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## Fighting Demons, Fighting Cancer

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# Fighting Demons, Fighting Cancer

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## Chapter 1: Fighting Demons

Demons. I'm surrounded by demons. To my left, soul-draining succubi shoot balls of magic, to the right stand acid-flinging Cerberuses, and straight ahead, gigantic, fire-breathing balrogs lurk ominously. First I charge the succubi, killing them quickly with a barrage of Level 20 fireballs. Next, I take the Cerberuses using the same technique. The balrogs, however, are immune to fire. I push F4 to change my spell to chain lightning and electrocute the spawns of Satan. Now, on to Lazarus, the teleporting super demon. I'll get him though, for I can teleport too!

Enter Mom: "What are you doing, Sweetie?"

"Killing Satan," I respond briefly, trying to ignore her.

"Well, that's good, how was your day?" she begins rubbing my shoulders.

"Fine."

"Please make her leave," I pray silently.

"Did you get your test back?"

"Yes, I failed."

"Really?" She hesitates, "You can do better than that."

"I don't know if I can...I studied so hard."

"Well, I'm sure you'll do better next time."

I smile.

"You are lying to me aren't you?"

She fell for it every time, and it never grew old.

"Hahaha, a little bit."

"Then how did you do?"

"I did pretty well."

"How well?"

"I got an A."

"Oh, good." She moves her hands from my shoulders to my neck. I grimace.

"Mom, I'm trying to kill demons here...can you please leave me alone?"

"No, I could never leave you alone! I love you! You are my baby boy!" Her smile gleams at the back of my head. I catch it in the monitor.

I shudder, "Dang."

"What is that?"

"That is a Lazarus...a demon. I'm trying to kill him, but you are hindering me greatly. Right now, you are risking the life of your son. You should be ashamed." The best part of teasing my Mom is that half the time, she does not even realize she is being teased.

"Huh? What is this on your neck?"

"I don't know, you tell me, you're looking at it." I contorted my head and eyes, demonstrating the logistical problem.

"There is some kind of growth...it's huge! Have you really not noticed it?"

"Well, I don't normally give myself massages, or stare at myself endlessly in the mirror...can I kill demons in peace now?"

"This worries me Ethan...I don't like it."

"It's probably just a large pimple...besides, I don't like you rubbing my neck, isn't it time for bed?"

"Have you ever had a pimple the size of a walnut?"

Lazarus kills me.

"Have you ever been halted in your pursuit of fighting evil by an overzealous mother? I have. Off with you, woman." I was only half serious.

She laughs, "I'm calling the doctor."

"Cool. I love you Mom; have a good night."

"Good night," she replies as she leaves.

The next morning, Mom called our family doctor. At first, his nurse said, "Oh, it's probably nothing, put heat packs on it." So we did and nothing happened.

A week later we called again and she responded, "Okay, try cold packs," and again nothing happened.

So we responded in the most obvious of ways: we ignored it.

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I've had horrible headaches since childhood. These headaches did not just throb, they were completely debilitating. Light and sound became the enemy, and if I tried to move, saw any light, or heard a loud sound, it felt as if my head were a baseball and someone had just hit a home run. The headaches seethed and vertigo frequently accompanied them. As a child, I had a toy cash register at my grandmother's house. During headaches, the register, with its slot machine-style rotating images, rolled quickly and uncontrollably in my mind. I'd become dizzy and disoriented.

Once, in kindergarten, I went to the office and declared, "I want to go home."

"What's a matter?" they asked.

"I have a headache." I held my head.

They took my temperature and treated me as if I were a lying villain. "You have no temperature; you have to go back to class."

As I began to walk out the door, I puked all over their office. Impeccable timing.

It was because of these headaches, that I saw Dr. Ryan, my neurologist.

*September 11, 1999*

Dr. Ryan was a chubby, jolly, white-haired man. If he had a beard, he would have looked like Santa Claus. In the last few months, I had gotten to know him pretty well. He had abandoned his huge practice in Los Angeles to get away from the stressful lifestyle of the city. He sincerely cared about the well-being of his patients, and he went beyond the doctor/patient relationship and became a friend.

When I went to his office, the waiting room was empty, and it was not long before we were called into the back. Diplomas and medical diagrams flooded the white wall of the room, in typical doctor's office fashion. Under one of the diagrams were a plethora of pamphlets explaining various neurological ailments. I grabbed one entitled "The Truth about Migraines." I intended to look at it. I never did. Like most pamphlets, it was wasted by some fool with good intentions. The lighting was less than spectacular, but it worked. I could see fine, but it did feel a little creepy. Perhaps all doctors' offices should.

When Dr. Ryan came in, he greeted us with a smile. "How are the headaches?"

\*This author wrote the paper as a Senior thesis under the direction of Dr. Davis Schneiderman.

"I still get them occasionally, but the Percocet works pretty well."

"Good, good. Is anything else bothering you?"

"No, everything is—"

Before I could finish the sentence, my mother grabbed the collar of my shirt revealing a growth the size of a walnut, "Look at this."

Dr. Ryan probed the bump carefully and cautiously. His eyes became hollow, and we waited for a response. Realizing the grave nature of his investigation, he announced, "You better see a real doctor," with a chuckle.

We laughed nervously.

"Most of the time these things are nothing, but you better have someone check it out. I haven't been in medical school in a long time."

#### *August 1996*

My mother can get things done. She is volatile, and at the slightest shaking, she will explode. I've been the object of this explosion many a time and deservedly so. On occasion, however, I have seen my mother destroy the fragile egos of innocent employees. These hardworking individuals were just trying to get by when my mother entered their life. She left them homeless and broken, perpetually sipping on their brown bag special.

"I'm here to pick up three reserved books under the name of 'Helm.'"

"Can I see some identification?"

My Mom passed her driver's license to the worker. "Here you go."

"Please, wait one second." The clerk typed quickly on the keyboard. "Ms. Helm. It appears that we are out of the books. Another order comes in two weeks."

"I can't believe this! I want to see a manager immediately!" she bellowed. My sister and I hid behind a bookcase a bit away, hoping that nobody we knew noticed us. The manager walked up after employee number one had run away in tears.

"What seems to be the problem?"

"You sold my books. This is unacceptable. My baby needs these books next week!" She found us and pointed at Sarah, who has hated the world ever since. Mom's face mimicked that of a demon's, her lips trembled as she harnessed the power of her anger, "You can't do this to people!" she added, before letting out a scream that sounded something like, "Raaarrggghhhhh."

"I'm sorry Mrs. Helm. We will get the books as soon as possible. Here is a \$100 gift certificate. We will call you soon." The manager handed the certificate to my mother clearly trying to convince my mother to leave without being so blunt.

"You called yesterday and then sold my books anyway! Come on, children! Let's go!"

As we stepped out of the store, confetti surely fell from the ceiling and everyone in the store celebrated.

#### *March 1998*

One day in the middle of a family card game, my mother decided to multitask. She picked up the phone.

"Wal-Mart Lawn and Garden, what may I do for you?"

"My name is Rebecca Helm, and I am calling to find out the status of a lawnmower we brought in for repairs."

"Helm...can you spell that?"

"H-E-L-M."

"Um...we do not have records of a lawnmower under the name Helm."

In Hulk-like fashion, my mother transformed from a sweet southern mother to a raving lunatic. "What do you mean you lost our lawnmower?" she bellowed.

My Dad, my sister, and I looked at each other with empathy for my mother's prey.

After being transferred to a manager, who she also berated, the manager agreed to give her a new mower.

"Well, we will just give you a new mower. When can you come into Searcy to pick it up?"

"Oh, God, are you in Searcy?"

"Yes, m'am."

My Dad immediately recognized what had happened, and yelled, "GIVE 'EM HELL, BECKY!"

Mom, who was laughing so hard she was crying, looked at my father with a finger over her mouth. "Shhhhhh!"

When my Mom called the Benton Wal-Mart, they had talked to the Searcy manager, and they wanted no trouble. They gave my mother a new lawnmower, even though they had our old one repaired. They gave us it, too.

