

laughing  
at my  
nightmare

shane  
burcaw



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*To my mom, Sue;  
my dad, Jon;  
and my brother, Andrew.*

**I fucking love you guys.**

## introduction

**The forest of pube-y leg hair sprouting from my** brother's leg bristles the tip of my nose as he stands over me on the floor of our rented minibus, yanking my shorts off. While I try not to laugh, since my bladder is on the verge of exploding after seventeen hours of driving down the East Coast of the United States. Until now, I have chosen to hold my pee despite stopping at multiple rest areas along the way. Highway bathrooms tend to be pretty shitty for people in wheelchairs and I can't sit on a normal toilet, so when I have to pee, I use a travel urinal that someone holds under my penis. I have to be lying down to do this, and the floor of a highway restroom is by far the least desirable place to lie in the entire world. So there I lie, in the tightly cramped quarters of our tour bus in the parking lot of a Wendy's in Daytona Beach at two in the morning while Andrew maneuvers my penis

into the little red travel urinal that I carry everywhere I go. We would have a lot more room if it weren't for the three cameramen surrounding us, capturing every angle of this intimate moment. I close my eyes, attempting not to accidentally make eye contact with a member of the film crew. Making eye contact will disrupt my stream.

It probably looks like we are filming a multi-fetish porno involving severely disabled people and urination. The back of the van is wide open, and I worry that a stranger might walk by. Although I guess it wouldn't be the worst thing that could happen. Besides, I'm used to people staring really hard at me. Whenever I'm out in public, it is pretty much a guarantee that several people will make it completely obvious that they have never seen someone like me before. By "someone like me" I mean an alien-like pterodactyl creature with a human head that uses a wheelchair. Okay, that's a slight exaggeration, but I must look awfully messed up if the looks I receive are any indication.

Because of a neuromuscular disease I've had since birth, my arms and legs are slightly fatter than a hot dog. My elbows and wrists are extremely atrophied; they look exactly like Tyrannosaurus Rex arms when I hold them against my chest. I am a few inches shy of five feet, and when I sit in my chair, it seems like I'm even shorter. My head is normal human size, which looks ridiculously funny/creepy sitting on top of my tiny body. Imagine a bobblehead doll in a wheelchair. I don't even blame people for staring. If I were a stranger, I would probably stare at me, too.

Over the years, I have gone through many methods for dealing with people who stare at me. When I was younger, I used to make scary faces at other little kids who were mesmerized by my chair because I got a kick out of their reactions. During middle school, I went through a stage where the constant stares really got under my skin. I remember doing things like approaching people who stared to ask them what they were looking at, pretending to cry to make an onlooker feel like a terrible person, and outright lying to people who had the balls to ask me questions about my disability. I would tell people that I was in a car accident that killed my whole family. I was young and stupid then and didn't know how to handle my situation.

I eventually got over my aversion of being stared at, which is why I am now okay with being filmed as a part of a documentary about the inaugural speaking tour of my nonprofit organization, Laughing At My Nightmare, Inc. It is only our first day on the road, and I am already discovering how ridiculous the upcoming week is going to be. When the pee jar is full, my brother hops out and rinses it out in the parking lot with half a bottle of Gatorade. Wendy's is closed at 2 a.m., and none of us wants to be in a van with a jarful of stench.

My mom would have a heart attack watching us improvise ways to take care of me on the road. But she is a thousand miles away at our home in Bethlehem, Pennsylvania, along with my dad. For the first time in my life, I am free.

This has not been the case for most of my life. I was born with spinal muscular atrophy, a disease that basically causes

my muscles to be extremely weak and to deteriorate as time progresses. Based on other books I've read by people with illnesses of some sort, this is normally the part where they dive into a painfully dull discussion of science and other stupid things that I don't care about. For the sake of my story, all you need to know is that physically, I am superweak, and constantly getting weaker. I have never walked. I've never even crawled. I've been in a wheelchair since I was two years old, and have relied on other people for pretty much every aspect of staying alive since I was born. Are you starting to see how my circumstances might hinder a sense of freedom?

