. But that did not stop him from trying! Right after completing a couple games with it, Jeff said, "I will give you $1000 to leave this on my chair."

We had not even established the manufacturing costs yet, but that showed how much he enjoyed that first experience.

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Don't stick a fork in us just yet – we might not be done!

From early on, we always had our sights set on getting bowling into the Paralympic Games. I mean, if bowling became a Paralympic sport, with the sanctioning we got through what is now the USBC, then dynamic wheelchair bowling could allow quadriplegics to participate, and the IKAN Bowler® could be in demand by countries all around the world.

Just before the pandemic shut things down temporarily, we went bowling with a fellow IKAN Bowler® user who is heavily involved in the movement to get bowling into the Paralympics, and he also has a manufacturing background. We are attempting to partner with him to find a new manufacturing solution and keep things going… all the way to the Paralympics. Good Lord willing, we will be able to do so.

I do believe we are attempting to partner with the right person, but that arrangement is contingent upon finding a new and at least reasonable manufacturing solution. If someone like Nike co-founder and philanthropist Phil Knight wanted to get involved, I could see the IKAN Bowler® really taking off. If Nike took it over, they have the deep pockets to manufacture it on a large scale – and thus lower the cost – and also the resources to market it properly, not to mention their instant brand recognition, etc. And if it becomes a Paralympic sport, Nike could sell equipment to countries worldwide. They could enable lots more wheelchair users to *Just Do It*.

But even if we are unable to continue, the IKAN Bowler® has definitely given hundreds – and probably thousands – of wheelchair users the opportunity to have fun and compete in a recreational, sporting endeavor with family and friends, and against anyone. Rehab hospitals like Shepherd Center have introduced many newly injured people to IKAN-style bowling.

And whatever happens, I also want to say that I am grateful for each person who took a leap of faith with us and invested in this journey, whether financially or with your time and efforts. We would not still be in business without all of you, and each of you. So thank you. And I do hope you see value in knowing that your contribution has at least given fun experiences and a quality-of-life boost to many people who live daily with what most observers would consider large challenges. I contend that those observers would be correct. (But I also believe that every human being faces challenges in life, if not daily, and yet, with proper support, life can still be good despite those challenges.)

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Our website is ikanbowler.com if you want to check on the journey, and my aforementioned blog should live on indefinitely since it is hosted on WordPress for free.

GOING BACK TO SCHOOL

When I regularly spoke with the homeless adults at Anthony House, my presentation evolved into including this quote from Robert Fulghum who wrote:

"Most of what I really need to know about how to live and what to do and how to be... I learned in kindergarten.

Share everything. Play fair. Don't hit people. Put things back where you found them. Clean up your own messes. Don't take things that aren't yours. Say you're sorry when you hurt somebody. Wash your hands before you eat. Please FLUSH. Warm cookies and cold milk are always good for you.

Live a balanced life – learn some and think some and draw and paint and sing and dance and play and work every day some. Take a nap every afternoon. And when you go out into the world, watch for traffic, hold hands, and stick together."

I concluded by adding, "Remember these things and everything else will take care of itself."

I thought it was a good way to wrap-up my presentation (before the Q&A session) because most of them didn't have an abundance of formal education, yet everyone either had kindergarten or could identify with most of those basic truths. Hopefully, that gave them the feeling that they did know and do have what it takes to live a good life.

But speaking of my presentations and education, when I spoke with the at-risk students at my high school (incidentally, my presentation was recorded and shared with additional classes) I included a PowerPoint slide with a bar graph that basically showed that the farther a person goes in school, the greater their lifetime expected earnings are. (The slide showed the average earnings of high school dropouts, to high school graduates, all the way up to people with doctoral degrees.) Of course, money is not everything, but it is obviously a needed resource.

That said, not everyone needs college to be successful. Learning a trade, joining the military, becoming an entrepreneur… there are many paths to success. And we all get to define what success means for us.

Being a quadriplegic, I felt like the more formal education I could get, the better. My pre-injury plan of teaching at the collegiate level was not out of the question, if I were to continue and earn a master's degree, or PhD. But of course a bachelor's degree must precede those pursuits.

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I was staying busy with our bowling endeavors and my speaking engagements, but I was also keeping my eyes open for the right opportunity to return to school.

A friend of mine, Joel is a 38-year-old man who became a quadriplegic in a car accident at the age of three. I'm sure everyone reading this can handle the arithmetic, but that's 35 YEARS that he has been paralyzed. Since his injury, he has also required mechanical ventilation (either a ventilator or diaphragm pacing system). Yet he graduated high school on time, and actually chose to leave the safety and security of his parents' home and went off to college for a couple of years. He lived on campus, assisted by nurses and caregivers.

When you are completely reliant on others for all of your physical needs, it is highly courageous to leave home and leave your parents, who are likely two of your best and most knowledgeable caregivers. Further, parents are often "emergency backups" if a nurse calls in sick at the last minute, or cannot make it for some reason.

So for Joel to make that choice and to live it out for a couple of years is quite impressive. It was also before online options were realistic choices, although my guess is that he would have made the same choice in order to "get out of the house" after high school, like many young folks do.

But for me, given how much my family helped with my care needs, and the fact that I had already been "on my own" and experienced some college life, I was content to wait for the right distance learning opportunity.

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Previously majoring in mathematics, I knew that I would need to switch majors partly because I did not think voice software could efficiently handle all the crazy symbols and equations that higher-level mathematics require (not at that time anyway). Even if my voice software could "speak math" there were other logistical issues like test-taking and proctoring that just did not seem feasible for offering a mathematics degree via distance learning.

Imagine my delight when I learned that the University of Florida would begin offering two bachelor's degree programs online: fire and emergency services and business administration (as of July 2020, they offer 24 bachelor's degree programs online; mathematics is not one of them).

So, finally, I could switch majors and become a firefighter! (Smile.)

Obviously, business administration was a perfect fit for me, considering we had recently launched a startup wheelchair bowling endeavor.

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I started back at UF in the summer of 2005 and I literally rolled across the graduation stage on August 9, 2008.

My approach was different. I felt like two courses per semester was plenty ambitious, given my life circumstances. Pre-injury, for some reason I wanted to get through school as quickly as possible, trying to take as many hours as I could each semester. Given that I had always had a part-time job while in college, clearly I was not 100% focused on learning as much as I could. I felt like all I needed was the degree and an opportunity, and I would be able to be successful in the future.

Returning to school, I wanted to prove that I could still be successful despite being paralyzed from the neck down. To me, that meant earning an A in every course and having a 4.0 GPA post-injury.

I will say that it was not easy – there were plenty of challenges along the way – but I did manage to earn an A in every course. Grades aside, I also studied more and learned more than I ever had before. In hindsight, it makes me wonder why I was previously trying to rush through school. When reflecting on life, many people look back and say their college years and experiences were the best of their life. I was loving my time in Gainesville, and I still don't understand why I was trying to graduate as quickly as possible. I'm still scratching my head over that one.

My first course back at UF was principles of marketing, which I thoroughly enjoyed. At the end of the course, I emailed my professor and said, "it was a pleasure learning and earning an A in your course."

He replied stating: "You didn't just earn an A, you earned the highest A out of 535 students who completed the course. Congratulations!"

That felt awfully good to read. (And I am able to quote him accurately, because I saved the email!)

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Candidly, returning to school was a bit daunting.

I mean, sure I could use my computer by voice pretty well, but what about test-taking? And notetaking? And how am I going to access a textbook?

At the time, most of my UF courses were following a pretty traditional model, i.e. professors would give in-class lectures which were recorded (for distance students) to go along with assigned readings from a textbook and/or supplemental materials, upon which we would later be tested.

Thankfully, I learned that students with documented disabilities can receive appropriate accommodations to help them/us be successful. This should be true at every school, thanks to the Americans with Disabilities Act (ADA) that became law literally 30 years ago (July 1990). To get started, I went up to Gainesville to UF's Disability Resource Center.

Because I had to work with a proctor to act as my hands, I was granted extra time for taking tests. Also, the Disability Resource Center would designate and compensate a student as a notetaker for me (i.e. a classmate would be paid to share their notes with me). Lastly, textbooks, if the publisher was unable to provide a digital version in a timely manner, then the DRC would actually use a high-speed scanner to create an accessible version for me.

Those were all deemed appropriate accommodations for me, although writing it now, I almost feel guilty for receiving such accommodations.

My aforementioned friend Joel, he can read a printed book that is set on something that looks like an easel, and he even turns the pages himself using a mouth stick (he can actually type 32 words per minute on a regular keyboard using a mouth stick; my jaw dropped watching him type – if you want to watch, search YouTube for Mouth Stick 101, which has more than 4000 views). Joel grew up using a mouth stick as his tool to do things, including using a computer. And to this day, he prefers using a mouth stick over voice software to control his computer.

In rehab, I could not move my neck hardly at all, so Shepherd Center never even introduced me to a mouth stick. Even today, with my neck being fused, I have very limited side-to-side range of motion, and almost no forward-and-back ability, so using a mouth stick is extraordinarily difficult (as such I don't do it). But if you put a book on my computer screen, I am good to go!

I'm just sharing this to show that there is more than one way to do things.

I actually had to take some prerequisites online via St. Petersburg College prior to resuming at UF, and though we got a "digital version" of a textbook straight from the publisher, it was poorly exported into Microsoft Word files that were largely unusable.

Thus, my mom and I literally scanned every chapter of the textbook – one page at a time – on my decisively low-speed scanner. I also named each page, and wrote macros to help me crop off the excess "edges" and make the pages more readable.

So I was not about to turn down the DRC offer to scan any inaccessible textbooks with their high-speed scanner! (I should add that the publishers rightly required me to purchase their textbook, before they would provide a digital version.)

As far as taking tests, my UF distance-learning classmates had to drive to proctored testing centers. But even if I joined them, because I had to verbally give answers to a proctor to write for me, I would need an additional proctor in a room without other students.

So UF said that if I could locate appropriate proctors who were willing to come to our house, they would pay them, and allow me to take exams at home. That was quite nice.

One person who was approved to proctor for me was my middle school English teacher with whom I have kept in touch over the years. I mentioned that because she is now retired, and volunteered to edit this book! (She also has extensive experience with editing and publishing – thank you Mrs. West!)

I acknowledge that it does take longer to verbally give answers to a proctor to write for me, and thus, extra testing time seemed appropriate. Plus, I have to do a weightshift in my wheelchair for a minimum of one minute every 30 minutes in order to prevent pressure sores. I generally tilt and recline back for a couple of minutes.

Shepherd Center showed us patients pictures of nasty pressure sores, and told us that we could either weightshift for a minimum of one minute every 30 minutes and prevent getting decubitus ulcers, or we could not weightshift and spend months in bed trying to heal them. That made quite an impression on me. So I pretty faithfully weightshift roughly every 30 minutes, whether I am at home, in a restaurant or a movie theater, at a ballpark or in a bowling alley – it doesn't matter. I do not want to risk developing a pressure sore.

But the extra time for test-taking allowed me to weightshift without too much concern about finishing exams in time. (The extra time was usually time and a half, or at most, twice the usual time; I didn't necessarily need all of that, however dictating written answers to a proctor, and solving economics problems probably took twice as long as I would have able-bodied.)

As for notetaking, I was thankful to have a classmate share his/her notes with me, but that accommodation I'm sure was born from the need to take notes on what an instructor shared live in class. Since I was watching recorded videos of the live classes, at my convenience, I could have paused the videos and took notes myself. It would've been quite tedious (one drawback to my original voice software was that dictation was just one word at a time) but I could have done it.

The bottom line is that after getting doctor verification of the disability, a trained counselor can help a student with disabilities receive appropriate accommodations. I probably should not have said that I almost felt "guilty" for receiving the accommodations that I did; it's just that I was not used to needing such assistance in school. It felt like they were going above and beyond what was necessary in order to level the playing field for me, but I am also sharing this so that other people with disabilities might realize that going back to school is feasible.

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Several of my classmates started something called GOSA: Gator Online Student Association. Basically, it was a message board where we could all meet remotely, at our convenience, and discuss courses, ask questions, and share best practices and tips for being successful. That was a valuable resource, and it helped supply some of the camaraderie and feeling of togetherness, despite the fact that we were learning from various locations all around the state.

GOSA remained active even after our class graduated, but eventually it was shut down after the rise of Facebook. (Facebook was not necessarily a perfect tool for filling the need that GOSA did, but it was good enough to largely eliminate the need for a dedicated message board.)

I met a lot of quality people in my classes and through GOSA, many who I still keep in touch with (mostly on Facebook).

We celebrated my graduation with family and friends at the Leesburg Opera House. I gave a PowerPoint presentation chronicling my journey to that point and also announced that I wanted to write a book (this book) to share some of my experiences and things I have learned from my time paralyzed. I am thankful that this book is finally materializing, and though I did not purposely delay writing it until 2020, I'm glad that I've had roughly a dozen more years to gain insight and experience life.

The most memorable aspect of the graduation ceremony itself was that I nearly broke the stage!

We graduated in the O'Connell Center, which was also where sports like basketball, volleyball and gymnastics were played. So the graduation stage was removable. In order to make it accessible for wheelchair users, it had a small metal lift. But with my ventilator on the back, I did not fit well. My feet pressed into the not-so-sturdy sliding door, and pressed it under the stage boards. So when they first started to lift me, part of the stage was coming up as well! (Smile.)

Most importantly, I fulfilled a lifelong dream of graduating from the only school I ever really wanted to – The University of Florida. I grew up a fan of Gator sports, and given that it was one of the top public schools in the country, and the flagship school of our state… it was the only place to which I applied in high school. (As mentioned earlier, even though I was accepted out of high school, I chose to go the community college route first, in order to save money.)

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If we could have shown that finishing my bachelor's degree was a necessary step to making gainful employment possible, then Voc Rehab probably would have covered my tuition and books. But Voc Rehab spent a lot of money modifying my van (over $18,000) and some more to widen doorways, and make our house accessible. So my parents decided to pay for me to finish my bachelor's degree.

But my bachelor's degree alone was not really enough in order for me to achieve realistic, gainful employment. A master's degree is the minimum requirement in order to teach at the college level, which with the increase in online options, teaching had become quite feasible for me.