My mother does not shield what she is. She is a loud, emotional woman who is not afraid of butting heads with anyone. She is determined and caring, especially when it comes to her children, their books, and our lawnmower. Thus, she did not hesitate to bring me to the doctor the morning after Dr. Ryan's suggestion, despite the fact that we had no appointment. Her baby was going to the doctor; she would not be stopped.

My father and I were not worried. Dr. Ryan said it was probably nothing, and these words stuck with us. It's easy to overlook symptoms when you do not expect disease.

#### *September 13, 1999*

As soon as we arrived at the doctor's office, my Mom began speaking.

"I know we have no appointment, but Ethan's neurologist said we need to have this tumor looked at as soon as possible." She sniffled, "We are scared."

The receptionist grabbed her hand and said, "It'll be okay, honey, we will fit you in." An hour later, a nurse called us to an examination room.

In today's medicine, it can be difficult for doctors to have a relationship with their patient. Insurance companies and hospital administrators push them to see as many patients as possible and medical training often serves to desensitize physicians from the emotional implications of their treatment. Many doctors struggle with this, and they begin seeing their patients as diseases and not human beings. They do not view their patient holistically, but instead by the disease that afflicts them.

Dr. Sudderth never fell into this trap. He treated human beings, not just diseases. He asked questions about the patient's life as well as the medical abnormalities. In the past ten years, he removed giant splinters from my hands, treated me for numerous colds, and gave me at least three strep tests. Yet every time I saw him, he asked about school, soccer, and life, and this time was no different. After small talk, he examined my lymph nodes by gently twirling his fingers into my neck to identify swelling. Then he checked under my armpits before moving down to my groin. After the examination, he prodded the tumor on my neck.

"So here is the deal: most of the time swollen lymph nodes are not a problem. In fact, these lymph nodes are probably no big deal at all. You see, lymph nodes swell due to infection. It is a natural process. It is a good thing. It means the body is ready for a fight. Ninety-nine percent of the time, these things are not cancerous. It is better to be safe than sorry though, so I scheduled a biopsy for tomorrow. The surgeon is Dr. Dixon, he is very good, and the scar should be minimal. Again, it is probably nothing. Do you have any questions?"

My Mom always had questions, although most of the time, I found them to be irrelevant. I got the impression

that she felt as if she had to prove something to the doctors. She wanted respect. My mother is an extremely intelligent woman. When she was younger, she thought of becoming a doctor, but an unfortunate incident involving sexual harassment and a difficult zoology class inspired her to seek another career. Instead, she became a hypochondriac. Rebecca Helm has never found a disease she did not like. Every time someone tells her of their rare condition, she pauses for a second and thinks, "This sounds like me!"

In the middle of one of my chemotherapy treatments, my mother sat solemnly, rotating her fingers around her neck. She looked at me and ordered, "Feel my lymph nodes."

"I don't feel anything."

"Really? I feel this bump."

"Mom, you do not have cancer."

"I hope you're right."

"Trust me, Mom, you are fine."

"Well, if I could take your cancer away, I would.

You know that, don't you?"

"Yeah, I know."

"I'm serious. I love you."

"I love you, too, Mom."

My mother is a good mother; good mothers worry excessively. My mother worried excessively. Conversely, my father and I saw no reason to be worried. Dr. Ryan and Dr. Sudderth had reassured us. Everything was going to be alright. I probably just had mono or something.

Despite this, nobody feels overjoyed before their first surgery. My mother prepared me for the worst. "Anesthesia makes me sick. The doctors have tried several different drugs on me, and I'm allergic to all of them. Once, I told the doctor not to use Demerol. He did anyway. I puked everywhere. I could have sued, you know? Anyway, you have to be ready for side effects. Surgery sucks."

My Dad had a different take on it. "It'll be alright."

I preferred Dad's response.

Mom and I departed early in the morning, just like we did everyday. Or not *quite* like we did everyday.

### **A Normal Week Day**

7:00 am: Mom wakes me up.

7:01 am: I fall asleep.

7:15 am: Mom: "What do you want for breakfast?"

7:16 am: Me: "Nothing." I close my eyes.

7:30 am: Mom: "Ethan, you need to get ready!"

7:31 am: I snore.

7:45 am: Mom: "We are going to be late! Get up!"

7:46 am: "Oh, shit," I think before jumping out of bed and throwing on clothes.

7:50 am: We leave for school which starts at 8:00 am. It is a fifteen-minute drive. In dramatic movie-scene fashion, my Mom speeds through several country roads, passing slow pokes recklessly as I brush my hair.

7:59 am: We are at school. I run to class.

8:00 am: I enter the classroom just before the bell rings. Mission successful. I ponder my future as a daredevil, or at least a sidekick.

### **September 14, 1999**

We didn't have to rush to surgery, and in fact, we arrived early. Eerie. It was probably inevitable though as I could hardly sleep. Not having had anything to eat or drink in 24 hours, sedation seemed a great idea. My stomach roared.

When I arrived at the hospital waiting room, a nurse brought me to a room to prepare for surgery. Surprisingly, I felt comfortable. The nurses were kind and personal as they prepped me for surgery. They tried hard to ease my nerves, and ultimately, they were successful.

Dr. Dixon entered the room with a glowing smile, and we fell in love with him immediately. "You must be Ethan."

"Yes sir."

"Well, it is a pleasure to meet you. This surgery is fairly simple. I will be taking a small sample from your growth. As always with surgery, there are risks, but the risks are minimal. Before I say anything else, I want to assure you that I've done biopsies such as this one many times and 99.9% of the time its not cancer. So relax, it will be over before you know it.

I'm not entirely sure why he told me to relax because in less than five minutes I'd be unconscious. "Well, thanks."

My mother warned him. "Well, I'm allergic to every sedative drug there is. Don't be surprised if he vomits."

"It'll be fine, Mrs. Helm. Don't you worry."

Before long our discussion moved far away from medicine. Formerly, he worked as an aerospace engineer, but he grew tired of working with numbers. He wanted to work with people, and so he became a physician.

Moments later, the nurses wheeled me into the operating room. Dr. Dixon said, "I just gave you some Demerol, you should be out in just a couple of..."

Dr. Dixon softly whispered my name. Lackadaisically, I pulled my head up and looked at him with a smile. With tears in his eyes he said, "Ethan, there is a 99 percent chance that you have Hodgkin's Disease." I looked at him and laughed; the Demerol had not worn off yet. Realizing this, the doctor gently laid me back in bed and told me to sleep.

While I lay unconscious, Dr. Dixon called my mother over, "Your son has Hodgkin's disease. Cancer." Mom cried loudly, and my Aunt Pam, who had joined her in the middle of the surgery, got up to join her.

"I don't understand. He's such a good boy. I always prayed that God would put guardian angels around him to protect him. I don't...understand." My aunt, whom had not even heard the news, understood it was bad. She hugged my mother and together they wept.

Then, Dr. Dixon, in one of those rare moments of pure and beautiful human understanding, knelt beside them. He grabbed the hands of the two mourning women, and prayed, "Dear sweet beautiful Creator, please heal this boy of his disease. Lord, help his life prosper. Dear God, be with this boy and his family as they endure this hard period. Guide them, oh, Lord, and keep them on Your narrow path. Show them Your mighty love, for it never fails. Protect them, Lord, keep them strong. Lord, Your love is more beautiful than the sunrise, Your mercy never fails. Lord, hear their cries and comfort them. Lead them beside quiet waters, oh, Lord. Restore their souls. In Christ Jesus's name I pray. Amen."

Dr. Dixon's prayer did not erase their tears. Nothing could. Yet in that moment of compassion and understanding, he did the best thing that he possibly could. The root word, *ángelos*, means messenger in Greek, and in this way, Dr. Dixon was more than a surgeon on that day. He was an angel.