So, how the hell did I end up a thousand miles away from home on an East Coast speaking tour with only my younger brother, two of my best friends, and a camera crew filming me pee? I have no idea. Life has been pretty surreal over the past few years. But when I really think about it, my existence has consisted of nothing but one absurd event after another.

I have always approached the problems in my life with a sense of humor. A big reason this book exists is because of the blog where I started to tell funny stories about my life. That blog, also titled *Laughing at My Nightmare*, has over half a million followers today. I guess wheelchairs are just "in" right now.

This is the story of life from the seat of my powered wheelchair as it has transpired during the first twenty-one years of my life. I might be dead by the time this book gets published, or I might not be. Either way, I hope for nothing more than to share my story with you and make you laugh.

## chapter 1

### a “normal” day

The sound of my cats trying to kill each other startles me awake. Oreo and Roxy don't get along very well, probably because Oreo is a prissy prima donna who cares only about herself, and Roxy has an inferiority complex. Every other day, Roxy snaps and attacks Oreo in an attempt to end her existence and become the sole recipient of my mother's love. Their death battles sound like a hurricane smashing through the house. I groan and look at the clock that hangs on the wall next to my bed, 9:45 a.m. Too early. Let them kill each other. I fall back asleep to the soothing sounds of Roxy tearing Oreo to shreds.

Only forty-five minutes pass until I wake up for a second time. I've never been good at sleeping in. This time, the sun slicing through my bedroom window has stirred me from sleep. I groan again.



“Andrew, can you get me up?” I call. I hear a groan escape his bedroom through his partly opened door. Mom opens it every morning before she and Dad leave for work to make sure he can hear me. I know he heard my call, but it wasn’t enough to will him out of bed. I wait for a few minutes, considering how annoyed I’d be in his situation. I call him again.

“Yea, one sec,” he calls back, still half asleep. I don’t sense annoyance in his voice, and I hardly ever do. He knows I need him.

Andrew groggily enters my bedroom wearing a pair of basketball shorts and no shirt. As per usual, we don’t talk much as he helps me get ready. He pulls my blanket off, rolls me onto my back, and after grabbing a pair of shorts from my dresser, gently and meticulously pulls them up my legs and over my butt. The shirt he chose is a little stubborn getting over my left arm, but he gets it on after a few tries and manages not to break any bones.



*Fun Fact*

*I drool so much overnight that I have considered hiring a lifeguard to watch me while I sleep.*

“Do you need to pee?” he asks.

“No. I’ll wait til later,” I say.

“Good, because I wasn’t going to do it, anyway.”

My little brother leans over the bed and slides his arms

under my knees and behind my shoulders, lifting and carrying me to my wheelchair. He sits me down gingerly, almost getting me in the perfect position (a nearly impossible task). He un-plugs my phone from the charger and sets it on my lap, walks to the kitchen to pour a cup of coffee, which he leaves on the edge of the dining room table for me, then comes back into my room. “I’m going back to bed. Are you good?” he asks. I thank him and drive to the dining room to find the coffee that will inject me with the energy to make it through the day.



This is how Andrew lifts me.

My laptop is sitting next to the cup of steaming coffee (more like coffee-flavored milk, Andrew made it very sweet). Part of Dad’s morning routine—after getting me up at 6 a.m. for a shower and putting me back in bed afterward—is to

open my laptop on the edge of the table so I have something to do when Andrew goes back to sleep. I can't physically type on a keyboard or lift the cup of coffee to my lips, but like all daily tasks, I've found ways to improvise. I have an app for my iPhone that transforms it into a wireless mouse pad and keyboard (I love you, Apple). Sticking out of my coffee is a superlong bendy straw that I order off the Internet. It is long enough so that the straw reaches my mouth when the coffee is sitting on the table. Little adaptations like these are what allow me to thrive.