But when I graduated with my bachelor's degree in business administration, that was the summer of 2008, in the midst of the great recession, which technically did not end until June 2009. So when I was thinking about graduate school during the recession and shortly thereafter, I read about a lot of people with MBA degrees (Master of Business Administration) who were out of work.

I did not want to be in the same boat with them, and further, I wanted to distinguish myself with a degree that was less common to make me attractive as a teaching candidate.

In 2010, I learned of a completely online Master of Entrepreneurship (ME) degree being offered by Western Carolina University. Their ME degree program was relatively new, yet already acclaimed and accredited, and taught by faculty with real-world entrepreneurial experience. It sounded perfect to me, and upon completion, would allow me to teach entrepreneurship at the college level, either at our local community college, or online.

It also could help me further our wheelchair bowling endeavors. But another thing I loved about the thought of teaching entrepreneurship, is that I had already learned that entrepreneurship is responsible for more jobs in this country than all of the Fortune 500 companies combined. So I felt like I could help students potentially be successful, and in doing so, I could have a small part in helping our economy and country. I thought of it like a multiplier effect, or at least a ripple effect (like throwing a pebble into a smooth pond, and watching the subsequent waves ripple outward). With my power wheelchair and ventilator, I am averse to getting too close to bodies of water, but I could figuratively be a small pebble.

Voc Rehab liked the above career path, and agreed to pay for me to pursue my Master's in Entrepreneurship at Western Carolina University.

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I began the ME program in the fall of 2011 and graduated in the spring of 2013.

The University of Florida's online bachelor's program could be completed at one's preferred pace, which for me was two courses per semester.

Western Carolina's ME degree had a specific curriculum path, and essentially required two courses per semester. Actually, each semester had two successive eight-week courses, which allowed us students to focus on one course at a time. I liked that very much. Further, the entire degree program was/is project-based, where students learn about essentially all the prudent tasks and primary aspects of starting a business, and do projects either related to their real or fictitious entrepreneurial endeavor.

Furthermore, instead of one professor acting as a "sage on the stage" dispensing knowledge, the ME program utilized (and still utilizes) the learning community concept. Basically, the idea is that since we were all working on the same aspects of business (e.g. analyzing strengths, weaknesses, opportunities, and threats, which is commonly called SWOT analysis) for our respective businesses, we would share our work on a discussion board and seek feedback from the learning community – both our peers and the instructor.

No offense, but instructors don't know everything, nor are they the only ones with valid viewpoints – especially with respect to businesses. The needs and wants of the marketplace (customers) are what drive successful businesses, and students in the graduate program are more than qualified to share their opinions, at least as potential consumers of one's product or service.

The learning community model works particularly well for teaching entrepreneurship, and can be quite effective in other areas of education also.

In the entire ME program, there is not one exam, or one traditional textbook. Our professors purposely assign "real world" books related to entrepreneurship, almost all of which have digital versions (e.g. Kindle versions) available. Our professors also do not give video lectures. They do sometimes share carefully cultivated videos related to entrepreneurship, most of which can be found on YouTube.

Our ME program instructors have collaborated to put great thought into the instruction, design, and implementation of each course, and how they tie to successive courses. The projects are real-world, business based, and I recall being challenged to expand my comfort zone in essentially every class.

Yet, I needed no special accommodations due to my disability.

And when I graduated in May 2013, I was honored to be selected by the faculty as the "outstanding ME student" for our graduating class (and I did earn an A in each course).

We went up to beautiful Cullowhee, North Carolina to the WCU campus for the first time for my graduation. And I got to meet several of my instructors in person for the first time as well (although we had previously discussed course-related topics by videoconferencing, so we had "met" before).

Those professors kind of recruited me to be a teaching assistant for them.

Considering one of my main goals all along was to teach at the college level, I eagerly and gratefully accepted.

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I have worked off-and-on as a WCU teaching assistant since 2015 for both graduate and undergraduate entrepreneurship courses. I even flew solo as lead instructor for one course.

My professors have encouraged me to seek a PhD, so that I can teach full-time.

We shall see.

FAITH, LOVE, AND HAPPINESS

It is now August, 2020. I have struggled for a couple of weeks to gain traction in writing this chapter. As the title indicates, I'm going to talk about faith, love, and happiness. To me, all three are related, but I know that not everyone will agree.

Full disclosure, the reason I've struggled to begin writing this chapter is because I want to share my faith, why I am a believer, and to do so in the most compelling way that I can, in order to potentially lead nonbelievers to reconsider.

I mentioned in the chapter on my initial hospitalization that I believe I had a near-death experience (NDE) corresponding with double pneumonia when seemingly nothing was going right. But I have never been able to share about that experience with words adequate enough to do it justice. It turns out that I'm not alone! (Smile.)

As I contemplated writing this chapter, I "stumbled upon" the story of a fellow high-level quadriplegic, Ryan Atkins, who shared a list of books that changed his life post-injury. One of those books is called "Imagine Heaven" by John Burke, a man who eventually left a career in engineering for full-time ministry. He tried to take the most data-driven approach he could to analyze people's near-death experiences and to see how they compared to Scripture.

One area that Burke focused on was the NDEs from accomplished professionals who (seemingly) did not have anything to gain financially by sharing their experiences, and also had credibility to lose. He also focused on the NDEs of children, and people of different backgrounds and faiths from all over the world – including people who did not believe there was an afterlife – to try to find the commonalities in their reported experiences.

I find the book quite compelling and fascinating at times, even though I have not yet finished reading it. I also smile thinking about the ways in which people try to describe their glimpse of heaven.

Ryan has a website, FlatOnMyBack.com, and a biweekly newsletter. He is quick to share that he aims to "spur others on to live intentional lives defined by lasting hope." And that he believes, "this is best achieved by adopting an eternal perspective."

I have not yet had direct communication with Ryan, but I am guessing that the book "Imagine Heaven" helped him to more fully embrace the concept of having an eternal perspective.

I do not recall using the phrase "eternal perspective" before, but it is actually what I have lived.

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For starters, I have learned that people need hope, and things to look forward to. In the big picture of life, what could possibly be better than knowing that no matter what happens, we will eventually get to go to heaven? That is a choice we can all make, thanks to the incredible gift that God and his son Jesus offer us (more on that in a bit).

I have read the Bible cover to cover multiple times. I like the New International Version, or NIV, because it seems like the most plain language version of the Bible.

In Luke 23:43 of the NIV, Jesus refers to Heaven as paradise, and how much easier is it to endure some type of temporary hardship here on earth, if you know that you will get to spend eternity in paradise? That is part of having an eternal mindset. It makes it easier to smile through something difficult, or smile through one of life's trials. (Hey, that rhymes – "smile through the trial!")

But if you've read the Bible, probably the two biggest takeaways that God wants from us are: (1) to love God as much as He loves us, and (2) to love our neighbors as ourselves. Those are the top two commandments, and everything else stems from those (paraphrased from Matthew 22:34-40 NIV).

Loving God, to me, means continually being thankful for all the blessings we have in our lives, and recognizing that they come from Him. How much does God love us?

John 3:16 NIV, "For God so loved the world that he gave his one and only Son, that whoever believes in him shall not perish but have eternal life." That's the most astounding gift imaginable.

As for loving our neighbors as ourselves, I believe that boils down to simply helping people when we can, and doing good things in our part of the world to help our "neighbors" (the people in our lives).

Reading "Imagine Heaven" seems to make it clear that God doesn't care about our awards and achievements, which glorify us. He wants to know how much we have loved – that glorifies Him. The reported experiences also make it clear that God loves us with a depth that we cannot comprehend until we experience the amazing peace, joy, and love that await us in heaven.

Above I said I am not alone in having difficulty sharing about my NDE in a way that can REALLY explain what it was like. In the book "Imagine Heaven" others expressed hesitancy to share simply because their words fall short of being able to do so accurately, with the vivid clarity and splendor of their experience. But that was for people who actually got a sample of what heaven is like.

For me, I did not get that far – but I was clearly given the choice to die and go to heaven, or to stay and do life as a ventilator-dependent quadriplegic.

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"I just want it to be over." That's what I kept thinking.

Laying in that hospital bed, after my injury ascended from C5-6 to C1-2 adding a ventilator, after developing pressure sores, having double pneumonia… I just wanted "it" – all the difficulties, the struggles, the grief – to be over.

During all the difficulties, visitors were much more limited, compared to in the beginning when my family and friends broke visitation rules. Before my injury ascended, the atmosphere was nearly festive, as I was excited to get to rehab and begin the recovery process. But when things were not going well, friends who came to visit would have to settle for writing in my visitor log. One friend wrote that she would keep checking to see when the hospital would put me back in "the party suite." (Smile.)

After struggling for at least a couple of weeks, I wanted to get back to the party suite atmosphere also.

I clearly remember thinking that I just wanted all of the struggles, all of the issues, all of it to be over. I wanted to be well again, to be made whole.

Lo and behold, I was about to get my wish.

I just had to stop breathing.

At first, I did not realize what was going on. But I was laying there, and I was with what I later determined to be an angel (it could've been Jesus, but I think it was an angel). He was giving me the choice to be made whole again, but I had to stop breathing in order to do so.

I actually remember my breaths getting shallower and shallower – then I realized what was going on.

I realized that if I stopped breathing, all would be well as I would get to go to heaven.

I also realized that now was the time to decide if I could do this – and wanted to do this – to stay and not go to heaven at that time.

And I decided, "I can do this."

And that was it.

I know that seems anti-climactic, but that's what happened. And how do my breaths get shallower on a ventilator? The double pneumonia was winning. I later learned that doctors told my parents that they were not sure I would make it. That coincided with what I experienced.

One of my aforementioned Quad Squad friends who is no longer with us, Wendell was also given a similar choice. He told me he was driving to work early one morning and was hit by a drunk driver. He actually had an out of body experience (which many near-death experiencers report) at the scene of his accident, where an angel gave him the choice to stay and be paralyzed from the chest down, or to go to heaven. Wendell had a young son at the time, and he chose to stay for him.

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I know that reading my account of what I call my near-death experience is not the most compelling story you have ever read. But if I could convey how real it was to me, you would understand why it cemented my faith. Reading "Imagine Heaven" further affirms what I already believed: that heaven is absolutely real. That means that John 3:16, God, and his son Jesus are absolutely real.

But I became a Christian and chose to have faith before my injury.

Hebrews 11:1 defines faith as "confidence in what we hope for and assurance about what we do not see." Pre-injury, my faith was based largely on what I witnessed from people I respected and regarded as both intelligent and educated on biblical matters – the clearly evident, wholehearted conviction with which they spoke.

I also liked the logic of having nothing to lose and heaven to gain. I mean, if Christians are wrong and there is no afterlife, then I guess our physical bodies simply die. And that's it.

But if we are correct in our choice to believe in God, Jesus, and the afterlife, then we have heaven to gain. And I would not want to be on the wrong side of that choice, because some people reported that hell is real with their near-death experiences. I don't know. I'm just sharing what I read.

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My faith is also the basis of my "no worries" philosophy.

It is difficult to relax, to enjoy life, and to be happy if you are actively worrying about something.

Please understand, I am human, and at times I feel quite vulnerable, since I am completely reliant on others for all of my physical needs, and reliant on a machine to breathe. But I have learned that it does no good to worry (unless you like ulcers). Instead I turn my concerns over to God, and let Him handle them.

I identify with a meme I saw in my Facebook newsfeed from a page called God Seekers, which compared worry to prayer like this:

"Worry is a conversation you have with yourself about things you cannot change.

Prayer is a conversation you have with God about things He can change."

Saying a prayer and turning it over to God allows me to exhale and alleviate the tension in my neck and shoulders that seemingly builds up without my knowledge. (Interestingly, I can tilt my head slightly away from each shoulder, and it feels like I alleviate the tension in my neck and opposing shoulder when doing so.)

Candidly, I became a germophobe post-injury. Being on a ventilator, having a trach, having a G-tube, and having an indwelling catheter – and NOT being in control of my own hygiene – all of that has made me more aware of germs, and my desire to avoid them.

"Bill, you have an immune system, and it needs to fight off a germ once in a while" says my dad, after one of my frequent inquiries asking if he sanitized (his hands).

It's hard for me to shut off the germophobe voice in my head, wondering what someone touched before doing something with me.

I can and do tell myself, "shut up, Bill. Good Lord willing, you will live, and if not – you get to go to heaven!"

There is that eternal perspective again. (Smile.)

Seriously, when the germophobe in me wants to worry about something, I will say a quick prayer and turn it over to God. But that's also true of everything that is beyond my control.

On a related note, when I was speaking with the homeless adults at Anthony House, I shared several different healthy perspectives, in hopes that one or more would resonate with them. One that I shared was the serenity prayer, which is used by the Alcoholics Anonymous program, and is:

"God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference." Amen.

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BibleGateway.com is a website with lots of free reading plans for the Bible. I like to do the annual plans beginning January 1 and either read the entire Bible or the New Testament over the course of the year. Even though I've been doing this for more than a decade, I don't come anywhere close to understanding every aspect of the Bible (which is okay; the Bible basically says we are not going to understand everything). Yet, since my schedule makes it difficult to attend in-person church services (even when there is no pandemic), I like to do a daily reading in order to feel closer to and pay my respects to God and Jesus.

I follow my daily Bible reading with my daily prayer. But I also say short little prayers throughout the day, such as, "Lord please let the catheter drain. In Jesus' name I pray, amen."

That might sound silly, but if the catheter is not draining, that can be a big deal. And that simple little prayer is how I turn the concern over to God, and not worry about it myself.

And God wants us to pray! (Smile.)

Philippians 4:6-7 says, "Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus."

The Bible literally has two sections titled: Do Not Worry – Luke 12:22-31 and Matthew 6:25-34 (NIV).

Here is part of the no worries Scripture, Matthew 6:25-27: "Therefore I tell you, do not worry about your life, what you will eat or drink; or about your body, what you will wear. Is not life more than food, and the body more than clothes? Look at the birds of the air; they do not sow or reap or store away in barns, and yet your heavenly Father feeds them. Are you not much more valuable than they? Can any one of you by worrying add a single hour to your life?"