Another angel was in the room that day. The angel, who my entire life I had known as Aunt Pam, had been through all this before. Nearly twenty years ago, she was expecting twins, James and Benjamin. The twins were due in early April, but something went wrong, and labor began in late November. The babies each weighed less than two pounds, and Benjamin died soon after birth, while James struggled to survive. The doctors were concerned. No child as small as James had ever survived in Little Rock,

let alone in the hospital. His small body fit in the palm of a hand. Even if he did survive, he would probably be mentally disabled. Jimmy Cramer, it turned out, was a lot tougher than the doctors thought. Not only did he survive, but he turned out to be a genius. By the age of eight, he could not put books down, and he earned a full scholarship for college after narrowly missing the cut to become a National Merit Scholar.

Just after birth, we merely wanted him to live. After the pain of labor, my Aunt had already lost one child, and she waited to see if she would lose another. I was a small child when it all happened, and I don't remember much. I remember the whispers of adults as they tried to figure out what to tell us. Were we too young? Mostly, I remember hugging my father as he wept. He picked me up and squeezed me tightly. I served as a reminder as to what his sister had lost. He could not let go.

My aunt's presence helped because she knew this pain. She knew what it was like to lose a child, and she was there to comfort my mother, and later, my father. In many ways, my aunt must have felt like she was living through it again. I had grown up around her. She too changed my diapers, and when I went to school with her (she is a kindergarten teacher), she claimed me as her own. I am fortunate to have grown up side-by-side with my cousins, who are still among my best friends. Dad worked with his parents at our grocery store, Helm's Grocery, and my aunt and mother helped out. Next door, my grandmother babysat us while taking care of the paperwork for the store. We were the American nuclear family, and we loved one another. We still do.

My diagnosis wrecked that nuclear family. We did not expect for the news to be so bad or so soon. Dad stayed at work, and Sarah remained at school, unaware of the surgery. Dr. Dixon had more patients to see, and if it weren't for my aunt, Mom would have been alone. While my aunt suffered greatly, she did her best to comfort Mom. She provided support to a mother scared of losing her son, from a mother who had lost one.

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An hour after Dr. Dixon's prayer, my mother came to my bedside. She thought it would be easier if she broke the news. She brushed my long hair from my face delicately and gently caressed my head. I looked at her eyes, red and swollen from the tears. She reached for my hand, "Ethan, Hodgkin's disease is cancer." I stared. I heard the words, but they did not register. I could not have cancer. I was a kid. Tears fell from my face, and I breathed heavily. I hugged my mother, and she reciprocated. In her arms, I wept. After several minutes, we pulled apart, both of us still leaking. We sat in silence. Mom continued caressing my hair. I was, and am, her baby.

Eventually, Mom gained enough control to drive, and we left. In vain, she told me everything would be fine. I answered, "Yeah, it will all work out," as I stared out the window. Quietly, I overwhelmed myself with questions: What is happening to me? Can I survive this? What if I do not survive this? Occasionally a tear would slowly drip from my eye. I was only fifteen.

As soon as we got home, Mom picked up the phone to call my father. She broke the news to him, crying the entire time. Already tired of hurting her, I moved away to drown out the noise. After fifteen minutes, he managed to calm her down a bit. She then handed me the phone. As I spoke to my father, I realized he was in a state of denial. He hung on to that one percent chance that it was not cancer, and he stuck with the optimistic idea until the doctors verified

the diagnosis. His voice was strong and confident, except for an occasional snuffle that he tried to disguise.

"Ethan, Papa wants to talk to you."

My grandfather was a 79-year-old man who was an orphan during the Great Depression. At the age of fifteen, he begged a restaurant owner to give him the scrapes off the plates for washing dishes. The owner denied him.

In my fifteen years of life, I had never seen him visibly sad. In fact, I seldom saw him without a smile. I loved him very much. I used to sit on his lap as he told me stories. Eventually, I would interrupt him, "Papa, I tell my own story." Then, I would ramble on endlessly, entirely unlike a child prodigy. My stories were hardly coherent, but he listened to every minute, and asked careful questions.

I picked up the phone. "Heya," he said, before his speech became entirely muffled by his tears.

"Hey," I sobbed, both of us inhibited from further speech by our tears.

He broke the silence. "I love you. God's going to get us through this."

"I know," I replied, although at the moment, I had no clue what God would do.

"You take care now. I'll see you soon."

"I love you, too, Papa."

I hung up the phone and did my best to suppress the liquid salt.

There was one more phone call that day. My sister recently entered her freshmen year of college at Lyon College in Batesville. She was my best friend. My mother recognized this, and because of it, she did not want Sarah to be alone when she heard that I had cancer. So instead of initially calling Sarah, she called a counselor at Lyon and asked her to go to Sarah's room to be there for her when Mom told her the news. As soon as my sister heard the doctor's prognosis, she asked to talk to me. Mom handed me the phone, and I said, "Hi."

She was already crying. She asked how I was doing.

I replied, "Pretty good."

She responded with, "No, you're not," and we laughed for a second. She talked for about ten minutes, while I listened and occasionally added in a phrase or two. It hurt to hear the pain in her voice. When our conversation was complete, I ran to my room, grabbed my pillow, and cried into it until I fell asleep.

When I look back at cancer, the physical pain never bothered me. The ramifications of the pain terrified me. The actual possibility that I might die before I turned 18—before I had sex, before I could vote—scared the crap out of me. The pain itself, however, began and ended. I don't recall the pain of the surgery, although cutting the body seldom feels good. Instead, I recall these two phone calls. Remembering the day that I broke the hearts of the people I loved is easy. Instantaneously, I am back in the moment, the quivering voices and never-ending sobs. Even now, almost seven years in remission, the tears come back when I think about it. They are rolling down my cheeks as I write.

I did not want to break their hearts. I did not will cancer on myself in hopes of throwing some kind of cancerous party. It happened. Yet, in those phone calls, I realized that other people shared my pain. In fact, every person who loved me shared my pain. They hurt when I hurt, and while I was alone in my room weeping, they were in their gardens attacking the soil violently as they, too, wept. They were in the bathroom, crying while the shower was on to try to prevent others from hearing it. They were in their dorm rooms, weeping into their pillows. They were holding

each other. The phone calls were the first time that I realized that my life did not belong solely to me. I had many family members and friends who wanted me to survive, not just because I wanted it, but because they wanted me to be around with them. While cancer made me feel isolated, like a lonely hero fighting a feverish demon, this could not be further from the truth. Behind me were an army of friends, family members, and kindred spirits rooting for me. We are much more entangled with each others lives than we would like to think.

One night I forgot this. I grabbed a knife and pressed it against my wrist. The path was too narrow. The road was too far. I could stand no more pain. My race was over. Death from cancer is a long, painful process, and I could not control it. Suicide is easy to control. It would end soon.

And when I remembered the phone calls, I dropped the knife and wept. I grew up that night through realizing how selfish I truly was. How could I give up on those who love me? They never gave up on me. I prayed for forgiveness and never considered suicide again.

And what of those doctors who raised our hopes to crush our spirit! How could they be so negligent? Why did they lead us on? "Ninety nine percent of the time it's not cancer." "It's probably nothing." It was something.

I have never been angry at any of these doctors. Flat out, I think the doctors knew more than they told me. The big tumor was located just above my right clavicle. That means it was at the front of my neck just above the base. Lymph nodes in the front of the neck rarely swell in normal immune reactions. Moreover, the tumor was both painless and firm, both of which are characteristics of cancerous tumors. From the tumor alone, it appeared that something in my body had gone wrong.

Like my family, however, these doctors did not want me to have cancer. None of them were used to diagnosing children with cancer. Dr. Ryan was about to retire. His specialty was pain management for migraines. Over the course of his career, Dr. Ryan had seen many patients with brain tumors. This time, however, he was the first to notice the problem, and in front of him sat a fifteen-year-old male and his mother. I imagine at that point, Dr. Ryan's fear greatly exceeded ours, and how could it not? He knew. I remember the grave tone of his voice, which he tried to disguise with humor when he said, "You need to see a real doctor." It worked. We laughed, but the reality of the situation was anything but funny.