Oreo walks past me toward her food bowl that sits on the kitchen floor. I am slightly disappointed in Roxy. One of these days she will accomplish her mission, and I will sleep beautifully until lunchtime. I open Netflix and put on an episode of *Breaking Bad* while checking my email and blog. Hundreds of new messages. At this point in my life, the summer of 2012, most of my days start by checking fan mail. Thousands of people from around the world write me to share how my blog has impacted their lives or made them laugh. I am twenty years old, and as my number of followers steadily climbs into the hundreds of thousands, I exist in a constant state of disbelief. The emails will have to wait, though, as will the rest of the work that is starting to pile up for my nonprofit. At that moment I just want to take a break from the insanity and enjoy my coffee while watching Walter White cook crystal meth.

An hour later my phone rings. It's Mom calling from work

as she does every summer morning to make sure Andrew and I haven't set the house on fire.

"Is Andrew awake yet?" she asks.

"Yeah, he's on the couch watching *The Price Is Right*," I lie, not wanting to give her the idea that he's being lazy or irresponsible.

"Whatcha up to?"

"Just watching Netflix."

"What are you guys gonna do for lunch?"

"I don't know. We're fine."

"I know you're fine. I'm just checking. Can't your mom be concerned?"

"Yup, we're good." We say goodbye.

Andrew comes out of his room shortly after. He collapses onto the couch in our living room, and soon, I hear Drew Carey telling contestants to spin the wheel coming from the television. A few minutes later, Andrew yells, "Yo, do you care if Ryan comes over later?" I don't. His friends and my friends inhabit our house most days of the summer, but he still always asks to make sure I don't need his help with anything before inviting people over.

"I just need my teeth brushed, hair combed, face washed, and shoes on," I tell him.

"Yeah, I guarantee that's not happening," he says. Ten minutes later, he helps me do all four things.

Ryan arrives, and Andrew informs me they are going to McDonald's and asks if I want anything. "A McDouble and a

large sweet tea,” I say. Andrew says, “Okay. So a cheeseburger and a small sweet tea because you weigh thirty pounds, and I’m not wasting money on food you won’t eat.”

Twenty minutes later, Andrew and Ryan come back with the goods. Andrew cuts my cheeseburger into four quarters and grabs me a plastic fork (metal forks are too heavy for me, but a fork is necessary since I can’t lift my hands as high as my mouth). We eat and play FIFA and go swimming. A summer day doesn’t get much better in my mind. It’s relaxing, simple, and nothing happens to remind me of the disease that’s slowly destroying every muscle in my body. Just a normal day in the Burcaw household. I say “normal” but what I really mean is “normal for us.” Ever since my diagnosis, the idea of normalcy has taken on a very different meaning for my family and me.

## chapter 2

### the lazy baby

**My life waved goodbye to normalcy in 1992 at the Sayre Childhood Center in Bethlehem, Pennsylvania.** I was nine months old, and while the rest of my classmates spent their days crawling around the room, pooping themselves and making a mess of everything they could get their hands on, I was perfectly content to sit wherever I had been placed, playing with whatever toy I had been given, or simply watching my other baby friends explore the world. I never moved. Crawling just didn't interest me.

My observant daycare monitor mentioned my complacent nature to my parents and suggested that they take me to a pediatrician. It was probably "no big deal." Sometimes babies experience delays in physical development, but it was probably best to play it safe and have a professional check me out. My pediatrician was more concerned. He felt that I needed to be seen by a neurological specialist.



I'm not sure how a sedentary baby winds up with such a grisly scar.

During the neurologist appointment, that “no big deal” became slightly bigger.

After spending an hour watching and interacting with me, the neurologist declared that she was almost certain I had a neuromuscular disease called spinal muscular atrophy (SMA). She couldn't be sure without performing a few significantly more invasive tests, but those needed to be done at a specialized hospital in Philadelphia, so the waiting continued. She warned my parents not to research the disease before I had an official diagnosis; the existing literature would only dishearten (read: scare the shit out of) them.