Not to joke, but the year 2020 has been a challenging decade (yes, you read that right, and I know it's only August – but it feels like much longer!) and it is understandable and somewhat natural to have some anxiety about the world we are living in today, whether you are paralyzed or not.

If you are prone to having anxiety, and I have had some myself (in the section on My Care, I will write about two things that have helped me, one pharmaceutical and one natural remedy) but 1 Peter 5:6-7 offers spiritual medicine:

"Humble yourselves, therefore, under God’s mighty hand, that he may lift you up in due time. Cast all your anxiety on him because he cares for you."

How amazing is it that the God who created heaven and earth – that He cares for you?! (Smile.)

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Before I begin talking about love – more specifically about romantic relationships and paralysis – I want to wind down this section on my faith by sharing one more of my favorite pieces of Scripture.

In challenging times such as these, and in life in general, Philippians 4:12-13 (NIV) gives me comfort – and a healthy perspective:

"I know what it is to be in need, and I know what it is to have plenty. I have learned the secret of being content in any and every situation, whether well fed or hungry, whether living in plenty or in want. I can do everything through him who gives me strength."

That last sentence, Philippians 4:13, is quite popular among Christians. It's a reminder that we can do all things with the help of Jesus, who gives us strength. And that passage as a whole basically says that you can be content in any circumstance if you have Jesus.

That is Scripture supporting the notion of having an eternal perspective.

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With every fiber of my being, I urge you to read "Imagine Heaven" – especially if you do not currently think the afterlife is real. Seriously.

If at some point you want to accept the gift of heaven that God and his son Jesus graciously offer, I conclude this section with the simple process to become a Christian.

Romans 10:10 NIV, "For it is with your heart that you believe and are justified, and it is with your mouth that you profess your faith and are saved."

I'm not a pastor, but I believe that all you have to do is say that you want to repent of your sins (none of us are perfect; we all make mistakes and sin) and accept Jesus Christ into your heart as your Lord and Savior. In doing so, you acknowledge that Jesus is the son of God in human form, and that he paid the price for our sins by dying on the cross. Further, he conquered death by rising on the third day (on Easter Sunday) and appeared to his disciples several times before ascending to heaven.

That's it! That simple process takes the fear out of dying and saves your soul, reserving a GLORIOUS place for you in HEAVEN! (ETERNALLY BIG SMILE.)

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After becoming paralyzed, people – especially quadriplegics – may wonder if they are capable of being in a romantic relationship, i.e. finding love, or staying in an existing relationship.

I was one who wondered, but the answer is a resounding yes.

That doesn't mean it's easy. Then again, having a fulfilling, nurturing, long-lasting romantic relationship generally is not easy, even for able-bodied folks. Right?

I was never much interested in simply dating, and that became even more accurate to describe my mindset post-injury. I was only interested in dating someone I could see as a potential life partner, i.e. a spouse (for me, a wife, as I am 100% heterosexual).

Candidly, I believe it's more about finding the right person who wants to merge their journey with yours, and "do life" with you – and vice versa.

Before I elaborate, please know that I am not trying to judge anyone else's relationship, but to state that this is my mindset, and how I think about relationships – especially given that I am paralyzed, and because paralysis makes having a successful relationship more challenging.

With that disclaimer, I used the term "romantic relationship" simply to denote the type of love or relationship that I was referring to, but from observation, it's pretty clear that the actual romance portion is not necessarily a (daily) constant. What is constant, or what I think couples should focus on, is living on a daily basis with each other, whatever the day may bring. Finding someone who enjoys day-to-day life with you, who wants to "do life" with you, whatever it entails… someone you want to wake up to and see everyday, especially if seeing that person makes your heart skip a beat… that's a potential life partner.

Doing life together on a daily basis should strengthen the bond of love, in the big picture (acknowledging that life, and days, may have challenges that can be relationship stressors, but handling them together should strengthen the bond).

I also believe that communication is the key to all relationships, from business to personal. Good communication builds trust. Trust is the foundation for a healthy relationship, and it comes from open, honest, frequent, good communication – especially with romantic relationships involving paralysis. Life partners should be comfortable sharing their fears, hopes, and dreams with each other, and want to merge the latter two as best as possible into their life together. You should be each other's biggest fans, and should enjoy talking with each other – about anything and even about nothing.

Additionally, I believe that couples in great marriages generally "work" to keep the romance alive. They continue to date each other – even after getting married, even after having kids, even while raising kids, and beyond.

Granted, stating all of the above sets the bar pretty high for finding a potential spouse, but why not at least start with knowing what makes a good (or great) relationship?

Of course this is all just my opinion, i.e. things I have observed, and at least in part, things I've experienced.

Notice I have not talked about sex yet. Of course that can be a significant part of such a relationship, but it should not be the foundation upon which the relationship is built (whether paralysis is involved or not).

Yes, I think there needs to be physical attraction, but ideally, there needs to be a superstrong connection. People age and looks fade. But liking the qualities your spouse has and the person that he/she is… preferably coupling that with an emotionally intimate and hopefully profound connection you have… all of that can last, and can grow even stronger. Many of the best relationships that I have observed are where people consider their spouse to be their best friend. That's not always true, but married couples should not grow weary of spending time together (although it's okay to need some space also).

I am kind of shooting from the hip here, just talking about things that I think the best relationships have (okay, technically I am shooting from the lip as I dictate this to my computer!).

Notice that I have not written anything that precludes a person with paralysis from being in such a relationship. But we cannot ignore the fact that paralysis does add challenges. The challenges are navigable, but not negligible.

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A paralyzing injury has to be one of the most challenging ways to test marital vows, especially at the quadriplegic level.

But I know of couples who have encountered that reality, and adapted. I also know of some marriages that were not able to survive. I write that with no judgment whatsoever, and I am actually glad that I was single at the time of my injury, so as not to have my girlfriend or wife face such a situation. Paralyzing injuries are – at least initially – devastating, and they impact more than just the paralyzed person. Entire families are impacted – spouses and parents often bear the brunt (in addition to their paralyzed loved one).

I think it is probably easier and potentially better to "find love" post-injury, when there is no previous history as an able-bodied couple. If "all you know" is the person post-injury, then the partner does not have to grieve the loss of the way things were. Also, the partner would be choosing to join the relationship with knowledge of the paralysis, and its associated challenges, rather than having paralysis thrust itself into the relationship like an enormously unwanted third wheel.

I still say communication is the most vital aspect. Whether it's a new relationship or an existing relationship, excellent communication will be needed for the relationship to survive, and ideally thrive.

I was in a relationship that thrived for about three years; we were engaged for about half of that time.

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Lisa was working as a occupational therapist assistant in the Ohio school system, and was looking for new activities for students who used wheelchairs. She found the IKAN Bowler® and my website. She sent me an email in February 2011, and I was smart enough to respond. (Smile.)

After several months with a ton of communication, including by video, Lisa was courageous enough to drive a thousand miles for us to meet in person. After we became an official couple, she would fly down during Christmas breaks, spring breaks, and during the summers when school was out.

Lisa said that the positives that I brought to the relationship far outweighed the negatives associated with my paralysis. She proved to me that I was (and am) still capable of being in a romantic relationship, and actually, my paralysis bothered me more than it bothered her. Ultimately, distance is the reason our relationship ended. She was heavily entrenched with her family and roots in Ohio, and – understandably – was apprehensive about leaving that stability for a relatively uncertain future with me and my family, so far away from her family.

Ending our engagement/relationship was not something Lisa did carelessly, or easily. I completely understand why and do not begrudge her for anything. I also remain grateful for what were three pretty excellent years together, and all that we shared. She proved to me that I am not only capable, but also worthy of being in a romantic relationship.

But my relationship status is single – and not looking!

And I am COMPLETELY okay with that! (Smile.)

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Candidly, it bothered me that Lisa had to physically put forth so much effort in terms of travel, and well, everything. Of course, she had to learn aspects of my care, so that we did not always need to have a caregiver around.

But chivalry is not dead. However, I feel like my ability to be chivalrous was largely paralyzed.

I wanted to be the one to put forth the extra effort. Thankfully, I was able to excel in terms of communication and giving her time and attention, and I was/am even capable "romantically" (I'll just leave it at that).

But it bothered me that I could not do little things like take her car and fill it up with gas. Or if we had a dog, I would not be able to get out of bed and go walk it in the middle of the night. If there was a bug or spider, she would have to dispose of it. I also wouldn't be able to take out the garbage, or cut the grass. I couldn't make dinner or do the dishes. (I think couples should share those tasks.) I could not walk up behind her, kiss the side of her neck, and give her a big hug. (I have learned to hug people by having them lean their head into the side of my head, and I can push/hug back, which isn't bad, but it's not the same.)

Yes, I could help by doing things like planning out meals, having dinner delivered on occasion, and hiring a lawn care service.

And, sure, I could plan nice dates for us, but spontaneity was largely gone.

As I will detail in the My Care section of this book, quadriplegics benefit from care routines, and going to bed and getting out of bed both generally take about two hours or more for me (we do a lengthy breathing treatment with both). Further, if I am going to stay overnight away from home, we have to pack up seemingly half of my bedroom and take it with us.

None of that makes dating impossible. But all of that, and more, would bother me.

However – none of that actually bothers me – because I am not in a relationship! (Smile.)

One more thing, while we do have a good track record for managing my care and health (thank the Lord) I also would not want to make someone a widow at a young age. Obviously, I have no idea how much time I have left on this earth before getting to go to heaven, but being injured at age 20… if I live to age 60… that is a whopping 40 years of being a quadriplegic on a ventilator. I'm not saying it's impossible, but living FORTY YEARS in this condition sounds like a monumental feat, and I would be surprised if something doesn't get me before then (I am writing this while self-quarantined due to the COVID-19 pandemic).

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But, please, if you desire to be in a relationship, please do not let my single-and-content perspective keep you from pursuing what you want.

If that's what you want, I will offer my opinion that a person would be wise to work on "getting their life together" or "building the best life you can for yourself" before seeking someone to join you on your journey, or with whom to merge journeys. If you have a life and direction someone else can see, it's easier for them to share your vision, and potentially see herself/himself with you. I think that's extra important for people with disabilities, whose future seems to be generally more uncertain than our able-bodied counterparts.

I say "able-bodied counterparts" because, of course, I am wanting my book to be helpful for paralyzed people. But I also want it to be helpful for anyone who has seemingly or legitimately difficult challenges.

I believe we all have challenges. Some challenges, like paralysis, are more visible than others. But things like mental illness can be invisible, and yet a legitimately difficult challenge. So be kind, because you never know what someone else is dealing with.

The bottom line is that I think we all want to be happy, and lead happy lives.

If you took a survey of parents all over the world, and asked them what they want for their children in life, I bet some form of "for them to be happy" would be included in nearly every response.

I want everyone to be happy. Thankfully, I believe it is a choice we can all make.

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One of the quotes that I shared with homeless adults at Anthony House, was this from our first First Lady:

"I am still determined to be cheerful and happy, in whatever situation I may be; for I have also learned from experience that the greater part of our happiness or misery depends upon our dispositions, and not upon our circumstances."

— Martha Washington (1731-1802)

One circumstance that I know she endured was living her entire life – 70 years – without air conditioning!

Not to joke, but many of us would be hard-pressed to be cheerful and happy without air conditioning.

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Some people journey through life thinking, "I will be happy when… I graduate from college… when I get married… when we have kids… when the kids are grown and out of the house… when I retire…" – STOP! (Smile.)

Being happy is choosing to enjoy the journey on a daily basis, not waiting for the milestones.

Sure, some days are more fun and exciting than others, and of course the milestones have extra significance. But today is the ONLY day that we ever, actually, get to live.

Think about that.

If you want to enjoy life, today is the day to be happy.

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Do you know what is THE ONE THING in this world that we can always control?

I'm writing this sentence so that you do not immediately see the answer, but at least ponder that question for a moment.

It's our attitude. We can choose to be positive or negative in any situation.

"There is little difference in people, but that little difference makes a big difference. The little difference is attitude. The big difference is whether it is positive or negative."

– W. Clement Stone (1902-2002; Businessmen, Philanthropist, and Self-Help Book Author)

I try to be positive, and I generally am. Before my injury, I learned that being negative is simply no fun. Being around negative people is no fun. Who would want to be a caregiver for me if I was bitter and negative? And not that I am trying, but I certainly could not attract a potential future spouse if I had a negative attitude.

I believe that – despite any challenges we may face – there are positives in every day that we can choose to acknowledge and to be happy about. Whether you are a believer or not, we can all recognize the positives (what I call blessings) and be thankful for the good things in our lives.

Part of seeing the positives is having a healthy perspective. Even though I am paralyzed from my neck down and breathing with the help of a machine, I wholeheartedly believe that there are always other people in this world dealing with something more difficult. I am trying to show that – for me – I no longer think being paralyzed from the neck down and ventilator dependent is that big of a deal. I mean, it is, but at the same time, I am genuinely comfortable, content, and happy with my life.

But yes, I fully acknowledge that the concept of being being paralyzed from the neck down and requiring mechanical ventilation to breathe would rightly be considered legitimately difficult circumstances under which to live.

So think about this: I am a similar age and injury level to a man named Khaldoon Sinjab. I've been Facebook friends with him for quite a few years. We have both been paralyzed from the neck down and ventilator dependent for more than two decades. But he grew up and incurred his injury in Syria. He had to flee Syria because of the war. He has lived in multiple Middle Eastern countries, and currently lives in United Arab Emirates, where he is thankful that the electricity is reliable.

Imagine being dependent on a ventilator – and living in a country where the electricity is not reliable! (Yes, ventilators usually have internal and external batteries, but still, electricity is critical.)

And yet, Khaldoon is married, has had three children with his wife post-injury, and works as a freelance IT professional.

True story. And you should see the smile on his face in pictures and videos with his family! (Smile.)

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Aside from choosing to be positive, and choosing to see the daily positives (the blessings) we have in life, it is easier to feel happy if we have something to look forward to.

I am almost reluctant to share this anecdote, but it really resonated with me.

Jerry Seinfeld has a show called "Comedians in Cars Getting Coffee" which I watched online several years ago. On each episode, Jerry invites a fellow comedian to take a ride with him in a classic car to go get a cup of coffee, and they share stories along the way.