Likewise, Dr. Sudderth and Dr. Dixon were not oncologists. Neither of them dealt with many kids with cancer. Typically, Dr. Sudderth dealt with colds and broken bones, and Dr. Dixon performed minor surgeries. Neither of them was a stranger to cancer. All doctors encounter it in the training process. Yet, nobody wants to tell a child that he may never live to the age of eighteen. Nobody wants to tell a parent that their baby might soon be dead.

All three doctors did not want it to be cancer. They did not want me to die. Throughout the course of my disease, each doctor monitored my case with care, even though they did not have to. Occasionally, they sent get well soon cards, and called my mother to check on me. The public seems to forget that doctors are human. In fact, most doctors decided to become physicians because they cared. And through the long and hard process of medical school in which each prospective doctor becomes acquainted with death, cutting up dead bodies, and making fun of their imperfections to try to lighten the mood, perhaps a small bit of that empathy dies. While they learn to pronounce death, and after having their hearts broken numerous times from

patients they have grown to love, they learn to hide their emotions. Yet, in reality, those emotions never leave. Instead, they are hidden in the back of their hearts as a guard from the emotional weariness that occurs when the process of healing fails. Due to my unfortunate circumstances, I got to see the empathy in these three outstanding doctors, and in the process of my treatment, I would meet many more who saw me as a person and not as a disease.

In my own life, I have heard people speak against doctors. My grandfather lost feeling in both of his hands and sight in one eye due to botched surgeries. Yet, without the surgeries, he would have still gone blind, and eventually he would have lost the feeling in both of his hands. Doctors are not malicious, evil creatures. They are not lawyers. They also are not Jesus. They aren't always able to heal. In our society, we focus more on the failures than the successes. Doctors are expected to lose their humanity. They can never make mistakes. What if we held ourselves to such high standards? Prozac anyone?

## Chapter 2: Back to School

"You're not going to school today," my mother announced. "You're not ready!"

"I'm fine, Mom."

"But it's just been two days. You need rest."

"I'm not even sore any more. What good will resting do?"

"Rebecca," my father piped in, "if he says he is ready to go back, we should let him go. Besides, its not often he begs to go to school."

"It's too soon," she replied.

"Let him be the judge of that." Already late, my father opened the door and trotted toward his car.

"Should I get my backpack then?"

"Yeah, I guess so."

We got into her gold Saturn and were on our way. Since the surgery, I had not said much. Three days ago, I was a relatively normal fifteen-year-old with a bright future and a smile on my face. Now, I was a cancer patient. The surgery had not been hard, and I had healed quickly. Physically, I was ready to go to school; emotionally, I was still in shock, struggling to come to grips with my mortality. I knew that everyone died eventually, but that eventually was supposed to be later...when I had kids, a wife, and even grandkids, not before I graduated from high school. I sat and stared out of the window. In vain, my mother attempted to break the silence. "What do you want for supper?"

"I don't care."

"Is there anything I can do for you?"

"I'm fine."

"Would you like me to make some cookies for dinner tonight?"

"No. Thanks though."

Whenever I had a cold, I had no problem accepting my mother's goodwill. Cancer was different. Diagnosis changed my life enough already. I longed for normalcy, and I resented the kind acts of my family. I wanted to take care of myself.

It is not hard for my mother to cry. If she were a superhero, it might very well be her special power. Her mother used to tell her, "Rebecca, your bladder is next to your eyes." Beyond being biologically impossible, Granny Annie's suggestion seemed substantiated. Yet, Mom's tears never had the yellow appearance of concentrated urine. Either Granny Annie lied or Mom drinks a lot of water.

When we arrived at Bryant High School her eyes were red and swollen. Black bags hanged underneath them.

She was still wearing the purple pajamas I had bought her for Christmas.

"Ethan, are you sure you're okay?"

"Yes, Mom, I'm fine."

I was not ready. I didn't know if I would ever be. My first day back to school was going to be hard whether it was today or a month from now, and I wanted to get it out of the way. Thus far, I had avoided breaking the news to anyone in person. I talked to my family on the phone and one friend on the internet. I had never uttered the words, "I have cancer."

I opened the car door, stepped out, and walked toward the English building to meet up with some friends, envisioning the conversation that was about to take place.

"So guys, guess what!" I would say.

"What?" they would reply.

"I have cancer!"

Then everyone would dance, and we all would be happy.

With each step, my feet became heavier. I lowered my head and took deep breaths.

As I marched forward, I looked up to see Dave, Jon, Ryan, Joe, and Alan standing in a circle. I lowered my head and entered it.

"Hey, Ethan, what's up?" said Ryan.

I had known him since third grade. I had known them all since elementary school, but we seldom talked apart from school.

"I...I have—"

"What is it?" Allan asked.

I took a deep breathe, "I have cancer."

My fists were clenched, and I was shaking. I held my head so low it was parallel to the ground. Joe and Ryan laughed. They all knew I was ridiculous and sometimes inappropriate. There was not much I wouldn't do for a laugh. I raised my head.

"Oh, God, Ethan, are you alright?" Dave asked while patting me on the back.

Immediately, Joe and Ryan began apologizing, and they have continued to apologize ever since.

"How did it happen?" Allan asked.

"I don't know."

"How did you find out?" Jon inquired.

I lowered my shirt to reveal a bandage on the right side of my neck.

They huddled around, offering words of support. Occasionally, one would pat me on the back, and slowly, I began to calm down. The bell rang, and we all went to our classes. When I got to my calculus class, I discovered it was school spirit day.

### Chapter 3: Staging and Statistics

I'm a number now

I'm a statistic

Survivor

Victim

Time will decide

*This poem was written shortly after my diagnosis in September 1999.*

After diagnosis, my mind focused on a single question: "How could this happen to me?" Cancer is something that happens to older people, not fifteen-year-olds. Thus, I did not expect it, and before Dr. Ryan's suggestion, I had not considered it as a possibility. Apparently, by the time I was diagnosed, I had had cancer for a while. Stage IV is the last stage of Hodgkin's disease. Stage I means the disease is contained within the neck,

stage II has progressed to the chest, stage III to the abdomen, and stage IV to another system. I had plenty of time to realize something was wrong, but I did not. I'm not sure if this is because I don't pay attention to minor details, like my health for instance, or if it just never occurred to me that I could be seriously ill. Most likely, it was a combination of the two.

*September 20, 1999*

Dr. Saccente looks like Raggedy Ann. Her hair is not quite brown and not quite red, a color I call subtle orange. She rarely appears professional to the casual observer, opting for baggy, comfortable clothing, instead of more restrictive professional attire. Upon first impression, it is unlikely that many would assume she is a doctor. In fact, she looks much more like a kindergarten teacher. As a pediatric hematologist/oncologist, perhaps this is to comfort the kids. More likely, it is part of her personality, and it is this personality that led her to pediatrics. In many ways, Dr. Saccente is childlike. She loves to laugh and her wild eyes and hands dance around the room as she relays stories. This is not to say that she is immature. She is not. Extremely professional (in all but appearance) and empathetic, Dr. Saccente is a wonderful person and an amazing doctor.

Dr. Saccente does not have the luxury of vanity. She works with extremely sick children. Most of the time, the first contact she has with her patients is either the diagnosis of a horrible disease, such as cancer, sickle-cell anemia, or hemophilia, or the first appointment the patient has had after a diagnosis. Nobody who sees a hematologist/oncologist has a minor illness. It's a serious job, a difficult job, a seriously difficult job, and as is always the case, pediatrics is the hardest. Kids are not supposed to die. Pediatricians such as Dr. Saccente put themselves through severe emotional stress to take care of children who at young ages are confronting circumstances harder than most adults have not experienced. Many of these children will be stunted by radiation, their internal organs will be scarred by chemotherapy, and those ones are the lucky ones in a lot of ways, because many more will die before side effects can take their toll.

Yet, in the midst of a hospital unit with kids waiting for their life or death verdict, Dr. Saccente remained jubilant. For me, she started as my doctor, and she became my friend (although, believe you me, she still is my doctor).