I need to take a little time to explain the boring facts about my disease. I apologize. If you'd like to make this paragraph more interesting, light your hair on fire and try to finish the

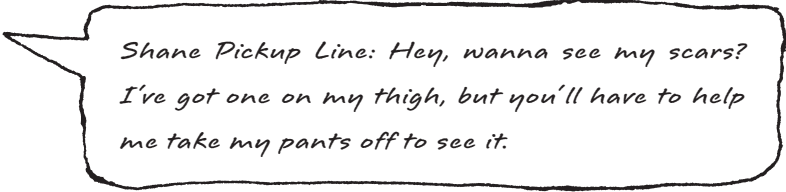
paragraph before your scalp starts to melt. SMA is a neuro-muscular disease that affects approximately .0001 percent of the population. (I can't wait for the hate mail that begins: Hey, Fucker, I looked up the prevalence of SMA, and I'll have you know the true percentage is actually .00023 percent." I've learned on my blog that people will get angry and argumentative over anything.) The human body has two proteins that help to create and maintain muscle tissue. An individual with SMA lacks one of those proteins, resulting in poor muscle development and progressive muscle deterioration over time. Basically my body just didn't feel like developing these proteins while I was in the womb. I was the laziest fetus you'd ever meet.

There are three main types of SMA, aptly named Type I, II, and III. People born with Type I usually die before their second birthday due to severe wasting of lung and heart muscle tissue. On the other hand, Type III individuals usually walk for a few years before their symptoms become apparent. Their muscles waste away much more slowly than those of people with the other two types. Type II is really a toss-up. It is characterized as being an unpredictable combination of Types I and III. Important disclaimer: people outlive their prognoses all the time, sometimes by many years. I provide them to give you an idea of the very nature of the disease.

A few months after receiving the unofficial diagnosis from the local neurologist, my parents and I experienced a tiny



glimpse of hell as I underwent the necessary tests to confirm the SMA diagnosis at Children's Hospital of Philadelphia. I don't remember it obviously, but I've heard the story from my parents a billion times. One of the tests involved inserting electrified needles into my thighs and shoulders, creating an electric current through baby me. Healthy muscles twitch and spasm when subjected to electricity. In my case, I reacted to the incredible pain with only tears; my muscles remained motionless. As if being electrocuted wasn't enough trauma, the doctors also cut a chunk of muscle from my thigh later that afternoon for another test.



*Shane Pickup Line: Hey, wanna see my scars?  
I've got one on my thigh, but you'll have to help  
me take my pants off to see it.*

The next day my parents were finally given the crushing news they'd been expecting to hear all along. Shane has Spinal Muscular Atrophy Type II.

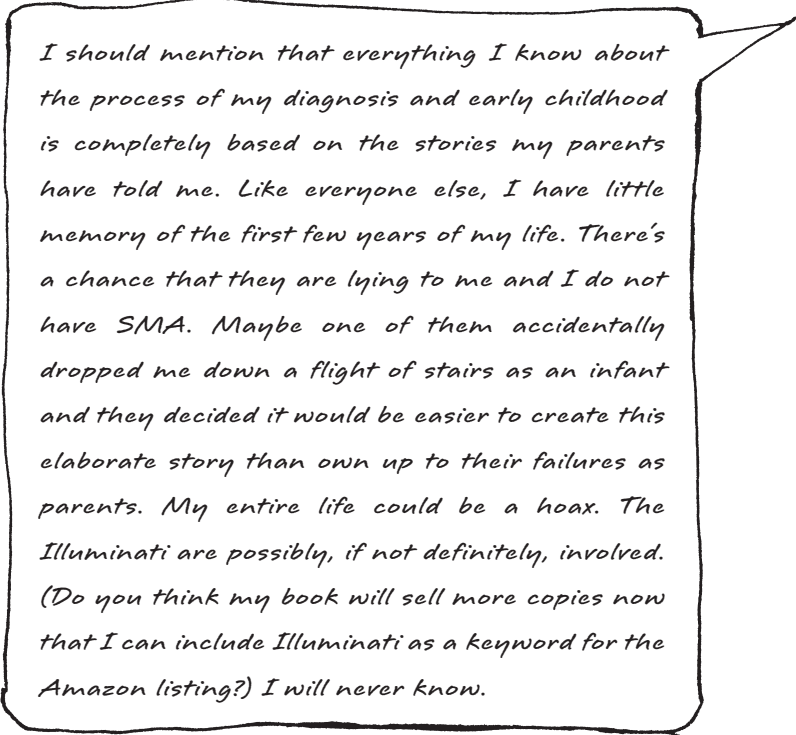
"Will he ever walk?" asked my father.