One episode was with his Seinfeld costar, Julia Louis Dreyfus. During their conversation, Julia mentioned that her mom said that (paraphrase) "people need something to look forward to" in order to be or feel happy. I think she said, big or small, it doesn't matter, but people need something to look forward to.

That really resonated with me, partly because these were two highly successful, multimillionaires who could literally choose to do anything in the world. And they essentially agreed with that profound nugget dropped by Julia's mom.

I look forward to lots of things.

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Becoming paralyzed literally slows life down and puts things in perspective. I mean, paralyzed people can still lead full, active lives – and I know some who are extremely active – but at the very least, getting ready for each day is a much slower process than when we were able-bodied. And having to remain seated instead of rising to our full height as we head out, that yields a different viewpoint and perspective – literally and figuratively.

Ultimately, being paralyzed leads to a greater appreciation for what most people call the little things in life.

On a daily basis, I look forward to getting in my chair. I've heard that some wheelchair users have disdain for their wheelchairs, resenting the fact that they need to use one. Not me! My wheelchair is essentially my legs; it represents freedom and the ability to get out of bed and do something.

One big issue newly injured people face is about accepting their injury or not. Many people are working their tails off doing physical therapy to try to promote recovery. And I wholeheartedly applaud and encourage them to do so. Some of them do it because they don't want to accept the prognosis of their current condition as being permanent. And there is absolutely nothing wrong with that.

I do not know what the future holds, or how long it will take for science to progress to the point that legitimate, low risk therapies restore function in paralyzed people with chronic spinal cord injuries.

But I do know that every day that I wake up unable to move my arms and legs, I can accept that as my current reality. It may not be true in the future, but if I wake up paralyzed, then bring in the wheelchair, and let's do something!

I came home from Shepherd Center on November 24, 1997. For nearly 22 years, I got out of bed EVERY SINGLE DAY – even if my wheelchair was broken (on the rare times that it was, I would get on my tilt table, or "hang out" in my sling from our ceiling lift).

My getting-out-of-bed streak came to an end on September 12, 2019, as I was dealing with some full-body swelling that would lead to my fourth hospitalization and a major surgery that I did not know I needed (more on that in the My Care section as well). But I am sharing about my streak as evidence that I look forward to getting out of bed each day.

I look forward to going outside and getting fresh air, even if I am just staying around our house. Being outside and feeling sunshine, and looking at a high blue sky, seeing the world God created… all of that helps to mentally refresh me and perk me up, whether I think I need a boost or not.

I look forward to eating two meals a day. In the My Care section, I will share what I often eat, and how I maintain a healthy weight despite not being able to exercise (some paralyzed people exercise using equipment powered by electrical stimulation of their muscles, like an e-stim bicycle, but I was told I could not do e-stim because of my pacemaker).

Not only do I look forward to eating two meals per day (my stepmom Donna and my aunt Barbara do a good job of providing dinners I like and some variety) but also I enjoy looking up restaurants, checking out their menus, reviews and pictures of their food, and planning occasional treat meals (to enjoy either in person or to go).

I look forward to watching sports, in person or on TV. Going to sporting events in person is something we occasionally plan, but watching them in high definition nowadays is often a better viewing experience (maybe not better overall experience, but better viewing). Among other sports, I enjoy watching college and professional baseball, football, basketball, and almost anything my Florida Gators play.

Occasionally, I look forward to watching some movies and TV shows, or reading a particular book.

When there is no pandemic, I look forward to going bowling regularly with my Quad Squad friends.

I always look forward to seeing family and friends, especially on special occasions – and we should probably think of every occasion as special. You never know when it might be the last time you see each other.

When possible, I look forward to planning some type of travel or vacation. One good thing about planning a trip well in advance, is having lots of time to look forward to it.

But that is generally true of a short local trip to visit with a friend or family member also, i.e. I look forward to doing that on occasion.

On a daily basis, I look forward to getting on my computer, checking my email for something good, and checking out what is happening in sports and on social media. Granted, social media can be draining, especially when it's election season (like now) but Facebook is a good way to keep up with friends and family and get glimpses into their lives without having to leave home.

So far, most of the things that I've mentioned looking forward to would be considered for enjoyment or entertainment.

When you are paralyzed – or even if you are not – learning to enjoy the day is important, however you do it.

But my primary care physician, the one who encouraged me to write this book, he came to the conclusion that in order to lead truly fulfilling lives, people need to "impart meaning" into their life, and into the lives of others.

I thought that was pretty profound. And thankfully, both can be accomplished by helping others.

I look forward to helping people; that's how I impart meaning into my life, and into the lives of others.

* * * * *

Here are a few more ideas about how to live a successful life:

What is Success?
by Ralph Waldo Emerson

To laugh often and love much;
To win the respect of intelligent persons and the affection of children;
To earn the esteem of honest critics and endure the betrayal of false friends;
To appreciate beauty;
To find the best in others;
To give of one's self without the slightest thought of return;
To leave the world a better place, whether by a healthy child, a rescued soul, a garden patch or a redeemed social condition;
To have played and laughed with enthusiasm and sung with exaltation;
To know that even one life has breathed easier because you have lived;
This is to have succeeded.

We don't have to check off all of those, but I think the more we can check off, the more fulfilling our lives will be.

* * * * *

Personally, it makes me feel good to help people, or at least to try.

I believe we can all help other people, even if it is simply by smiling or being kind. Sharing a smile or kindness costs us nothing, and is something even people paralyzed from the neck down can do.

I know people who are hearing impaired, but the majority of us have the ability to listen. Sometimes listening to someone open up about a problem, that simple act can be helpful (hint: ask someone how they are doing, and take a genuine interest in their answer). A lot of people have a tendency to want to try to offer a solution (I am guilty of that) but I have learned that "acknowledgment makes things better" even if there isn't necessarily a good solution. Listening and acknowledging the person's experience can make it a little easier for them to deal with. We are all human. We all have challenges. Our challenges are generally different, but it's all relative.

Those are simple ways we can all help. Those are couple of things I try to do when given the opportunity. Sometimes Facebook affords such an opportunity. Sometimes people ask for prayers. I can pray! That is another way I can help. (If you are or become a believer, you can too.)

I also help worthy causes with daily donations – which only costs a little of my time.

For more than 20 years, the GreaterGood family of websites has helped a variety of charitable causes with sponsors (advertisers) paying for visitors to "click to give" – which is free to the visitor. Currently, going to GreaterGood.com will allow you to help at least 10 worthy endeavors for the time it takes you to visit and click each one respectively (they make it easy; click one, and you'll see which ones remain for you to click).

That is another simple way almost all of us can help, and is something I look forward to (or feel good about) doing every day.

Those are simple little ways that we can impart meaning into our lives, and into the lives of others.

I don't think I had the wherewithal to do this when I was initially injured, but the more recent times that I have been hospitalized, I have tried to take an interest in all the people coming in to help me. I try to learn their names, and ask "how long have you been doing this" job. They are human beings performing services to help you, not robots going from room to room. It seems like I always get good care, and I think it is due in part because I try to be kind and treat people like people. Their jobs can be stressful and demanding. Trying to show some appreciation and understanding, i.e. being kind can help.

That's true in other areas of life as well, with other people providing services. Think about it. How many teachers are in it for the money? I would say close to zero, as the pay is generally not reflective of all that teachers do, especially the ones who truly put their heart into trying to help educate children (and adults).

I also impart meaning into my life by working as a teaching assistant. What I like most about doing so is twofold: lightening the load of the hard-working professors I assist, and of course helping the students.

Have you noticed a theme? I like the notion of people helping people, and being kind. Another way to put it, "love your neighbor as yourself" which brings me full circle to the beginning of this chapter. (Smile.)

* * * * *

At the beginning of this chapter, I mentioned my belief that faith, love, and happiness are all related.

They certainly can be.

As I wrote previously, we can all choose to have faith, and look forward to going to heaven.

We can all choose to be thankful and love God, and love our neighbors as ourselves.

And we can all choose to be happy… today and each day we are given.

This Scripture from 1 John 4 (NIV) sums it up for me:

7 Dear friends, let us love one another, for love comes from God. Everyone who loves has been born of God and knows God. 8 Whoever does not love does not know God, because God is love. 9 This is how God showed his love among us: He sent his one and only Son into the world that we might live through him. 10 This is love: not that we loved God, but that he loved us and sent his Son as an atoning sacrifice for our sins. 11 Dear friends, since God so loved us, we also ought to love one another. 12 No one has ever seen God; but if we love one another, God lives in us and his love is made complete in us.

* * * * *

I have an addendum on the next page, but above is how I want to conclude this chapter on Faith, Love, and Happiness – which also finishes the "My Story" portion of my book.

I find it interesting that, aside from minor editing, I finished writing this section on August 23, 2020 – the 23rd anniversary of my injury.

CHAPTER ADDENDUM: An Off-the-Radar Way to Impart Meaning

For any responsible, capable adult with available time… if you want to do something meaningful… might you consider helping someone with a disability like me, or my friends?

A few ideas:
- Take a meal to a neighbor who is unable to cook
- Mow the grass for a little old lady who lives alone
- Clear a driveway or sidewalk of snow for a wheelchair user
- Consider being a part-time caregiver

The thought of being a part-time caregiver is not on most people's radar as a possibility, but it can be an excellent way to add fulfillment to one's life by making a difference in someone else's.

It can be a great part-time job for an empty nester, or a young retiree, or even a college student.

The reason I listed those first two is because people nearing "middle-age" or even "older" adults are generally ideal because they are likely past child raising (and thus do not have young children at home who of course must be priority number one).

Besides family members, my best caregivers have been people with no medical background, but are conscientious, capable adults with good character, a willingness to learn and desire to help.

We actually prefer potential caregivers to have no medical background, so we can train them in my care from a clean slate.

Formally, private duty caregiving is sometimes called being a PCA – Personal Care Attendant (or Assistant). In some situations, formal training may be required, but most important is having the heart to want to help, and the time and ability to do so.

* * * * *

Acts 20:35 NIV, "Jesus himself said: 'It is more blessed to give than to receive.'"

My Care

The "My Care" portion is the second major section of my book.

TIPS FOR QUADRIPLEGIC LIFE

I am beginning the section on "My Care" with tips that could help other quadriplegics. One of my quadriplegic friends, Ian Mackay, said there's no need to "reinvent the wheel" when trying to figure out how to live your best life, post-injury. People in the spinal cord injury community have already found solutions to many common problems, and we can all learn from each other.

In that spirit, here are things that I have learned in the course of my care that may be helpful to others:

Projection Clock: when you can hardly move, it can be difficult to see a clock. Projection clocks "project" the time wherever they are aimed, i.e. on to the ceiling or a spot on the wall. This can be helpful in a dark hospital room or a dark bedroom. Not that I am advocating shopping at Amazon, but for reference, Amazon has multiple models available in the $15-$30 range.

U-Shaped Pillows: my head is almost always against either a pillow or my wheelchair's headrest. In bed, fluffy pillows usually rub my ears when I am on my back, and when I am turned on my side, it can be difficult for my ear to be comfortable against the pillow. The classic U-shaped travel pillow can help. When I am on my back, we squeeze the pillow together underneath my head with the open-end of the "U" pointed down (perhaps slightly tucked under my shoulders/back) which allows me to pretty easily turn my head a little side to side without rubbing my ears.

When I am on my side, I like the pillow in the same direction (pointed down) but with my ear in the middle, and the sides and top of the upside down U-shape supporting my head. When positioned well, it's comfortable and does not rub my ear. They can be purchased lots of places for under $20. Note that some have zippers on one side, which is not a problem if it's flipped over and away from one's head. I should add that another solution is wearing a stocking cap in bed. That can also protect ears from fluffy pillows.

Click to Alert Someone: I mentioned this in the chapter on my initial hospitalization, but in case a reader is just looking at these tips, having a way to get someone's attention is worth mentioning again. It seems many quadriplegics have a trach and a ventilator at least temporarily, during the initial recovery before weaning. As explained earlier, speech may not be possible at that time, so making a "clicking" noise with your tongue or cheek can be a way to signal a nurse or caregiver that you need something.

As for how to click, it might be easier to try to do without reading a description, but basically, keep your lips open and close your teeth (bite down but not hard) then press your tongue against the top of the back of your front teeth, and pull it away quickly. That's one way to make a noise that can alert someone. Doing something similar with your side teeth and cheek/lips open is louder. (If needed, I will do a demo video.)

UPDATE – Another Way to Alert Someone: since writing this chapter originally, I have learned to make a "bopping" noise, which seems to be more effective than the clicking noise. I close my mouth, then try to keep my lips sealed together as long as possible while opening my mouth. Doing so fairly quickly produces a "bop" sound, and doing so repeatedly, i.e. "bop-bop-bop-bop" is pretty discernible for anyone listening.

Sometimes the "click-click-click-click" noise that I described above is difficult to discern from the other noises in the room. But alternating "bop-bop-bop-bop-bop" and "click-click-click-click-click" is pretty effective at getting a caregiver's attention, especially if I follow up one set of both with another set.

Convex Mirrors: I have two of these large, round mirrors mounted on the ceiling above my bed, and another on the wall in front of me in my computer room. The two over my bed allow me to watch and instruct caregivers, and thus are good for training, but also it is simply more interesting to look in the mirrors and be able to see myself in bed, and also see much of my bedroom. I have one mounted in my computer room so that people cannot sneak up behind me. (Smile.) For reference, Amazon has quite a few convex mirror options from $10-$100.

Prevent Foot Drop and Toe Redness: a key training point in rehab is to keep skin in good condition by placing pillows and such to alleviate pressure from bony prominences, like one's elbows and heels. When I am on my back, I have a contoured pillow that goes underneath my calves, which my feet "hang over" (so my heels are above the mattress). I'm guessing that is commonly taught, BUT what is not commonly taught is that we stack two normal (or thick) bed pillows in between my feet, long ways (the longer side of the pillow goes up towards my calves).

By stacking two of them on top of each other, and partly on the mattress and contoured pillow, this gives the stacked pillows enough height that they are above my toes, and a blanket can go on top and rest more on the pillows than on my toes. Pushing my heels together slightly allows the top pillow in particular to help keep my feet upright, and turned slightly outward. Otherwise, my feet have a tendency to want to turn in (i.e. be pigeon toed) which is good to prevent.