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One of my Dad's best friends, Spencer, would not visit me after diagnosis. He told my Dad, "I just can't look at sick kids. I can't handle it." This angered and hurt my father in ways Spencer never knew. Unfortunately, they never reconciled. Spencer died of a heart attack a few years later.

Many people share Spencer's feelings. They do not want to be reminded of the world's pain, and that pain is extremely visible in the eyes of a child. In the same way, people do not want to hear of genocide, starvation, or the inequality of healthcare throughout the world. They do not want to see children dying of diarrheal illnesses, malaria, or tuberculosis, although eleven million children die from treatable diseases such as these every year. In modern American culture, comfort is valued over pragmatism, and selfishness is valued over selflessness. Ignoring the problem does not make it go away, but for many, forgetting about the problem provides more immediate personal benefits.

While many people hate looking at the painful imagery of sick kids, I can tell you right now that sick kids have inspired and changed my life, and perhaps it is this inspiration that keeps Dr. Saccente, and similar individuals who help children with chronic diseases, smiling.

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Caleb stood at around three feet six inches, but he was not a child. His face looked young, his voice was high pitched, and he had trouble keeping his breath. Pituitary gland tumors are common. Malignant ones are not. Caleb was not supposed to live. Yes, the sixteen-year-old boy who looked like he was five was nothing short of a miracle; as he put the microphone into his tiny hands, he let out all of the love in his heart, which, despite his size, was very big.

Lean on me  
When you're not strong  
I'll be your friend  
I'll help you carry on  
For it won't be long  
'Til I'm going to need  
Somebody  
To Lean On

The boy continued to sing with such emotion, such happiness, and such hope, that we were all at a loss for words. The boy had wisdom beyond his years. Unlike other survivors, he could not escape from his illness. Constantly confronted with the fact that he is half the size he should be, constantly referred to as a little kid, and constantly patronized and picked on, his path has not been an easy one. However, the song Caleb chose to sing was not negative, and his face never wore a frown. Caleb was happy, happy to be alive. This lesson of happiness is among the best side effects of cancer. When death stares you in the eye and you are able to walk away, life gains value. After all, most of our day-to-day problems are not cancer. After cancer, most problems seem miniscule, and if you can learn to smile with chemotherapy dripping into your veins, you can smile through nearly anything.

Every time I have volunteered to help kids with cancer, I have had experiences such as this one, in which a child, who has been through so much, has profoundly touched my heart and reminded me of the blessing of life. Dr. Saccente has these experiences on a daily basis, and she smiles.

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Our first meeting with Dr. Saccente sucked. She explained the nuances of my disease thoroughly, starting with the staging process, then the long-term plan, and finally the installation of a port (a semi-permanent internal IV which makes access to the blood supply easier). She told all of this to two strikingly different people. My mom took notes furiously as if she would be quizzed, while the words glazed over me like a puck over ice. Occasionally, I tried to follow her, but I got lost on the phrase, "You have cancer."

Dr. Saccente's words legitimized my mother's role as undercover internet physician. Carefully, she probed Dr. Saccente with questions, while I sat still listening quietly. Mom had already become an expert through the internet and fired questions left and right.

Doctors hate the internet. The internet gives patients the ability to use and abuse information. Any person can visit wikipedia or web M.D. and become an

expert on any disease or disorder. In the minds of many patients, this hour of research is roughly equivalent to four years of medical school, a couple of residencies, and a fellowship. Yet, hospitals do not recognize this informal medical school training, much to the chagrin of internet-loving patients who are not afraid to give the trained physicians advice and demand certain prescriptions. Hypochondriacs also love the internet. It fuels their fire and enables them to think of new symptoms which, if faked, can be used for another doctor's visit. Mom loves the internet.

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Staging is a necessary but painful process whereby doctors try to determine the extent of the spreading of the cancer. It is extremely important because chemotherapy has a variety of long-term and short-term effects, and the doctors customize treatment based on the stage to minimize for this. For the patients, this time period is terrifying, as it can literally mean life or death. A good prognosis translates to less therapy and high cure rates, while a bad prognosis means more vomiting for a longer period of time and an escalated chance of death.

Cell division is normally regulated by density-dependent growth, meaning that once cells become too crowded, they stop dividing. Cancerous cells continue to divide without regard to cell concentration. Thus, cancer can kill by draining patients of energy (every cell has metabolic needs). Cancer's arsenal includes many life-taking weapons. Cancer in the bone marrow prevents the body from producing enough blood cells, which causes immunological problems in addition to restricting the flow of oxygen. Cancer in the lungs blocks gas exchange, in the intestines it blocks food absorption, and in the liver, it prevents the production of important chemical messengers. In all, cancer disrupts homeostasis, and this is the reason why it, and really any disease, causes death. The body likes constancy, and because of this, the systems of the body work together to obtain homeostasis. Cancer wrecks this equilibrium and prevents it from recovering.

Lymphocytes, a type of white blood cell, power the immune system by fighting foreign substance, such as fungi, bacteria, or viruses which enter the body. Lymphoma is cancer of lymphocytes. Two primary classifications of lymphomas exist: Hodgkin's and Non-Hodgkin's. The biggest difference between the two types of lymphomas is that Hodgkin's disease includes the presence of Reed-Sternberg cells, massive cells derived from B-lymphocytes. In fact, Hodgkin's is the only cancer known to have Reed-Sternberg cells. Non-Hodgkin's, conversely, is associated with a variety of different types of lymphocytes. There are over thirty types of Non-Hodgkin's lymphomas. Hodgkin's is one of the most common types of childhood cancers. Due to its frequency, Hodgkin's is better understood and easier to treat.

We prayed for this disease, which at the fourth stage gave me a 40 to 50% chance of five-year disease-free survival, not a reassuring statistic. In effect, the statistic means half the people with the disease are alive and have no evidence of cancer within five years. Yet in comparison to Non-Hodgkin's, Hodgkin's is wonderful. After five years, only 20 to 30% of patients with advanced Non-Hodgkin's disease survive with no sign of cancer. Our hopes had shifted from the miniscule chance of misdiagnosis to the lesser of two evils. We wanted Hodgkin's disease.

As I learned more about my disease, I wanted treatment, and I wanted it immediately. In the back of my mind, I viewed cancer as a worm which continually burrowed into my body, wiggling rapidly through my body, and threatening to take control at any minute. Cancer is not a



worm. I knew this, but rationality should never be required of a fifteen-year-old who just discovered his own mortality. The worm needed to die sooner rather than later.

During the staging process, I felt like a lab rat. Doctors performed numerous tests on me: blood tests, X-rays, cat scans, MRIs, and bone scans. I failed all of them. Unable to will the cancer out of my body, the diagnosis remained, and in fact, worsened. At the top of the humerus, which makes up the shoulder joint, the bone scan glowed brightly. Normally, light is good and dark is evil. Not this time. Only 1% of all Hodgkin's patients have bone marrow involvement. Even fewer pediatric Hodgkin's patients have had bone marrow involvement, and in fact, only two had been diagnosed previously. Given this information, the oncologists at the hospital held a meeting. They decided that they were no longer convinced that it was Hodgkin's. In three days, they would continue experimenting on their lab rat, this time through surgery.

*September 30, 1999*

A small army accompanied us to the hospital. The conscripts included the Albrittons, the Wolfes, Aunt Pam, and Pastor Larry. Even before the surgery started, their presence was therapeutic. Instead of talking about the obvious, fear, my dad and Mr. Albritton discussed my father's bizarre conspiracy theory views. Dad is a big fan of weirdness. UFOS, demons, conspiracy theories, mythical creatures, you name it, he loves it. Do not be mistaken. He is neither insane nor an idiot. In fact, Dad is a verified genius. Weirdness is a source of entertainment for him as it allows his imagination to roam freely away from the realm of reality. He does not like reality. Albritton also likes weirdness. So they discussed it, and especially how it pertains to the Bible. To most of us, it didn't, but hearing them talk about it made a tense circumstance much easier. Perhaps they both are a little bit insane.