To this day, he tells me that hearing the doctor's response was the hardest moment in his entire life.

But therein lies a peculiar detail that defines my family. Finding out about the diagnosis was the most difficult part for them. Accepting it and figuring out how to deal with it came almost naturally.

My parents decided that this diagnosis was not going to cripple the happy life they had imagined for themselves and their son. Life is beautiful, with or without a severely debilitating muscle-wasting disease. Before grief and sorrow even had a chance to sink their teeth in, my parents made a decision. My life would be normal. SMA was not the end, but the beginning. A bump in the road. An obstacle to rise above.

And so, the journey began.



*I should mention that everything I know about the process of my diagnosis and early childhood is completely based on the stories my parents have told me. Like everyone else, I have little memory of the first few years of my life. There's a chance that they are lying to me and I do not have SMA. Maybe one of them accidentally dropped me down a flight of stairs as an infant and they decided it would be easier to create this elaborate story than own up to their failures as parents. My entire life could be a hoax. The Illuminati are possibly, if not definitely, involved. (Do you think my book will sell more copies now that I can include Illuminati as a keyword for the Amazon listing?) I will never know.*

## chapter 3

### learning to drive

**As a baby I wasn't much different than any other** baby. Other than not being able to crawl, I was not limited in any other way. My mom tells me that it was almost nice never having to worry about where I was because I was always exactly where she put me.

I started talking in complete sentences at a very young age, a common trait in SMA Type II-affected individuals. It makes sense. I probably became aware that communication was vital to getting what I needed. If I couldn't reach a toy a few inches away from me, all I needed to do was ask someone and they were more than happy to help. This reliance on others began when I was a baby, and has followed me since.

The real fun began in preschool at the age of three, when I got my first wheelchair. I attended a preschool that specialized in helping the physically and mentally disabled; the only "special" school I've ever attended. It ultimately served me

well. There was a physical therapy center within the building, and that is where I learned how to drive.

At first the therapists put me in a small vehicle that looked nothing like a wheelchair. It was basically a box on four wheels. In front of me sat four large arrow buttons, pointing forward, backward, left, and right. I curiously pressed the forward arrow and almost fell over at the unexpected lurch. My eyes lit up as my young mind began to comprehend the independence I suddenly had. Up until this point in my life, movement of any type meant being carried by my parents, or being strapped into the jogging stroller that they used to take me places. I had been conditioned to appreciate my surroundings from wherever I was seated, but now, if I wanted to move left and further inspect the fascinating bug on the wall, all I needed to do was press the left button until I was closer.

This training chair didn't last long. Therapists use it to teach children the basic concept of using a wheelchair to navigate through the world. A few days later, they brought a real wheelchair for me to try. After strapping me securely in place, the therapists explained that instead of directional buttons, I would now use the joystick that sat in front of me to control my movement. This would allow me to have 360 degrees of control of my chair's direction. And, the therapists said, this wheelchair was a lot faster, so I needed to be careful.

Less than twenty seconds later, I had smashed full speed into the padded wall on the opposite side of the therapy room. The therapists gasped. I cracked up laughing.