Spray Bottle for Cooling Off: most quadriplegics do not sweat, so being outdoors in the heat for prolonged periods can be dangerous. About 20 years ago, we went to a college football game in Central Florida in January. It was USA All-Stars versus State of Florida All-Stars. But it was sunny and unseasonably hot that afternoon (probably in the low 80s) and the accessible seating section gave a good view of the action, but had no shade.

Thankfully, I think it was Pandora who advised us to keep a plastic spray bottle in my van that we could fill with water and spray exposed skin, as well as clothing, to help keep cool. My dad went up and down the row of wheelchair users spraying anyone who wanted it. One quadriplegic was dressed in black clothing and felt like he was roasting (he may have been, literally) and he was so thankful that my dad kept coming to help cool him down.

G-tube: even if you learn to eat a normal diet by mouth again, consider keeping your G-tube (if you have one post-injury). When I began eating again, I wanted to get rid of my G-tube so that my body would be "more normal" but Pandora convinced me to keep it for six months before making that decision. It turns out, that the G-tube is great for getting water and meds while I sleep (I don't have to wake up) and it is also handy for taking medications that I don't want to swallow, either because it tastes gross, or I have trouble swallowing (like large pills). In hindsight, I am quite glad I have kept my G-tube. I buy replacement tubes for under $30 and we replace them at home roughly every three months.

Ambu Bag: even if you are not on a ventilator, I recommend quadriplegics have an ambu bag (also called a BVM – bag valve mask). Before the coronavirus pandemic, you could buy an ambu bag for under $20, and it could help a quadriplegic eliminate some chest congestion. Even quads who are able to wean off of the ventilator, generally their ability to cough remains pretty weak, so getting chest congestion can lead to pneumonia fairly quickly if you are unable to get it out. Plus, frequent coughing for a quadriplegic can be tiring, and the ambu bag can give the person a break, as well as a really large breath of air that can be used to help cough up the secretions. As of August 2020, you can still get one for $20 on Amazon.

Quad Cough: that is something folks should learn in rehab, ideally. There are multiple ways to do it. It's almost like doing the Heimlich maneuver, but instead of dislodging food, the goal is to expel secretions. Rather than try to explain it well in words, I think it would be better to do a quick Internet or YouTube search for "quad cough" to see examples, and how to do it properly. It can work in conjunction with the ambu bag to help someone eliminate secretions.

Pulse Ox: I talked about using a pulse oximeter to check my oxygen saturation levels during breathing tests in the chapter on Home. Even if you are not on a ventilator, you might want to be able to check your oxygen level, which could alert you to a problem if it is several points lower than your normal readings. I like to check mine daily. When COVID-19 first hit, it was hard to find the fingertip pulse ox devices, but now Amazon has many available for under $25. I think it is good to check daily; it might help keep pneumonia from sneaking up on you.

Blood-Pressure Cuff: per the discussion on autonomic dysreflexia in my chapter on Home, every quadriplegic should have a blood pressure cuff. I have two that I like. Upper arm cuffs are more accurate than wrist cuffs, but I have one of each (we use the wrist cuff for a quick check, if I am curious as to what my BP is, but use the upper arm cuff if I am experiencing AD and want the most accurate reading). There are some highly rated upper arm cuffs available on Amazon currently from $28-$39. They also have highly rated wrist cuffs for under $30.

Medical Tape Dispenser: if you use medical tape regularly, this is nice to have. We change my G-tube dressing once per day, and finish it by taping down two sides of a 4x4 split drain sponge (taping it down is not truly necessary, but it does keep it in place). But if you do a search for "medical tape dispenser" you might be surprised at the options, or lack thereof.

Long story short, I found a heavy duty, desktop tape dispenser with a nonskid base that fits 1 inch and 3 inch cores. More importantly, it's also wide enough to accommodate 1 inch wide tape, and heavy enough (3.1 pounds) to not slide when pulling the tape with one hand. My dad likes it so much (compared to not having an easy-to-use dispenser) that he suggested I include it with these tips. The one we have is currently $12.99 on Amazon. Since it's relatively heavy, we leave it where it's easily accessed on top of the "nightstand" next to my bed (it's actually an old filing cabinet we use for storage).

Medical Tape: there are many types to choose from, and to each their own, but we like a hypoallergenic paper tape, specifically Micropore Surgical Tape by 3M (reference number 1530). I generally buy a box of 12 rolls for $6-$10 (with 10 yards of tape per roll). That lasts quite a while.

Rounded Tip Scissors: we don't use them to cut the above tape (thanks to the aforementioned dispenser) but if you ever need to cut off a bandage, or maybe even clothing, these are safer than traditional pointy scissors. We quadriplegics are always needing to prevent skin issues, so using rounded tip scissors can keep even the best caregivers from accidentally causing a flesh wound. Lots of buying options exist for under $8.

Sonicare Toothbrush: my dentist said that people who cannot brush their own teeth often have significant dental issues. So he was pleasantly surprised to see my teeth in good shape overall (I think I have had three or four total cavities in more than two decades of not being able to brush my teeth). And that might be more impressive, considering my teeth get brushed generally once per day. I am certain that my Sonicare toothbrush is a large reason for the lack of issues. I've talked with multiple dental hygienists, and at least one dentist, and all have good things to say about Sonicare toothbrushes.

They also recommend Oral-B electric toothbrushes, but I have not tried an Oral-B and see no reason to, since my teeth feel so clean and polished after using my Sonicare. But right now, there are highly rated versions of both Sonicare and Oral-B rechargeable toothbrushes between $25 and $50.

Camelbak: some quadriplegics have enough arm function to lift an "adaptive" water bottle, for lack of a better term. I like to use a Camelbak drinking system, the same type that bicyclists, hikers, and military personnel use. My quad friend Rhonda gave me my first Camelbak. We both use sip-and-puff controlled wheelchairs, and the sip-and-puff gives us a place to attach the Camelbak hose (using small cable ties). That allows us to take a drink as often as we want without bothering a caregiver. It also allows me to "rinse" my mouth well after eating something sugary, or chewing a vitamin C (which is ascorbic acid). I like to rinse my mouth three times after having something like that, which probably contributes to the health of my teeth (in addition to the Sonicare mentioned above).

Incidentally, since all we ever put in my Camelbak is water, it generally stays clean for several weeks. We clean mine every two weeks. Generic Efferdent tablets (normally used for cleaning dentures) clean it well.

Plastic-Less Disposable Straws: flexible drinking straws can be a necessity for a quadriplegic. Thankfully, there are eco-friendly, 100% plant-based compostable straws that work well at a reasonable price. I usually buy boxes of 200 for $9.99 at smile.amazon.com (which is identical to Amazon.com, but with a small portion going to charity). I also have some reusable silicone straws, but it can be difficult to determine if they are clean on the inside. That's why I like the plastic-less disposable straws. We keep some on my chair for dining away from home (but I also have my Camelbak filled with water).

Tervis Mugs: my favorite drinking vessel is a 16 ounce, insulated, BPA-free plastic mug with a handle. Being lightweight, dishwasher safe, and having a handle make it caregiver friendly. It's also the perfect size for the aforementioned plastic-less straws, and the mugs have a lifetime guarantee. Depending on whether you want a plain one or a fancy one, they are generally $10-$20. You can get your favorite sports team's logo or other emblems if you wish.

Stocking Cap and Headphones: I am generally cold, so even in my 77° or 78° computer room, I wear a stocking cap and a blanket, along with a longsleeve shirt and long pants as I sit in my wheelchair, working (or having fun) on my computer overnight (doing weightshifts roughly every 30 minutes). Wearing a stocking cap when cold is not exactly a novel idea, but combining it with lightweight headphones is a good tip. More specifically, I have lightweight Panasonic RP-HT21 headphones that we "tuck" into the flap of my Carhartt A20 stocking caps.

The headphones are light enough that they will stay in place even when I tilt and recline, and having one layer of stocking cap between them and my ears makes them comfortable enough to wear for sometimes eight hours (I like to listen to music, and sometimes I will watch a show also). I gave specific product numbers because those Panasonic headphones are the lightest I have found – and are surprisingly good – for less than $10! One can last years; we replace them when the little foam speaker covering is worn out. And the Carhartt A20 stocking caps are my "everyday" favorite stocking caps (they are comfortable, durable, and generally $15 or less).

The Most Practical Haircut: if you are unable to shower (I get a bed bath) then the easiest hair "style" to maintain – and keep clean – is a buzz-style haircut. I also contend that it looks good, whether you have a full head of hair or male pattern baldness (like me). Yes, I wear a stocking cap most of the time anyway, but I still would embrace a short buzz cut regardless. We wash my hair quickly and easily with a few washcloths. No combing or brushing required AND it allows caregivers to check for skin issues (there can be pressure sore-type issues when your head is against a pillow or headrest nearly 24/7). But I also acknowledge that maybe having extra hair might help prevent pressure issues.

I also call it the most practical because pretty much anyone can cut it in a home setting. It's also a great value, as you can get several years of haircuts for the one-time cost of the hair clippers (generally $20-$40). Lastly, I think a short buzz cut is a very confident-looking haircut – and can even look good on women. Just rock it.

Sip-And-Puff Logic: if you need a power wheelchair, and do not have enough arm ability to use a hand joystick, then I believe your primary options are: chin control, head array control, and sip-and-puff control. Admittedly, I have never tried either of the first two, but I like my sip-and-puff because it also gives me a place to attach my Camelbak drinking tube, and my microphone for my computer. With my limited neck range of motion, I need my Camelbak right in front of my mouth. People should also know that the amount of breath required to initiate hard and soft sips and puffs can be precisely calibrated for its user.

Pull-Up or Slide down for Better Posture: in the early days after coming home, sometimes I would not be in a good sitting position after transferring to my chair. When I was not positioned well to begin with, over a period of hours, I would literally begin to slide down, which must have been awful for my posture. So when that would happen, I would tilt my chair all the way back, and a caregiver (or any strong human) would pull me up by my armpits. We eventually learned that the best way to get me in my chair is to have it tilted/reclined pretty far back when transferring to it. I now train caregivers to kind of slide me down the back of the chair, so that my butt is all the way back. If I start out in good sitting position, I do not slide down during the course of my chair time.

Simple Arm Booster for Better Posture: I am not sure that there is such a thing as a wheelchair that will fit its occupant perfectly, throughout the years of its use. That is partly because our bodies can change over time. But we don't always need to break out the Allen wrenches and try to adjust something on the chair. For example, we place a folded up washcloth underneath my left forearm, near my elbow (but we want my elbow to a hang over the end, so that there is no pressure on the bony elbow prominence). That simple little "arm booster" allows me to sit straighter in my chair.

Faux Sheepskin or Fake Lambswool: speaking of my arms and my chair, obviously I cannot move my hands. Where they sit on my hand rests, that's where they stay (generally – we do strap them down with terrycloth headbands, that I usually buy new by the dozen on eBay) but they do not breathe on the plastic/rubber/Naugahyde, whatever that material is. So we cover my hand rests with faux sheepskin. It's plush and can keep my hands from getting red or stinky. We also use small pieces of faux sheepskin underneath my triceps when I am on my back in bed, to keep my elbows off my mattress. It can be difficult to find the thick, heavy-duty faux sheepskin fabric. But it is durable, washable, and should be helpful for a long time if you find some.

Skin Prep: my hands have no muscle, i.e. they are completely atrophied. Even with the faux sheepskin, sometimes the base of my thumb bone can get red, and look like it wants to nearly poke through my skin. As long as the skin is not broken, we can put a wax-like barrier on it using something called skin prep. It comes in individually wrapped little towelettes, and wipes on. It dries quickly, and if you want to "add a coat" you can dry it extra fast with a fan, and add more.

You should be able to get a box of 50 for under $10. It's also good for prepping skin where tape needs to be applied. Regarding my thumb bone, we also use a rolled up washcloth under my hand/wrist to allow that bone to "float" without touching anything.

Bag Balm: it's an all-purpose salve that is good for skin issues. It was developed for farmers more than 100 years ago, and I think it is mostly petroleum jelly with sulfur in it. My nurse Pandora called Bag Balm the "cure-all." We use it with my trach care and G-tube care. My ENT (ear, nose, and throat) doctor's nurse, said that I had the nicest looking trach stoma she had ever seen.

Also, one night before a speaking engagement, I had a large pimple forming. Pandora put a heavy coat of Bag Balm on it before I went to sleep, and I swear it was gone in the morning. Lastly, I once read that country music superstar Shania Twain used it on her lips, so I tried it on mine instead of lip balm when the corner of my mouth was cracked and sore. It healed in just a couple days. An 8 ounce can is usually around $9.

Vinegar Wraps: the knuckles on my fingers kind of develop little calluses from my caregivers doing range of motion. We learned at Shepherd Center that wrapping my hands with vinegar soaked washcloths or hand towels for a bit (30 minutes or so I think is good) softens them up and allows a surprising amount of dead skin to be wiped off easily. The little calluses can be peeled off. We probably do this a few times a year, but once a month might be optimal. We use regular white vinegar, diluted to half strength with warm water. Placing them inside Ziploc bags (which can be reused) can create a little greenhouse effect, and can help control the wetness.

Wheatgrass Poultice: we have used the pulp left over from juicing wheatgrass to treat a couple of minor, open skin issues (like a small issue on the back of my head). My dad has grown and juiced wheatgrass for years (he has a video on how to grow it, and talks about many of its health benefits: search YouTube for Jim Miller wheatgrass class). A wheatgrass poultice can help heal some stubborn issues. Growing and juicing your own is best, but for convenience, health food stores/restaurants that sell fresh wheatgrass juice should also be able to sell leftover pulp.

Inconvenient Weightshifts vs. Months of Bed Rest: the best way to heal a pressure sore is to prevent it. I mentioned in the telling of my story that Shepherd Center showed us pictures of nasty pressure sores, and urged everyone to relieve the pressure on one's butt and sitting bones. They also showed us a skeleton in a seated position to show how "bony" our sitting bones are. They recommend tilting and/or reclining for a minimum of one minute every 30 minutes – even if you have a good seat cushion.