The surgery flew by, and in the end, the doctors had taken bone marrow from both of my hips and my left shoulder, installed my port, and performed a spinal tap. They got a little greedy. When the surgeon came to my parents, he told them that it looked like Hodgkin's disease, and my Mom smiled and raised her hands. The surgeon looked at her as if to say, "What is wrong with you? I just told you your son has cancer."

My Mom caught his look and announced, "Hodgkin's disease is better than Non-Hodgkin's! He has a chance!"

The surgeon looked at my mother as if to say, "You are completely insane."

And so it seemed that everything was settled and therapy would begin. It is never that easy. The doctors had a conference. They were not convinced it was Hodgkin's. To their knowledge, Hodgkin's did not skip from stage II to stage IV. They sent all my scans to a leading expert in New York, while my family waited anxiously. We all wanted treatment. We were afraid the delay was hurting my chance of survival. If we had the option, we would have thrown chemicals at the problem hoping that some of them were appropriate. We did not have the option. After waiting two weeks, the final diagnosis arrived. Hodgkin's disease was confirmed, and treatment began a few days later.

After nearly seven years of remission, I still hate looking at survival statistics. First of all, statistics vary greatly. It is hard to glean useful information from them because different sources report different findings. The confusion from statistics bothers me considerably less than the application of them. One chart I found suggested twenty-year survival rates for patients with pediatric Hodgkin's diseases are roughly 20% lower than five-year

survival rates. This gives me a 20 to 30% chance of living until I'm 40.

I try not to focus on this. Instead, I try to focus on life. I have so many reasons to praise God. I'm 23, heading to Kenya or Guyana, and then medical school. I've had a remarkably successful collegiate career. And most importantly, Jesus Christ died for my sins. Salvation is infinitely better than anything could ever be bad.

A piece of me wants a family. I want to see my kids grow up, and then their kids. I want to hear their first words. And that piece of me hates these statistics the most. I do not want to leave a wife a widow or a child fatherless. It is best for me not to think about these things. When I have so many blessing to focus on, it seems silly to concentrate on these hypothetical problems and yet, it's hard not to sometimes. So it goes.

#### **Chapter 4: Incompetence**

I rarely know where I am, nor do I really care. My sense of direction is atrocious, and even when I know my location, I don't know how to get back from where I came. However, it is not fair to say I live in the moment. I don't. I find the moment boring. You will rarely see me scanning a room to become familiar with my surroundings. Instead, my mind lives perpetually in some kind of dream world. My daydreams are not magical. There are no unicorns or dragons, and surprisingly, I'm not scoring the winning goal of the World Cup. In my dreams, I try to conquer the world's problems. I contemplate poverty, world hunger, the broken nature of man and flaws of modern American culture, or I contemplate the beauty of God's grace. If I live in the clouds, they are not beautiful cumulus marshmallows. My clouds are dark, malevolent cumulonimbus, the burnt remains of would-be smores. Sometimes, my dreams are simpler, and I focus on a girl or the song in my back of my head (often this occurs simultaneously). My head moves back and forth as if it was a metronome and my feet pound the floor, my favorite drum set.

In the physical world, I am much less contemplative. I never notice when someone gets a haircut, and it frequently gets me in trouble. I forget about the sandwich I put on the stove, and it transforms into a mixture of cheesy ash, which is only edible with a lot of Cajun seasoning. I am incredibly unobservant. I always have been. Perhaps the problem stems from my childhood, in which my sister, Sarah, two and a half years my elder, was clearly in charge. I followed Sissy around constantly, and I needed to do so. Until the age of five, my family could hardly understand anything I said. I mumbled quickly and softly, and only my sister could translate. So she did, and my parents had to go through my sister to understand everything I said.

As the leader, Sarah had certain responsibilities, which included constantly telling me what to do. "Bossy," as she became known after I heard my mother scolding her, was in charge. When I was four, Sarah and her friends (who were all evil) decided to play dress up. They, however, did not want to try on clothes; I was the guinea pig. They did not ask me, "Ethan, do you want to play?" Instead, Sarah looked at me, and said, "Bubba, come here." There was no escape. Of course, they had a great time destroying the small amount of dignity I amassed by the age of five. I did not like it. Boys do not wear make up. They do, however, when "Bossy" says so, and for a brief moment in my young life, I was a transvestite.

Fortunately for me, it took my Mom thirteen years to determine that I was not retarded. I used this to my

advantage many times. The conversation went something like this:

"Go make your bed," my mother ordered.

"But Mom, I don't know how to make my bed!"

"Yes you do, I showed you last week."

"I don't remember how."

Sighing, "Sarah, go make your idiot brother's bed."

My mother rarely called me idiot, and never in this instance, but I'm sure she thought it.

"Yes, m'am."

My sister glared at me as I continued playing with my toys.

Like all siblings similar in age, we fought a lot, but that all stopped by the time I turned thirteen and had outgrown her. We became friends, and I willingly followed her whenever she let me. When she started driving, she let me come along frequently. I never cared where we were going or how we got there. Being with my big sister was good enough for me.

In the months before my diagnosis, there were clear signs that something was wrong. Most people would notice if they had a huge walnut growing on their neck. Not Ethan Helm. Some of the other symptoms were equally dramatic, but we ignored them, although certainly not intentionally.

The most dramatic symptom also serves as the most disgusting. For several weeks before my diagnosis, I woke up every night with my sheets completely drenched in sweat which transformed my resting place into a water bed. Having lost our gills millions of years ago, it is hard for humans to sleep in ponds, and as such, nightly I took off the sheets, brought them to the laundry room, and redressed my bed. A few times, I had to complete this process twice. It was a fishy situation, but I never attributed it to sickness. I'm a sweaty, disgusting guy.

I've always been disgusting. When I was three, my mother caught me eating raw ground beef. A few weeks later, she caught me drinking out of the toilet. Disgusting is my natural state.

And I've always been a sweaty guy. In 7<sup>th</sup> grade gym, I had to bring gym clothes every day because if I let them sit overnight in my locker, my clothing would ferment. After a bit of ridicule, I opted to buy an extra uniform and bring a change of clothing everyday. Today, my situation is no different, and after I play a game of soccer, I look like I've fallen into a river. As disgusting as it sounds, it actually works to my advantage on the field. Nobody wants to make contact with me. I can't blame them.

Before 1999, I had never needed an ark to escape from my bed. This is to say that despite my sweaty nature, the night sweats were not normal. I used the blistering sun as an excuse. The summer of 1999 scorched Little Rock, and it was the hottest August in recorded history. When my parents purchased fans, nothing changed. Yet, I ignored any problem other than my room being a sauna.

There were less obvious hints to my illness as well. Some were relatively minor, like the week of classes I missed with the flu, which lasted for a couple of weeks after I went back to class. Who would have thought that a bad cold was actually cancer? Not us.

A few weeks before my diagnosis came my first scare. As I ran after a soccer ball during practice, I began to feel like a test tube in a centrifuge. My chest tightened up and I began to bark as I crawled on all fours. My team stared in horror. My coach rushed to my side and placed his hand on my soldier. "What the hell is going on?" he probably thought. "Are you okay?" he said.

I was too busy coughing to reply. After three minutes, a mixture of blood and mucous came up, and the coughing stopped. The world was still moving around, but I

was able to speak. "I think I'm okay now," I lied. Spitting up blood is not okay. As I lay next to the goal, unable to continue practice, my coach said, "Ethan, you have to tell your parents about this."

I didn't. Normally, I would not have to. My Dad and I fell in love with soccer together. He came to all my practices and all my games, until that year. The store was failing and Dad could not afford to take any time off. So instead, Mom dropped me off at the field, and Dad was not there to see the falling, coughing, or blood.

When Mom picked me up, she asked, as only a musician could, "How was rehearsal?"

"Mom, it's called practice. You don't rehearse soccer."

"I like calling it rehearsal."