I was reprimanded for putting myself and other people in



Three months later, I was offered a contract by the Phillies. Nana Jean and I playing baseball in her front yard.

danger. How was hitting a padded wall dangerous? I asked. This question earned me a stern speech on maturity and responsibility, two values I had to learn at a young age. Clearly though, they didn't understand that I was in complete control the entire time. I wanted to hit the wall. In fact, crashing into the padded walls of my preschool became one of my favorite activities. I've always been a bit of a thrill-seeker.

Luckily my parents had a good medical insurance policy that covered the cost of a motorized wheelchair, and the therapists at my preschool were able to convince the insurance company that I needed one for independence at such a young age. I had my own wheelchair a few months later. From that day on, I spent almost every waking hour in the seat of that ridiculously expensive (\$28,000) little vehicle.

My family—which now included a little brother named Andrew—and I lived on a quiet street in Bethlehem for the first eight years of my life. Maple Street was lined with towering maple trees that created a tunnel of shade during the summer. Along either side of the road were several town houses. Our home was brick and had a cozy, covered front porch with a baby swing that my dad would push me in to break up the constant wheelchair routine. We didn't have much of a front yard, and the moderately sized backyard was mostly taken up by the winding wooden wheelchair ramp that my dad built so I didn't have to sleep outside. For my brother, our friends, and I, the front sidewalk and back alley became the primary places to play. My enjoyment of wall-smashing quickly turned to sports once my brother was old enough to play them, which was about two days after he began walking.

## chapter 4

### whoops!

On a humid July day when I was six, instead of racing around outside with my neighbors, I was sitting on the toilet, strapped into my specially adapted backrest, quietly weeping at myself for being so stupid. What was wrong with me? On my bare lap sat our house phone, waiting for me to gather the nerve to call my neighbor, Ben.

A few hours before Ben and I had been spending the day the same way we spent every day of our summers, playing cops and robbers, cowboys and Indians, and other crazy games of our young imaginations. On that particular day we were constructing an epic volcano in Ben's backyard sandbox. By "we" I really mean Ben. Sitting in the sandbox was difficult for me at this point in my life, so I sat above in my wheelchair and played the role of bossy friend who wants to help but can't sit in the sand.

“The left side needs more sand.”

“Careful you’re gonna wreck it.”

“You should try to dig a moat around the outside.”

“Oh my God! Move, move, move! I just saw a huge pincher bug by your foot!”

The pincher bug I spotted quickly destroyed our desire to finish the sand volcano, even though Ben’s mom was going to allow us to make it erupt with vinegar and baking soda. Instead, we spent the next hour spraying stuff (mostly each other) with Ben’s garden hose. It was around this time, after drinking copious amounts of water from the hose, when I noticed that I needed to pee.

In my preschool days, I viewed going to the bathroom as nothing but a nuisance. During the summer, going to the bathroom meant stopping whatever awesome game Ben and I were playing, returning to my house, having my mom carry me upstairs, undressing, using the toilet, redressing, being carried back downstairs, and finding Ben again. The whole process probably took twenty minutes, but that’s a lot of time to a six-year-old. For this reason I chose to ignore my bladder on most summer days, holding my urine until it became painful and then some.

The “full bladder pain” became noticeable while we were playing with the hose, but I put it out of my mind when Ben’s mom brought out a new Super Soaker to play with. This would be a great weapon to use in our next bank heist.

Half an hour later, as we quietly crept around the back of





A life of crime does terrible things to people. Left to right: Myself, childhood best friend Ben, his brother Harry, my brother Andrew.

the bank that we were robbing (our neighbor's shed) with our fully loaded Super Soaker, I began to sweat. My breathing became rapid and shallow. This was not a nervous reaction to the felony we were committing, but rather my body trying to tell me that I was going to explode if I didn't pee soon. But you don't just go to the bathroom in the middle of stealing one billion dollars from the most highly guarded bank in the entire world.