Full-blown pressure sores can require months of bed rest, and I would rather be in my chair for 12-14 hours per day without developing a sore, with the comparatively minor inconvenience of weight-shifting for 1-2 minutes every 30. Plus, the skin integrity of a healed pressure sore is never as strong or durable as it was before. That is another reason why I choose to weightshift.

Numbers to Make Times Easy to Remember: to help me remember when I finished my previous weightshift, I use sports jersey numbers from some of my favorite players. For example, if I finish a weightshift at 3:23, I can envision Babe Ruth (3) and Michael Jordan (23) having a conversation. I also use some Scripture verses as well (like John 3:16) but I have a notepad file filled with jersey numbers from 0-60, which allow every clock combination.

Compression Socks: even if you weightshift regularly, compression socks can help to mitigate "dependent edema" which is common for quadriplegics. My feet did not swell hardly at all until I got closer in age to 40, but I have been wearing compression socks since roughly age 37. I will write more about dependent edema later, but wanted to mention my favorite compression socks, which are Vitalsox patented graduated compression socks (VT1211). You can buy them on Amazon (remember to use AmazonSmile) generally from $15-$20 per pair.

Yes, that sounds expensive (it does to me anyway) but before discovering these, I bought some fancier ones that were more like medical socks, and a good price was $25 per pair. These have good durability and also come in fun colors. NOTE: my dad says they are much easier to grip and put on me if his hands are a little wet.

Caregiver-Friendly Bed Additions: high-level quadriplegics like me should qualify for a fully electric hospital bed, which can raise not only the head and foot, but also the entire bed should go up and down. However, home hospital beds do not go up nearly as high as the beds that are actually in hospitals. But I know of two good ways to elevate the bed height at home, which can make it easier on caregiver's backs. Even a few inches of extra height can make a significant difference for a caregiver.

The first is to replace the small casters with much **larger stem casters**. The hard part was trying to determine what diameter the stems needed to be, in order for them to fit the bed legs without requiring modification. I wound up with six inch stem casters, which probably added a net of four inches to the bed height, after replacing the original casters. We would've liked the new casters better if they had brakes, but I was not able to find some with brakes and the needed stem diameter.

So to keep my bed from rolling all over our tile floor, I bought a pack of four bed stoppers (**furniture caster cups**) to go under the wheels. It is not particularly easy to get all four of the caster cups under the wheels, which is why we are careful to not knock my bed out of them.

The above solution might not be ideal, but it works for us, and my caregivers appreciate the extra bed height. We also have an exit door in my bedroom that is wide enough for my bed to roll out of in the event of a fire, which makes the 6 inch casters a nice addition for us because they roll much better than the original casters.

Another solution is to add a relatively **thick mattress topper**. I have yet to do this, however, Rhonda swears by the ROHO Prodigy mattress topper, which she has used to help ward off pressure sores for years (but she still turns at least once while in bed, as do I). She says it goes right on top of an existing mattress, and most fitted sheets will go over both. I am thinking of getting one of those, rather than a whole new mattress. It does have air-filled compartments, but worst-case scenario, if an area unexpectedly goes flat, my body would wind up on my mattress. Plus, simply changing the sheets allows for an easy visual inspection to see if any of the compartments need more air.

I like that the ROHO Prodigy is not mechanical and does not require electricity. So if the power goes out, it will not go flat. For reference and research purposes, Amazon has the ROHO Prodigy Premium Mattress Overlay for just under $300, which is less costly than a new mattress (but Rhonda says it can be purchased a little cheaper elsewhere). Rhonda also says it would be easy enough to pack for traveling.

Travel Mattress Topper: speaking of traveling, one of my quadriplegic friends who travels frequently, he uses a Drive Medical Med Aire Alternating Pressure Pump and Pad System on top of the hotel mattress. I am not sure it's a good long-term home solution, but short-term, his endorsement plus reviews I read make it seem like a good option, especially for the price. Amazon currently has them for about $50.

Developing Routines: one of the best pieces of advice for newly injured people is to develop routines. Having routines helps to eliminate some of the uncertainty for both the person and for the caregiver(s). It helps both know and remember what needs to be done, and how much time to allocate (especially if you have a deadline). Having good care routines is a big key to remaining healthy. Some of the routines should be taught and developed during rehab, but those will likely be tweaked in a home setting, and others may be developed. I will be writing about my routines in detail.

Find the Most Mutually Convenient Schedule: one aspect to having healthy routines is finding the most mutually convenient schedule. When I was on a normal schedule, sleeping in bed overnight, my dad would need to turn me in the middle of the night. After doing so, he had trouble getting back to sleep. It can also be more difficult to find night nurses, rather than daytime nurses (or caregivers). So we flipped my schedule to where I sleep in bed during the day, and am in my chair working on my computer overnight.

As I dictate this, like most nights, my dad is asleep on a bed near me in my computer room. He often gets 6-8 hours straight without interruption. Other nights, I might have a brief caregiving issue or two throughout the night, but he's often able to go back to sleep quickly. This schedule also allows me relative independence and time to get things done on my computer overnight.

Amazon Alexa or Google Home: speaking of schedules, both Amazon Alexa and Google Home are terrific for setting alarms and reminders by voice. My understanding is that both of the competing brands do very similar things, from answering questions about the weather to enabling full home automation by voice. I have Alexa, and we have one of the Amazon Echo devices in my bedroom. The Echo has a pretty darn good speaker (considering it's a single speaker) and we often listen to music when doing my going-to-bed routine, or getting-out-of-bed routine. My dad really enjoys listening to a playlist I put together with all of his favorites.

White Noise Machines: I have one on my computer desk that essentially "drowns out" moderate environmental noise, and allows my voice software microphone to hear me better. Without a little white noise, it seems that my microphone would pick up too many little noises like someone walking on our tile floor near me. I also use a white noise machine to help me sleep, since I sleep during the daytime. We also brought the white noise machine to the hospital the last couple of times I was hospitalized, since those are notoriously noisy environments. Amazon has a variety of white noise machines in the $20-$25 range.

Audio Baby Monitors: being on a ventilator, I generally should not be alone. We use baby monitors so that people do not need to be physically within earshot at all times. They are reliable enough that I am comfortable with a caregiver sleeping in another room as long as they have the monitor on, so I can wake them if I need something, or if my ventilator alarm goes off they should hear it. The VTech DM221-2 that we have was $50 two years ago, and is currently $40. We can also use the intercom-like "drop-in" feature of Alexa as a backup method for summoning help.

TIP: if you're going to use a baby monitor and a white noise machine at the same time, try to separate them with a physical barrier like a shelf. For example, during the day when I sleep, I need the white noise machine relatively close to me and with the volume relatively high. But a caregiver needs to be able to hear me on the monitor also. We have the white noise machine on a shelf above my head, and we used to put the monitor on the same shelf. But we found that my caregivers can hear me much better now that we placed a little peel-and-stick adhesive hook on the wall underneath the shelf and hang the monitor on that.

Hands-Free Computer Use: I operate my computer 100% hands-free. I do need someone to turn it on initially (although we could probably use Alexa and a smart plug to allow me to do it by voice) and I also need my microphone attached, but otherwise I can control it 100% independently. I will share specifics about my computer set up and voice software programs I use later on. Multiple ways exist to use a computer hands-free, including by: voice, mouth stick, head mouse, a mouth controlled joystick-mouse (called a Jouse), and even eye tracking.

Rehab hospitals should have assistive technology experts that can help newly injured people find the best solution for them, but of course Internet searches can yield more information about these options (and others I might not be aware of).

Hands-Free Smartphone Use: likewise, quadriplegics can operate a smart phone both by voice, switch input, mouth stick, or even by sip-and-puff. In addition to the aforementioned assistive technology experts at rehab hospitals, my two "online help" tips (coming up shortly) are probably the best ways to learn how.

Eye Exercise Info: if you spend long hours looking at a computer screen, you might strain your eyes. That's another good thing about doing weightshifts, i.e. it gives my eyes a break from looking at my computer screen from roughly the same distance. I was also taught that the eye is a muscle that needs to be stretched. So I close my eyes and "look" as far up as I can rotate my eyes, then as far down as I can. Then I stretch them left and right, followed by the diagonals in a multiplication sign. I also "massage" my eyes by squeezing them shut tightly, and rolling them up and down (those who know me, know I am an accomplished eye-roller!). (Smile.)

Not Caring What Others Think: I need to do that when I (eventually) read reviews of this book, because I know that not everyone will love it or even like it. And it's not easy "to put myself out there" like I am, but I do believe some of these pages will help some people, and that makes it worth exposing myself to potential criticism. Similarly, when wheelchair users go out in public, we are "exposed" to some curious eyes. Some people are bothered by being stared at. I choose to not care, especially if it's children who are staring. Kids are curious, and they probably do not see people in large power wheelchairs often.

I smile thinking back to one time when we were picking up my (then) fiancée Lisa at the airport, and a little boy saw me in my big, fancy power wheelchair, and said, "Hey mom – WOW! A transformer!" (Chuckle.)

Be Courteous, Part I: it is one thing to not care what other people think if you are acting appropriately, but I also do not want my presence to detract from someone else's experience. By that I mean, when I go to the movies, we cover my two illuminated displays. Since I am almost always cold, we cover my wheelchair's control box with part of my blanket.

Also, I have what was originally purchased as a fancy bib, that can attach to my headrest and is the perfect length to cover my ventilator display, and even allow me to weightshift without the bib touching the floor (yes, I do weightshift in movie theaters – it's not easy to pick a good time, and I don't stay back long, but I do relieve the pressure on my sitting bones by shifting several times during the movie).

I also try to remember to cover my displays in dark restaurants. (If we forget the bib, an extra blanket from my van, or a cloth napkin can work.)

Be Courteous, Part II: as mentioned previously, I usually work on my computer overnight while my dad sleeps on a bed in my computer room. He is snoring lightly as I dictate this (smile). To help him sleep, I use something called "nightlight mode" on my computer, which is set to dim the bright lights on my screen from 10:30 PM to 7 AM. That makes the lights a little less intense on my 32-inch monitor (a large screen like this costs less than $200, and is another way to reduce eye strain).

After discovering nightlight mode, I also discovered high contrast mode. That basically reverses the color scheme. So for example, in this notepad file that I am currently dictating in, the background is black with white letters, instead of a white background with black letters. That also keeps it darker in here while my dad is sleeping.

Online Help, Part I: many people are unaware just how many instructional videos are on YouTube. I have learned many computer "how to's" from doing Internet searches, which often lead to YouTube. Searching the little box on the Windows 10 taskbar for nightlight mode or high contrast mode should result in easy instructions. But, if not, or if it's a more involved task, someone has probably described how to perform the task, or made an instructional video demonstrating it. That's true from computers to car repairs to growing a vegetable garden, and almost anything you might want to learn.

Online Help, Part II: a website called CareCure.net hosts a message board used by paralyzed people (including me, occasionally) to share information about all types of Care issues, as well as research efforts trying to Cure paralysis. It also has some extremely knowledgeable spinal cord injury nurses who help answer questions. There is also a "CareCure" Facebook group, although the actual website is more active. That said, there are several additional Facebook groups that can be good sources of information as well. Two large ones that I am part of are "Spinal Cord Injury USA Group" and "SPINAL CORD PEER SUPPORT USA" which are both private, so sensitive issues can be discussed without your entire friends list being privy.

Be Grateful: I think the most difficult aspect of being paralyzed from my neck down and ventilator dependent is being physically dependent on others for most everything (besides controlling my computer and wheelchair). Nobody HAS to help me. I need help, but I am cognizant of the fact that my caregivers – even my parents – they CHOOSE to help me. I could share some horror stories with you about some other people's experiences, but I want to keep things positive. Just remember that it is wise to express gratitude for anyone giving good effort to provide good care, or any form of help.

That said, strangers in public, if you see a wheelchair user, please do not assume that we need help. Many well-intentioned people have aggravated perfectly capable wheelchair users by insisting on "helping." If we look like we might need help, please ask. Thank you.

Acknowledge People: in much the same way that I believe we quadriplegics should acknowledge – rather than ignore – people who are helping us (e.g. talk with and look someone in the eye when they are doing something for you) service providers like waiters and waitresses – and even medical personnel – please look at us wheelchair users and address us directly if you have a question.

Candidly, it can be disheartening for someone to immediately ask our caregiver a question that we can answer. If the wheelchair user wants their caregiver to speak on their behalf, then okay. But it's always best to acknowledge and try to ask the wheelchair user first. (Thank you – that concludes the etiquette portion of these tips!)

Keep Inventory of Supplies: home life is easier if you have the supplies you need. It is wise to make a list of things you need/use/take regularly to help make sure you don't run out. We inventory my medical supplies, medications, and supplements. I put mine into an Excel spreadsheet that I print out and ask a caregiver to inventory generally once a month. Then I scan the inventory sheet (actually two sheets) so that I can order supplies when needed. If you have any maintenance medications, it is a good idea to get a prescription for a 90 day supply delivered by your mail order pharmacy, and have auto-refills enabled.

Keep Emergency Supplies: wheelchair users may need supplies that cannot be easily purchased at a local store. Point being, when venturing away from home, it is prudent to have a "catheter kit" or any other essentials you might need. I have a large plastic bin in my van filled with emergency supplies, roughly enough for a week. Some wheelchair users keep emergency supplies in "backpacks" on their chair, which is also wise. Zip ties and Allen wrenches are good to have for potential emergency repairs away from home. While not necessarily emergency supplies, I keep a small LED flashlight attached to a "quick release keychain" on my chair, as well as a small bottle of hand sanitizer on each side of my ventilator (on the back of my chair).

Autonomic Dysreflexia Cards: one of the wallet cards available free from the Christopher and Dana Reeve Foundation is a good item to keep with one's emergency supplies, or in your wallet, or both. I wrote about autonomic dysreflexia and how serious it can be in my chapter on Home. You can print your own or request the CDRF mail some to you. A quick Google search should locate the proper webpage.

Waiting for the Other Shoe to Drop, Part I: my Grandma Willi said that she used to worry for almost her entire adult life, thinking that it was inevitable that something bad would happen, i.e. fearing that the other shoe would drop. She finally stopped worrying after my injury, because she felt like one of the worst things that could happen did happen. My mom came to the same conclusion.