"Unless you can convince my team to pick up brass instruments to play while we run around the field, it's not rehearsal, and if you convinced us of that, it would be gross negligence on your part. One should not run with a tuba. Call it practice, Mom."

"Oh, well how was practice then?"

I sat silent.

"Well how was it?"

"It was fine."

And I left it at that.

At the age of fifteen, I still had big dreams: to become a World Cup hero by leading the United States to our first ever victory. If I was to become a World Cup hero, however, first, I needed to start on my high school team. It is hard to become heroic on the bench. I had the skill to start, but I did not have the fitness.

Since childhood, I've always been large. In fact, by 3<sup>rd</sup> grade, I weighed 100 pounds. I was not the fat kid. Instead, I was the fatter kid. Mom called me "husky." I was also tall, and my divulging this information is more of an attempt to excuse my lardiness. So even though I have not grown since I was 13, know that truthfully this height dialogue is for my retrospective self-confidence. I was fat, and my height is irrelevant (5'10").

To become a World Cup hero, I had to cut off a few pounds. Exercise causes weight loss. Dieting causes weight loss. Cancer causes weight loss. One of these is not considered a good weight-loss program. I was too ambitious. Every day, I exercised with the high school soccer team, ate as few carbohydrates as possible, and unknowingly allowed my cells to replicate uncontrollably. Ironically, the diet I chose, the Atkins diet, is really only slightly healthier than cancer. It is completely counterintuitive, and that is why I liked it. A diet in which eating fat is encouraged is a dream come true. Who needs bread when you can just add a few more layers of cheese? Despite the ridiculousness of the diet, the pounds began to fly off. In a period of four months, I lost over thirty pounds.

During my diagnosis, I never wanted to give cancer credit for this weight loss. I had worked hard for it. The doctors always asked if I had had a sudden weight loss, and I would tell them yes, but I would explain I was trying to lose weight. Yet, most likely, cancer was the most effective weight-loss component. The doctors never sat me down and told me that cancer made me lose weight, but in retrospect, the doctors were probably thinking to themselves, "Oh, shit," when I told them about the thirty-pound decline.

## Chapter 5: Fighting Cancer

"Blarrrrghhh," I began.

The noise of reverse peristalsis is hard to describe. Partially this is because that the noise is inconsistent. Sometimes it is more of an "uhhh," while other

times it is more of a "bluah." On occasions, it is a violent "arrrr." The noise never sounds like its more common name of barfing. Vomiting contains way too many syllables. Phonetically, these terms sound like cancer, which at least helps portray that the action is vile.

"Oh, poor baby," my Mom responded while cleaning my mouth with a wet washcloth and softly patting my back. Fifteen-year-old males do not like to be called baby. Yet, in my weakness, I allowed her to continue to belittle my manhood.

"Is there anything I can do?" my Dad questioned.

"I don't think so.... Raahhhh"

"Tim, go to bed. You have to be up in a few hours."

"I can't sleep with this going on."

"Geeeeerrrrrr...me neither."

The puking began four hours earlier. According to Word Net, reverse peristalsis means, "The process of wave-like muscle contractions of the alimentary tract that moves food along." No food came from my mouth. I had not eaten in twenty-four hours. Instead, the liquid that poured perpetually from my face consisted of a mixture of dark yellow bile and stomach acid.

Mom had already called the hospital twice, and each time they advised her to wait and try to give me anti-nausea medication.

Unfortunately, they did not seem to understand that no such medication exists.

Chemotherapy is a puking lobbyist. It begs for vomit, and the body gleefully obliges. Anti-nausea medication is a myth unable to stop the evil bureaucrat that is chemotherapy. Pill form anti-nausea medication mystifies me. It is destined to become vomit. In the middle of puking, it merely becomes vomit seasoning. Some of the oral medications are supposed to absorb through one's tongue, yet I have a sneaking suspicion they actually just enhance the putridity. If you have ever tasted bile, you realize that this is not an easy accomplishment. Pharmaceutical companies, however, are extremely sophisticated and powerful. Their medications flavor the bile in all the wrong ways.

"Are you sure you don't want to take the Phenergan?"

"I'm...orrrrrghghhh," Water from the toilet bowl splashes as I spew a big load of snot-like sewage. "Positive."

Since I was a child, my mother had an irrational love for anal suppositories, evidence of my mother's sadistic nature. Shoving something up my ass to make me feel better never seemed like a good idea to me. Before cancer, in fact, I'd prefer vomiting. Now, I'd shove anything up my ass to stop puking. Yet I still had my hesitations. First of all, Phenergan had consistently failed me. More often than not, diarrhea, one of the other pleasantries of chemotherapy, would quickly follow, and even when it didn't, my induced bulimia continued. I had no faith in the drug, and I was not in the mood to shove anything in my anus. Anemia put me at risk for rectal bleeding. I prided myself in having a non-bleeding rectum.

"Well what should we do?"

"I don't know about you, but I think...uheeach...I'll just continue vomiting."

"That doesn't seem productive."

"Tell me about it."

"Don't you think you should stop?"

"Yes Mom...ahrrrrr...that would be nice."

"Poor baby."

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CHEMO! CHEMO! CHEMO! That's right ladies and gentlemen; chemotherapy forcefully removes calories

from your body. It beats the fat out of you, and at the same time it builds a hatred for food deep into your soul. Before long you will be thinking, "Food...noooooo!" That's right, while you take our wonder drug chemotherapy, you will not desire food. The thought of it will make you sick! Literally! But wait! It gets better. Chemotherapy solidly works your abs. During each act of reverse peristalsis, your body makes a sit up-like motion, all while purging calories! Chemotherapy is like liposuction, Bowflex, and diet pills all in one, and the best part is you don't have to do anything. Once you hook up the IV, bam! Watch the pounds fly off. You just sit there and the chemo does all the work. Goodbye, Richard Simmons! There is no chance I'll be "Sweatin' to the Oldies" again. Why work for your weight loss when chemicals can do it for you? Warning: Toilet not included. This diet can get a little messy and will likely kill you.

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"I'm going to call the doctor again."

"Pleeeegghhhh...Please do."

"Oh, poor baby!"

Moments later Mom returned to the bathroom.

"Want to go back to the hospital?"

"Sppppaaaaa...that's a silly....blaaaaarrrr...question."

"What do you mean?"

Dad stepped in, "What do you think he means Rebecca? Of course he doesn't want to go back to the hospital. We don't want him in the hospital either, but he has to go."

Sometimes Mom misses the painfully obvious things. My Dad is often more than happy to ridicule her for it. Frequently, this caused a fight. Not this time.

"Urrrrhhh."

"Poor baby!"

They helped me to the car, somehow managing to avoid adding putrid decoration to their clothing. I was not as fortunate. Dad handed me a vomit bag and went to bed. Mom sped to the emergency room.

Drained of energy, severely dehydrated, I wished for death. I had given all that I could give, puked all that I could puke, and still my body demanded more. My throat ached with each new vomit barrage. The small amount of food in my system lasted only thirty minutes, leaving stomach acid and bile left for hours upon hours. Each new barrage burnt my throat. Tears and snot dripped down my face and across my lips. My entire body hurt. I shook. Fortunately, the pain served to drown out my thoughts which focused on my death, seemingly fast approaching. Every chemotherapy treatment had been bad, but this one had been particularly horrific. I became increasingly certain of my own death, and gradually, death became something I desired.

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When the *John Harvey* exploded, it did so in style. Witnesses in the *US Pumper* said that the ship disappeared in a moment, and in its place loomed a huge mushroom cloud. The vortex from the blast supposedly turned the *US Pumper* around 35 degrees. Unfortunately, the carnage from the explosion was only beginning. Mustard gas filled the air, and many soldiers and seaman complained about the burning in their eyes. Before long, lesions corrupted their flesh and breathing seemed impossible. Eighty-three soldiers were suffocated by the gas, and over nine-hundred others died from the bombing. Ironically, the only battle in

World War II which included death because of chemical warfare was unintentional.