When the bank guards opened fire with their machine guns, Ben leaped behind a birdbath and fired back at the windows of the shed. It was the climax of the heist. Ben desperately shouted for me to run in for the money while he covered me, but I couldn't pretend anymore. I couldn't even move. A

small trickle of urine forced its way out of my body and I lost control.

I closed my eyes and basked in the orgasmic feeling of my painfully swelled bladder emptying. Nothing on earth mattered. Not the fact that I was peeing in my pants. Not the fact that I was doing so three feet away from my best friend. Not the fact that I was in the middle of my neighbor's backyard. Not the fact that halfway through the emptying I was sitting in a warm puddle. Not the fact that six-year-olds don't pee in their pants. Not the fact that it was running down my legs into my shoes and socks. Not the fact that my mom was going to kill me. Not even the fact that Ben had been shot by the guards and was now lying dead next to me.

"I'll be right back," I said nervously as I finished peeing and started for my house. I didn't think Ben noticed what had just happened, and keeping it that way suddenly became my biggest priority. He'd obviously never treat me the same way if he knew I was a baby that peed his pants. I was entirely convinced that he would associate me peeing in my pants with me being in a wheelchair and he wouldn't want to be my friend anymore.

I dialed Ben's house number through watery eyes from the seat of the toilet. His number was the only phone number besides our own that I knew by heart, probably from calling it every morning to find out when he could come outside to play. As it rang, I gritted my teeth and tried unsuccessfully to stop my hyperventilating breaths. I hated my mom for

making me do this. She had reacted exactly how I had expected her to when I arrived home. Lots of yelling about how I needed to learn to stop what I was doing when I had to go to the bathroom. Playing is not more important than taking care of your body, blah, blah, blah.

When she asked if I still needed to go more, I lied and said that I did, making the brilliant reasoning in my six-year-old brain that she would not be as mad if she knew that I had at least been able to somewhat control my bladder. She was. My chair was literally dripping with piss.

After strapping me onto the toilet, she handed me the phone and said, "Call Ben and tell him why you are not allowed back outside today." I stared at her in horror, knowing she had already made up her mind.

Ben's mom answered the phone, "Hello?"

"Hi . . . is Ben there?" I sheepishly asked. I felt like she knew.

"I'll go find him. I thought you guys were outside . . ."

"Hello?" It was Ben.

"Hey, Ben." I started crying again, glancing to make sure my mom wasn't in the bathroom. "Ummm . . . I can't come back out to play."

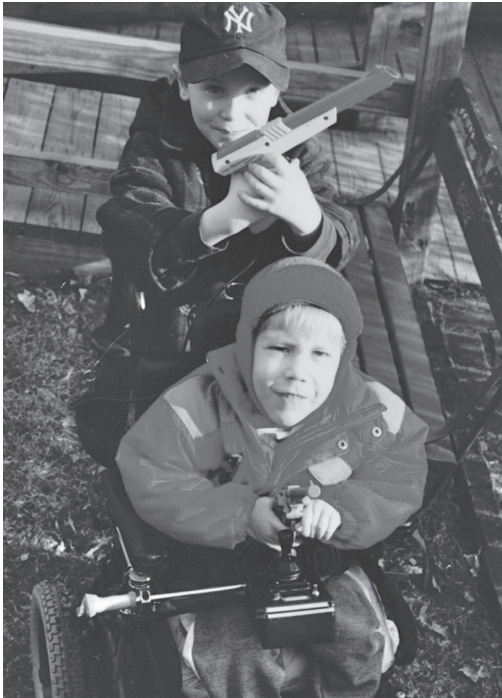
"Aww, man! Why not?" he moaned.

"Well, I was really, really sweaty when I got inside, and (huff, huff, huff) my underwear and shorts and wheelchair were like wet from the sweat, but my mom thought it was pee so she grounded me. She thinks I peed in my pants," I

lied, still extremely embarrassed by the fake story I was telling him.