Of her three boys, I'm probably the most "responsible" by nature, and she figured if I could become paralyzed in my bedroom of my college apartment (granted, I was intoxicated) then why worry about her youngest (my little brother) riding motorcycles? She figured if something bad is going to happen, it's going to happen. I agree, and say: take precautions, but LIVE YOUR LIFE.

Waiting for the Other Shoe to Drop, Part II: the expression apparently comes from people living in New York City apartments around 1900, when it was easy to hear the neighbor above you drop their shoe on the floor, and then you waited for the next one to drop. What if your neighbor realized how loud the noise was that dropping the first shoe made, so they set the other one down quietly?

It's not a great analogy, but my point is that the other shoe might not drop. So don't keep waiting for it to drop. Besides that, this list is tips for *quadriplegic life*, not tips for merely surviving. And if you are a quadriplegic, arguably the biggest shoe that could have dropped already has. So again I say: take precautions, but LIVE YOUR LIFE – as you see fit, as best you can.

Waiting for the Other Shoe to Drop, Part III: the primary caregiver for a quadriplegic expressed worry that "another issue was imminent." This woman is among the most adept and prepared caregivers I know. If an issue arises, she is as equipped to handle it as anyone. So I gently reminded her of her experience and ability, and that "the other shoe might not drop" or at least not imminently. Take precautions, but live your life.

Get Outside: after his injury, Ian Mackay was in the doldrums, much like all of us quadriplegics are until we figure out how we can live life again. For Ian, that meant getting outside and enjoying bicycle trails in the Pacific Northwest where he lives. His passion is outdoors. Even though he cannot move his arms or legs, he has a smart phone he can operate independently, and he is comfortable venturing out on his own and rolling up to 20 miles by himself – as long as he has a caregiver available to call.

Yes, that's pretty gutsy. But that's living to him. Being on a ventilator, I am not quite that daring. We are all comfortable with different degrees of risk. Take the precautions that you feel you need to, and please live your life.

Check out IansRide.com for more about my friend Ian, and as he frequently posts: get outside! I believe doing so is good for one's mental health and preventing cabin fever, even if you are just getting fresh air and sunshine outside your home.

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I am sure my fellow quadriplegics could share many more tips, but what I have shared are some of the more identifiable things that we have come to find helpful over the years of managing my care.

NURSING COVERAGE AND CAREGIVERS

Providing the care that quadriplegics need is a large concern for newly injured people. To some extent, it's ongoing as well.

Who is going to do it? If we have outside help, who is going to pay for it?

Those are two of the biggest questions new quadriplegics (and their families) have. I will talk some about several scenarios.

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I was blessed to be able to come home and live with my parents, and also be covered by private insurance.

In the beginning, we had 24/7 coverage for LPN (licensed practical nurse) care from our insurance. I believe that lasted about a month, before getting reduced to 16 hours of coverage per day.

Around-the-clock nursing coverage actually has pros and cons. That means shifts are generally 8, 12, or 16 hours. So you generally need 2 to 3 nurses per day – every day – and there are 168 total hours per week to cover. Thus, a fair estimate is needing at least five or six nurses to "staff" a 24/7 case. That may not be practical.

It can be hard to find that many nurses, especially ones for whom quadriplegic shiftwork is a good fit. But if the coverage is approved, then the home health nursing agency will want to get paid, and thus want to fill as many shifts as possible. That's the business side of the theory anyway.

Early on, our nursing agency sent a lot of what Pandora called "warm bodies" to fill shifts. Many did not seem to have the desire to learn my care, which is specialized. Every quadriplegic has specialized care. Yes, we have some common needs, but how we prefer these needs be met can vary significantly. So even people with experience working with quadriplegics should be open-minded to learning a person's unique care needs and preferences.

The good news is that by sending out quite a few different people to fill shifts, we were able to find some that were a good fit. And after that first month or so, when our coverage got reduced from 24 to 16 hours per day, it actually became a little easier to fill the shifts with people we were comfortable with. Of course, that meant my family had to cover eight hours each day without nursing help, but aside from not having formal nursing training (they did receive some training from Shepherd Center) my family knew my care as well as anyone.

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For several years, we had a night nurse and a day nurse. They were some very loyal ladies who became like family. Eventually, we became concerned about what would happen when we exhausted our one million-dollar catastrophic injury insurance cap. So we made the difficult decision to voluntarily reduce our coverage. Our thought process was something like this: it is better for us to have eight hours a day for four more years, rather than 16 hours per day for two more years.

Thankfully, before our insurance cap was reached, the one million-dollar limit was removed, which was a huge relief. That meant we could stick with eight hours a day of coverage indefinitely (or so we thought). But that also meant my family now had to cover 16 hours per day – every day. Actually, it became more than that.

Because my parents needed to work, and thus I needed a nurse while they worked, we chose to have one of our loyal ladies work Monday through Friday for eight hours. That was easy for the nursing agency to cover, since it only required one of their nurses. Apparently insurance saw how we needed those eight hours five days per week, and formally reduced our coverage to 44 hours total per week. You might be wondering: what good are those extra four hours, or how might they be used?

In hindsight, we may have been able to find a good way to use those four hours, but we never did.

With 40 hours a week of nursing coverage, that meant my family had to cover the remaining 128 weekly hours. For us, that meant that we needed to find some outside help, i.e. caregivers.

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With Donna being a county judge, she worked with quite a few clerks at the courthouse. One clerk, Jackie, was widowed at the age of 52 back in 2002. Understandably, she had trouble leaving work each day and going home to the house she had shared with her husband. Donna had the idea that maybe she would like to come help with me in the evenings.

That was a terrific idea. Jackie is now retired from the clerk's office – but STILL working with me! (Smile.)

Jackie is a wonderful caregiver and one of my closest friends. We consider her to be part of our family. At one point, she was a live-in caregiver, staying in our guest bedroom for a little while after she sold her house.

I am only mentioning these details (with Jackie's permission) to give other folks ideas about who might be an ideal caregiver, and how to make having one more feasible (i.e. consider sharing your space in exchange for caregiving time).

Interestingly, Jackie said she does not actually think of herself as a caregiver.

"I'm just me," she said, before going on to say that she thinks of working with me more like helping a friend.

For several hours a shift, she helps me with tasks. Essentially, that's what caregiving is.

Most of our caregivers have been people we knew, like Jackie, or have been found through networking. Donna liked a woman who was assigned to clean the judges' chambers at the courthouse. She became a terrific caregiver. Donna also liked a woman working at a department store in our local mall. She also became a terrific caregiver.

I'm not going to mention additional names, or try to make sure I mention every caregiver I have had, but I do want each one to know that I appreciate them for having joined my journey, and that I am grateful for their efforts and their time that they shared with me. They are all human, and have different strengths, but I am thankful for each one who joined our caregiving team.

What does it take to become a terrific caregiver?

First, caring enough to want to help a fellow human. None of us are perfect, but as long as someone cares enough to try to provide good help in the manner in which I need it, then that person can be a terrific caregiver.

Dependability is pretty critical. That's why we look for adults who are likely beyond child-raising age, or at least people who do not have young children at home who obviously must be their number one priority.

Conscientious, trustworthy adults who want to help and are willing to learn my care – that's what we look for. Of course, caregiving for me does require some physical ability also.

Availability is another important aspect. Hopefully one's typical availability meshes with one or more of the shifts we have: morning shift, dayshift, late afternoon/evening shift. My family almost always does the overnight shift, unless they plan a trip or something.

How do you find caregivers?

That is a question I've been asked quite a bit.

I know some people who have had success finding caregivers on the website Care.com. The key is to be proactive, and actively seek out people you think might be good candidates. Not everyone will be a good fit.

I think some of the more ideal candidates might be stay-at-home moms or dads whose youngest child just went off to college. Or someone who retired relatively young and would like something meaningful to do.

In my mind, those are (likely) conscientious adults who might have good availability. But they might not have ever considered the thought of being a caregiver, or working with someone like me. That leads me to one of my favorite pieces of advice: "they cannot say yes, if you don't ask!" (Smile.)

Some people might be willing and able to help, but maybe not with every aspect. They can still be a valuable team member. Not all of my caregivers are fully trained in every aspect of my care. Generally, we will train someone for the morning shift or the evening shift, and see how that goes, before attempting to teach all that is involved with my care.

On a side note, I personally have a "caregiver zero liability" policy. I don't want to sound dramatic, but we are all human, and we are all going to die from something. I do not want people to be scared to work with me for fear of something bad happening, and worse – the possibility of being held responsible! That will not happen to any of my caregivers.

To expand on that, we train all of my caregivers. We will not leave a new caregiver alone with me unless we are comfortable doing so. That does not mean that it is impossible for something bad to happen. It means that we trust that the caregiver has the knowledge, ability, and desire to try to prevent something bad from happening. I know my care as well as anyone. I can help troubleshoot most any situation, as long as I am conscious, and if I am not, then call an ambulance. (Smile.)

That's the same thing someone should do for anyone who needs help, right?

I think most quadriplegics become pretty stable, medically speaking, after our bodies (and minds) get adjusted to our new normal. I know that I'm a lot more medically stable than I was when my heart stopped at Shepherd Center four times before they put a pacemaker in me. My pacemaker is only set to kick in if my heart rate were to fall below 40 beats per minute. That sounds low to me, but my cardiologist assured me that's not all that uncommon when sleeping. Right before I fall asleep, my pulse is often in the low 50s, so I guess it's not that big of a deal to get down around 40 bpm. My pacemaker is almost never used, so that means my heart has a good track record for working well on its own. My cardiologist says my heart is strong.

With the ventilator and my pacemaker, I jokingly say that I am bionic. (Smile.)

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Besides personal networking, I know people who have had success with hiring local college students to do caregiving. Local nursing students might be inclined to learn about and help provide care for a quadriplegic, but nursing or medical knowledge is not a requirement.

Frankly, we tend to prefer for our caregivers to not have a medical background, because sometimes people with a medical background feel like they know best, and are reluctant to learn my specific care needs and preferences.

One good thing about hiring local college students is that there should be a good supply of candidates, but a drawback is that even ones who find the work meaningful and enjoyable, they are likely to move on after a couple of years.

Networking at church is another good place to find potential help.

As far as a help wanted ad, I like something like this:

"HELP WANTED: might you like a meaningful part-time job?

Consider helping a quadriplegic. Call 555-1234 for more information."

I can see that posted on a college bulletin board, or a church bulletin board, or on Facebook. If someone is going to be a good fit, I would think they would respond well to that simple message.

But I also know people who will tell you that life can still be good – even with just one primary caregiver, and little-to-no nursing or caregiving help.

That's the situation my aforementioned friend Rhonda was in for roughly the first 20 years of her post-injury life.

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Rhonda's mom Jackie quit her job and became Rhonda's full-time caregiver in order to keep Rhonda out of a nursing home. They lived together in a modest apartment until cancer ended Jackie's life in 2012. Rhonda also lost her dad that year, and has essentially been "on her own" since. How has she managed?

Rhonda now has a team of people to help provide the round-the-clock care she needs. I believe she has Medicare and also a Medicaid waiver program that combine to provide 24/7 CNA (certified nursing assistant) care. On a related note, it is actually cheaper for taxpayers for Rhonda to live in her apartment with help provided, rather than in a nursing home. But as mentioned previously, it can be difficult to staff a case 24 hours per day, seven days per week. So Rhonda also has a small team of caregivers who cover any uncovered CNA shifts. But Rhonda has to pay those caregivers out of pocket, which means she has had to rely on the generosity of others in order to stay out of a nursing home.

Hey, the theme of this book is that life can still be good – a sentiment Rhonda agrees with and tries to show – but I didn't say it would be easy. But that's true for many people from all walks (and rolls) of life.

Personally, I am highly impressed with Rhonda's fortitude. She has managed to stay out of a nursing home since losing her mom roughly 8 years ago. She might try to throw a little credit my way, but I will reject that. All I did was organize some bowl-a-thon fundraisers to help her pay for care. (The real credit goes to God, Matthew 19:26 "with God all things are possible.")

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Rhonda has worked quite hard to stay out of a nursing home, but I do know some quadriplegics who have lived for years in facilities. While it is certainly not an ideal place for a younger person, I know of at least two quadriplegics who have furthered their education (online) while living in a nursing facility, and they have also been able to take some memorable and meaningful trips.

One common theme among people who have made the best of living in a nursing home, is that they have taken the time to get to know some of their fellow residents. Nursing homes can house some colorful characters with interesting stories, and getting to know one's "neighbors" can make the time there more interesting and meaningful. Taking an interest in people can make the time better for you both. And getting to know the staff can lead to better care also.

I also know of quite a few quadriplegics who basically have a sole primary caregiver, whether it's a spouse or a parent, without hardly any additional help. I know of a quadriplegic who has 84.5 hours per week of nursing coverage approved – yet where they live in Alabama, they have zero hours covered due to a severe nursing shortage in their area (thankfully the young man has two excellent parents who provide his care).

On a side note, nursing shortages are common in many areas throughout the United States, which means there are many good paying jobs that cannot be outsourced or done by robots for people who are able and interested in helping others. Lots of different types of nursing and healthcare jobs should be in demand for years to come since baby boomers are aging, and medical advances are increasing survival rates for people of all ages with different types of health issues.

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As far as my nursing coverage, after my stepmom retired, Medicare became primary and our private insurance became secondary. At the same time, we discovered that very few home health agencies provide "shiftwork" in our area anymore, which I am sure is partly due to nursing shortages. We did find an agency to take my case, but somehow our out-of-pocket co-pay expense was actually more per hour for nursing care than what we could hire private caregivers for. No, that does not make any sense. But because it's the reality, we now cover all of my care ourselves – with a combination of family and private caregivers.

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Ultimately, I wholeheartedly believe that life can still be good, even for quadriplegics, in almost any scenario.

There's a sign on my computer room wall which reads, "it is what it is, but it will be what you make it."

I believe we all need to choose to make the best of it, no matter what "it" is.

The bottom line is that you gotta do what you gotta do. Some situations are better than others – BUT if you read my chapter on Faith, Love, and Happiness, then you know that you can choose to accept God's gift of spending eternity in paradise. And if you have chosen to do so, then remembering that heaven (eventually) awaits you should make any of life's temporary difficulties easier to bear.