“Oh . . . darn. Okay, well, can you play tomorrow?”

We did play the next day, but before we tried to rob the bank again, I went back to my house to get ammo and body armor (and to use the bathroom).



Wheelchairs also make great getaway vehicles. Ben riding on the back of my wheelchair.

## chapter 5

### helplessness is a real bitch

One of my biggest fears has always been not knowing how much longer I have to live. My fear of death is more of a long-term, always-in-the-back-of-my-mind type of fear and usually does not largely affect me on a day-to-day basis. I have another fear, though, and it toys with my mind almost every day, or night, I should say. This fear is completely unjustified, slightly embarrassing, but very real. I am terrified of being stranded in my bed.

I can't do much of anything on my own, including getting in and out of my bed. Every night, someone in my family lifts me out of my wheelchair and puts me in my bed. I am so weak that once I lie down, I rely on other people to move my body and limbs into comfortable positions. Once I am in a sleep-worthy position, usually on my left side, curled up like a baby, the family member that helped me with the transfer

turns off my lights and leaves my room. This is when my brain starts to run wild.

If I ever become uncomfortable or need to roll to my other side during the night, I have to yell loud enough to wake someone up so they can come help me. In a typical night, I roll at least one or two times. This reliance on others to stay comfortable is where my fear of being stranded in my bed arose.

*Actual conversation with Andrew:*

*Me: Can you pull my socks off?*

*Andrew: No. You're just trying to get naked.*

*This isn't Girls Gone Wild, Shane. It's time to go to sleep.*

When I was a young kid, say six or seven, there was one single incident I can remember that I believe initiated this whole stupid fear. Our house on Maple Street was a two-story house, which is absolutely the worst living situation for a family with a kid that can't walk. All of the bedrooms were upstairs, so every night, my mom or dad carried me up that flight of stairs to put me to bed. Since I was young, they made me go to bed a lot earlier than they did, so they put me in my bed and then went back downstairs. My parents used a baby monitor well past my baby years; they had to, or else they never would have heard me calling for someone from all the

way up in my room. I remember getting anxious between the moment I yelled one of their names and the moment I heard one of them start to climb the staircase. Did they hear me? Should I call again? And I often did call them way more than I needed just to make sure they could still hear me.

Anyway, there was one particular night when my mom put me to bed and told me that she and my dad were going to sit out on the front porch for a little while. My six-year-old brain did not like this because of the distance and walls that would be separating me from their ears, but my mom assured me that they would have the monitor on and that I would be fine. She left my room and about ten minutes later, I decided I needed to call them to make sure they could hear me.

No reply. No footsteps. I called again, louder. Nothing.

Panic started to flood my body and I continued to yell for them. Little did I know the monitor had died and they couldn't hear me at all out on the front porch. I began to cry profusely, all the while screaming for them at the top of my lungs. I was completely certain that something terrible had happened to them, and I was going to be stuck in my bed until I died. For a good forty-five minutes, I tried with all my might to call someone, anyone, for help. When my parents decided to come back inside, they immediately heard me screaming, "HELP ME!" as if I were in serious pain. They ran upstairs and calmed me down, but I was already scarred. The reality that I am absolutely helpless in my bed became burned into my mind.

Even today I can't sleep with my bedroom door closed. If I ever go to bed before my parents, I lie there and worry until I hear them both go to bed. If I know that only one person will be home in the morning, I wake up before everyone else leaves and ask them to put me in my chair so that if something happens to them, I won't be stranded. I literally have never taken a nap during the day because I'm afraid that when I wake up nobody will be home and I will be in pain.

My brain tells me that there is nothing to worry about, that my family knows I can't be left alone in bed. But there is always that tiny what-if that ruins everything. What if I wake up in a considerable amount of pain and my dad is at work, my brother is at a friend's house, and my mom falls and hurts herself in the basement?

After experiencing that feeling of total helplessness, it's hard to convince myself that everything will be fine.