For my family and me, I realize that I am quite blessed to have had four family members choose to learn and help with my care: the two parents with whom I live – my dad and stepmom – as well as my birth mom and older brother. Actually, Grandma Willi and Grandpa Loren learned some aspects of my care so that they could help out also. I will always be grateful for each person's help, and my family's collective help.

One big positive that has resulted from my being injured is that I have, or had, a closer relationship with each of the aforementioned family members. I put "had" because both my mom and grandpa have since passed. But keeping an eternal perspective, I look forward to seeing them both again in heaven. And I am quite thankful that my injury gave us more time together than we would have had otherwise.

Caregiving wise, my goal has always been to have a large enough team of people involved so that my family members can help me when it is relatively convenient for them to do so. Or put another way, I don't want people to cancel plans or have my paralysis keep them from doing or pursuing something they want.

That is the flipside to being so dependent on other people for my physical needs. It's not just that I prided myself on being highly independent prior to my injury. I have stated previously that such physical reliance on others is the most difficult aspect of being paralyzed from the neck down. I say that not just because I would GREATLY prefer to be able to take care of myself, but I'm also keenly aware that when people choose to spend their time helping me, they do so at the expense (opportunity cost) of doing something they might rather.

Thus, I try to make sure that their time spent with me is enjoyable, and that they know I appreciate their help. One way I try to do that is by having a positive attitude, and saying please and thank you also helps.

My mom once said that my injury was a tragedy. But in her eyes, as a parent, she said it was much more bearable because I choose to be positive.

In general, my family members have all been able to keep pursuing the vocations and endeavors that they have wanted to pursue, for the most part. And I am thankful for that. Also, occasionally, my injury has given them a good excuse to get out of doing something they were not up for doing. My dad jokingly calls it "playing the Bill card" (it's not something he or we have done often). I am only mentioning that so families in similar situations can see another potential positive.

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For anyone local to the Leesburg, Florida area who is reading this, we are almost always keeping our eyes open for the opportunity to add someone who might be a good fit to our caregiving team. If you or someone you know might be interested in helping me/us, please contact me. But you would be wise to first want to know more about my care, and the next chapter is designed to help with that.

AN OVERVIEW OF MY CARE

I'm writing this to potentially help other quadriplegics and their caregivers, but also to help orient new potential additions to my caregiving team. My care has evolved over time, and not everything will apply to every quadriplegic. If you are reading this chapter in my book, some stuff might be redundant, but this overview of my care is written to stand alone. Thanks for understanding.

First, it's vital to know that caregiving for a quadriplegic – especially in the beginning – can seem overwhelming. That's normal.

But it should feel much easier once care processes are learned and routines are developed. Having good routines eliminates much of the uncertainty, and should lead to healthier situations – physically and mentally – for both the quadriplegic and the caregiver(s). By care processes, I mean things like how to do transfers, how to turn and position in bed, how to dress and undress, etc. (the various aspects of a quadriplegic's care). Once you learn those processes, then you can develop good routines. Getting into routines is when it gets easier.

Even some of my longest tenured caregivers expressed feeling overwhelmed in the beginning, and were unsure if they could do this. Maybe our training approach in the earlier years was a little raw, but all of my long-term caregivers became comfortable with my care after learning the care processes, and developing routines.

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Probably the best overview I can give is to simply take you through a day of my typical caregiving needs, and the corresponding shifts. So let's do that.

MORNING SHIFT/Put-Bill-in-Bed Shift: most days, I am in my chair working on my computer overnight. Thus, I go to bed in the morning. We usually start the process about 6:30 or 7 AM, and it takes close to three hours.

Getting in Bed, Primary Tasks:
- untether me from my computer (simply remove my headset and my microphone, and unplug my chair ventilator from the outlet, so I can roll into my bedroom)
- catheter management (prepare the catheter and cath bag for transferring; like most of what you are about to read, this is easier than it might sound)

- transfer me from my chair to my bed (place a sling behind my back and under my legs, then connect it to the ceiling lift to transfer me)
- ventilator management (switch me from my chair vent to my bedside vent; this may sound a bit daunting, but simply requires pushing three buttons total, taking one circuit off my trach, and putting the other circuit on)

Once I Am in Bed, Primary Tasks:

- remove the sling (I don't sleep with it underneath me)
- start the nebulizer (I do a breathing treatment with sterile saline)
- do leg range of motion (we teach six ways to stretch my legs)
- undress me (I don't sleep with my clothes on)
- catheter management (clean and prepare it for my time in bed)
- do meds and supplements (I take some by G-tube and some by mouth)
- feed me breakfast (I will write about what I eat later)
- brush my teeth (guide the sonicare toothbrush around my teeth)
- use the CoughAssist several times, as needed (I still call it an in-exsufflator)
- do arm range of motion (we teach this, and everything you are reading)
- do trach care (use Q-tips to clean around my trach, and replace the dressing)
- wash my face (we use washcloths, a small basin of water, and soap of course)
- prepare me for sleeping (among other things, I sleep with my head covered!)

That is the bulk of the morning shift, or what we do to put me in bed. Again, we train people to do all of those tasks. Of course there is some related cleanup as well.

If that last bullet piqued your interest, I do indeed sleep with my head and face covered. It is one of the advantages to breathing with the ventilator circuit attached to my neck (smile). My face is also the only place that I can feel the covers, or have that cozy "bundled up" feeling.

Temperature regulation is an issue for quadriplegics. My body does not sweat when I get hot, and it does not shiver when I get cold. Or as my dad explains, "Bill's internal thermostat is broken." Thankfully we have an external thermostat that works well to keep my rooms anywhere from 75° to 78° Fahrenheit as I generally need.

My body temperature usually runs cold, and is often 96-something degrees before I go to sleep, which makes having my head covered feel nice and cozy. If by chance I am warm, we still cover my head, but also can point one or two six-inch fans toward me. They clip to a shelf above my head and can cool me through the covers, which are somewhat porous and usually not tucked-in tightly.

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Most days, the morning shift tasks are completed by about 9:30 or 10 AM. Some days we only have a caregiver for the morning shift, and one of my parents will listen out for me on the baby monitor after the caregiver leaves. Many days I will sleep for a couple of hours without needing anything until it is time to turn me on my side, roughly around 11:30 AM or noon.

So if my parents are "on duty" during that time, they might not have to do anything except listen on the monitor in case I need something. If the morning caregiver stays for the dayshift, I may ask her/him to take inventory of my meds, supplements, and/or supplies. Or I might ask her/him to do another little project, like clean my Camelbak drinking system.

Dayshift, Primary Tasks:

- do meds and/or supplements via the G-tube per my daily schedule
- catheter management (the bag usually needs to be drained a few times throughout the day)
- use the CoughAssist machine as needed
- turn me on my right side, if it is not a bowel program (BP) day
- turn me on my left side, if it is a BP day (my bowel routine is every other day)
- if trained to do so, do the BP, if it is a BP day
- after roughly 3 hours, turn me back flat to my back
- do my laundry and any respiratory "dishes"
- perhaps do a project, or my bed bath
- listen out for me in case I need something

Yes, someone can still be a helpful caregiver without learning to do my bowel program. Understandably, people often balk at the thought of doing it, and it is usually the last aspect of my care that we teach in order for someone to be a "fully trained" caregiver. But I am told that actually doing the bowel program is not nearly as bad as one might think.

MILDLY GRAPHIC DESCRIPTION: With my BP, I will first be turned on my left side (in bed). Then we set up a disposable pad (we call it a Chux) and some paper towels to contain the output. Next, using a disposable glove, we insert a suppository, which helps my body do most of the work. And then we usually wait to do a predictable cleanup process. Baby wipes and disposable gloves work great, and we keep plenty in stock. After 45 minutes, my body is often done and the output can be removed (and not to be too graphic, but according to my dad, it is often an impressive pile – hey, I eat two good meals each day, and only have a BP every other day, so it should be a large quantity).

Since it is good for me to stay on my side for roughly 3 hours, we leave a clean Chux in place, just in case my body puts out a little more. Obviously, my buttocks area gets cleaned as part of the bowel routine. While I am on my side, we wash my back also.

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During the pandemic, a number of factors reduced our caregiving schedule to just Jackie and my parents. Jackie has been doing seven hour shifts from 2:30-9:30 PM four days per week, and my parents have combined to cover basically everything else.

Thankfully, my parents make a good team. Donna is good at making/preparing my meals, and feeding me. So she does both whenever we don't have a caregiver. She is also good at listening out for me and handling respiratory or catheter needs when they arise. My dad handles those issues also, and does the other aspects of my care.

I get a full bed bath on BP days, if not every day.

When Jackie went on an RV trip for five weeks during the pandemic and we did not have any of our other caregivers, my dad said, "Bill, you don't stink, and you don't get dirty enough to need a full bath every day. It's not like you are out playing in the mud, or sweating outside doing manual labor." On a side note, my dad would often accompany me on my speaking engagements, and he liked to point out that I have not done any physical chores or lifted a finger around the house in more than 20 years. What a slacker! (Smile.)

Regarding my hygiene needs, he's right. Normally speaking, I don't sweat at all because of my injury. My body just gets oily in some places (primarily my face, the back of my neck, and my back) which we can and do remove easily with a clean, dry washcloth.

When we regularly had a nurse five days a week, plus caregivers on the weekend, I was bathed every day. But when Jackie was on the aforementioned vacation, my dad decided that doing a full bath on BP days was sufficient. On non-BP days, he would clean the necessities, i.e. my armpits and groin area. We also either wash my face with soap and water, or simply use a hot, wet washcloth on my face (and dry it off too). On days that I get a full bath, we wash my hair once I am in my chair with some washcloths (and soap and water). Doing so is sufficient considering my preferred supershort buzz cut.

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Most of the above generally occurs before it's time to get me out of bed.

LATE AFTERNOON/EVENING SHIFT/Getting-Bill-Out-of-Bed Shift, Primary Tasks:
- start the nebulizer (I do another breathing treatment with sterile saline)
- use the CoughAssist several times, as needed
- do meds and supplements (I take some by G-tube and some by mouth)
- do trach care (same as described in the morning routine; we do it twice daily)
- do G-tube care (clean around the stoma and change the dressing; we do it once daily)
- if I did not have a bath, then clean the necessities as mentioned above
- catheter management (clean and prepare it for transferring to the chair)
- get me dressed
- put the sling underneath me (so we can transfer to the chair)
- transfer me to the chair

We teach people how to operate my chair, and how to position me correctly in my chair. Once I am set up in my chair, it is nearly mission accomplished, but there is some cleanup involved (linens and more respiratory dishes created from doing the nebulizer and using the CoughAssist). We may or may not wash my hair in my chair, as noted above. That's basically it. The entire process generally takes close to two hours, or more (it also depends on whether we are chitchatting a lot, perhaps distracted by TV or music, or more focused on getting me up).

Depending on whether I am put in my chair in the afternoon or evening, we might go somewhere and eat dinner out, or pick up food and bring it home. Or if I am put in my chair in the evening, my caregiver often stays for dinner and feeds me (Donna usually prepares dinner, unless we bring food home). Staying for dinner is optional, but if so, we usually provide dinner for my caregiver also. For example, when Jackie works 2:30-9:30, she and I usually eat dinner together in my computer room.

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OVERNIGHT SHIFT, Primary Tasks:

- use the CoughAssist as needed (most often 0-2 times overnight)
- do meds and supplements (I take some by G-tube and some by mouth)
- make sure I am set up on my computer for the night
- sleep on the bed near me in my computer room, or
- sleep in another room with the baby monitor

Yes, you read those last two bullets correctly. When I am in my chair overnight, I can weightshift independently, drink water independently, and use my computer independently. Consequently, I am comfortable with my caregiver trying to get a good night of sleep while I am awake overnight. This is usually my dad's shift, and he typically sleeps well for 6-8 hours, depending on how early he chooses to go to bed.

My ventilator has good alarms that are loud enough to wake a sleeping caregiver, and if it is not alarming (i.e. everything is working as it should, which is at least 99% of the time) then I should be able to use my voice, or make a loud clicking noise to rouse a sleeping caregiver if I need some help.

Since coming home from rehab at Shepherd Center in November of 1997, my ventilators have been extremely reliable machines. Once set up properly, they should alarm every time the tubing is disconnected from me – intentionally or unintentionally.

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So that's an overview of the care I need on typical days. Those are the routines we do to manage my care and life.

We call my typical schedule "caregiver friendly" because the majority of my caregiving needs can be met during the day, while I am in bed. The impetus for switching me to a nocturnal schedule was largely because my dad often had trouble getting back to sleep after waking up to turn me in the middle of the night. He likes this better, and I have more time and independence to do things on my computer overnight as well. Another bonus is that most people generally prefer to work during the day, rather than overnight, so it makes finding caregivers a little easier.

But considering my schedule, we try to schedule doctors appointments, etc. at the earliest morning time possible, or the latest afternoon time possible. That allows us to stick with roughly the same schedule, "only" throwing us off by a few hours.

For traveling, or special occasions where I need to be up most of the day, we temporarily reverse my schedule. Basically, I just go to bed at night, and we abbreviate and modify my typical routines. I use the analogy that traveling for me is like camping, i.e. when we stay away from home, we do things a little differently.

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Caregiver wise, we feel blessed when we either have help in the morning to put me in bed, or in the late afternoon/evening to put me in the chair. Sometimes the morning caregiver will stay for some or all of the day shift also. It is a super luxury to have full coverage with non-parental caregivers from morning to night.

Training wise, we first have a new potential caregiver shadow someone experienced through either the morning or afternoon/evening shift, whichever they think they might like to work. I can give verbal instructions for a lot of things, but it is helpful to see how it's done. Then over the next few training shifts, the trainee will become hands-on with the tasks, receiving instruction as needed. No caregiver will be left alone with me until I am comfortable with their level of training (you have to at least be able to operate the CoughAssist machine; I have a video on YouTube showing how we use it: search for "Bill Miller how we CoughAssist" and you should find it easily).

If you are thinking of working with me or someone else with a significant physical disability, even learning just enough to be able to "hold the fort down" while the primary caregiver(s) can have a few hours off or away, that can still be helpful. So are things like bringing meals. I am just offering food for thought (pun slightly intended).

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Next I will share details of my care.