The Bombing of Bari is one of the untold atrocities of World War II. Tactically, it prolonged the war considerably as the Allied Forces had to delay their assaults into northern Italy and the Balkans.

Yet, without this battle, millions of cancer survivors around the world, including myself, might be dead. Fifty-three of the people killed by mustard gas were autopsied, and when doctors discovered that mustard gas obliterated bone marrow, which decreased production of platelets, leukocytes, and red blood cells, they saw potential for treatments for fast dividing blood cancers such as lymphomas. After some tinkering, a mustard gas derivative known as mustine, also known as mustagen, was shown to have occasional success in treating even late-staged Hodgkin's disease. In other words, the first chemotherapy drug was derived from mustard gas, and without the Battle of Bari, it may never have happened. This drug is still used today, and it was an integral part of my chemotherapy.

In my life, I have subscribed to only a few certainties: There is a God, my Dad is not trying to kill me (but my sister and mother are suspect), sitting too close to the TV will make you go blind (or at least according to the yells of my grandmother), ketchup and mustard are tools of Satan and not enjoyable condiments, Hitler did not save my life, and gravity is the enemy...it must be destroyed.

While most of these beliefs have been continually validated, my discovery of the tragedy of Bari showed me that perhaps I should reevaluate the list. As it turns out, Hitler, in a roundabout way, did save my life. After all, if it weren't for Hitler, there would be no World War II, no Pearl Harbor, no Holocaust, no attack on Bari, Italy, and no chemotherapy. Surely, chemotherapy could have been developed at another time in another way, but it was not. It was developed because of a war that claimed seventy-two million lives. It was developed from the orders of a crazy, anti-Semitic fascist. The same anti-Semitic fascist who, in a round about way, saved my life.

What if no bombs had hit the *John Harvey*? There are three things that could have happened: 1. Chemotherapy is never developed. Ethan dies. 2. Chemotherapy is developed later, Ethan lives and has the same painful side effects. 3. The scientists who researched chemotherapy spend their time looking for other cures for cancer, and they find one that produces no side effects. Ethan's treatment includes drinking syrup that tastes like bubble gum and has no side effects. Ethan likes bubble gum. Hitler, you son of a bitch, you ruined everything!

Throughout the course of my treatment, nurses frequently told me to keep on fighting. "This is a battle you can win!" In 1978, Susan Sontag challenged this war metaphor. In her words, "As long as so much militaristic hyperbole attaches to the description and treatment of cancer, it is a particularly unapt metaphor for the peaceloving." As a cancer survivor and a pacifist, I disagree with this statement. Cancer is not only a war; it is a civil war, in which a person's cells revolt. These rebel cells want to take over. They hoard nutrients, divide rapidly, and strive to take control of new strategic positions. They burst through blood vessels, adhering to them and then breaking through to additional systems. The rebellion is continually changing, with mutations creating a stronger, more volatile army. Chemotherapy then bombards the cancerous cells without regard to civilians. The rebel cells die along with civilians, causing massive, uniform devastation. Medics come as paratroopers from a syringe. They reduce nausea, stimulate the immune system, and provide fresh blood and new bone

marrow. Implantable ports fortify the supply line, giving the patients much-needed resources.

The war is multifaceted. Emotional as much as physical, the soldier feels the effect of the war. The beeping of the IV line reminds the patient of the brutality of the war like the firing of distant shells. Physically and emotionally exhausted, the soldier fears death. The shrapnel takes its toll as the soldier places his head over the toilet and hurls. Perpetually tired, the marching becomes tedious but the choice is to continue or die, and death increasingly seems the better option. Fellow soldiers pass away at an alarming rate, and the support cards from friends and family seem almost trivial. They claim to understand, but they do not. They have no clue what war is like. The officers have no answers as to when the war will be over, and slowly the dread which comes from war becomes normal, and the soldier ponders, "When will I return home?" I cannot think of a better metaphor for cancer than war. It echoes my experience perfectly.

Some individuals, such as Susan Sontag, claim that the metaphor is damaging and unrealistic. She points out that cancer is a naturally occurring phenomenon. Yet what is war? Is the most constant historical trend known to man completely fabricated? I'm a pacifist, but I am not delusional. War is not a new phenomenon, nor is it something that scientists synthesized or politicians drafted. It is an ancient way to settle conflict between peoples. I do not like war, just as I do not like cancer, but that does not make either one disappear. If so, my therapy would have been much easier.

Another knock against the war metaphor is its tendency to dehumanize patients by making them either a survivor or a victim. This particular claim is irrational; the war metaphor does not prematurely turn people into body bags or worse yet, frogs. Rather, it merely identifies one type of suffering with another. And in this identification, the metaphor provides hope through the symbolism of fighting. Fighting implies not giving up. Soldiers do not give up, even though they face many difficult obstacles. Likewise, cancer patients cannot afford to have a defeatist attitude. Numerous studies have linked optimism with an increased immune response during cancer treatment. This innate defense can play a large role a patient's survival.

In some instances, a soldier can do everything right and still die, and the same is true with cancer patients. Sometimes chemotherapy, radiation, and bone marrow transplants fail. Ships carrying mustard gas occasionally explode. The future is unknown. Cancer patients gain nothing from giving up. Even if cancer ultimately does kill a person, it is better for that person to die with hope and a smile on their face, than to die depressed and resolved to defeat.

Two years after treatment, I wrote this poem titled "Soldiers."

We are soldiers  
We fight because we have no choice  
If we lose we pay the ultimate price  
We know this, but we trudge on anyway  
Quitting will do us no good

The sun rises  
And then it falls  
And we fight on, fatigued and broken  
Fighting for our war to be over

Fighting to see if we will win  
Fighting to see if we will die

Our war contains no guns  
Our war contains no violence  
Our war is inside  
Our bodies have betrayed us  
.....So we betray it back  
Hoping our second betrayal is better than the first  
Sometimes it is  
But often a comrade is killed by his only protection  
It is tragic  
But there is no other way to win the war

As we fight our war  
With needles stuck in our bodies  
Often unable to move  
We think  
We cry  
We shake  
And we tuck it inside  
We pick ourselves up  
Shake the dirt off our clothing  
And wait for tomorrow

Tomorrow is another day  
Generally it's just like the first  
The medics come in  
And give us our drugs  
Our savior and our poison  
And then again  
We think  
We cry  
We shake

When the war is over  
...We return to our lives  
Our comrades dead  
And God has spared us  
We live with guilt  
We live with torment  
We live with fear  
What if it comes back?  
Why didn't we die?  
We think these thoughts  
We still cry  
Pain gone  
But not forgotten

...Others go to a different world  
In a casket of gold they go to a different land  
Their families left with the pain  
That was once manifested inside  
Inside, but not alone  
This war is fought by all  
By friends and  
By family  
By the survivors  
And By the fallen

It brings down the biggest  
It brings down the smallest  
This war that we all fight does not care who it  
strikes down  
Chemo pumping through the veins of the victims  
Tears running down the cheeks of the family  
The realization that should set in

The realization that doesn't set in  
That this enemy does not care who you are  
Cancer is an indiscriminate disease

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Conversation 1: Recurring Fatalism  
*Frequency: Biweekly*

"Are you going to die?"  
"I hope not."

Conversation 2: Ignorant Fatalism  
*Frequency: Monthly*

"Cancer, can they even treat that?"  
"Supposedly, yes."  
"Are you sure? Aren't they still looking for the cure  
for cancer?"  
"Well, if you come to my funeral in the next year,  
assume they are lying."

Conversation 3: Survival Motivation  
*Frequency: Stupidity this profound could only occur once.*

"Dude, if you die, I'm going to kick your ass."  
"If I'm dead, I somehow don't think I will care."

Conversation 4: Inappropriate Truth  
*Frequency: Weekly*

"Yeah, a good friend of mine recently died from  
cancer."  
"That sucks."

Conversation 5: Almost Reasonable  
*Frequency: Monthly*

"Does it hurt?"  
"Does what hurt?"  
"The cancer."  
"Do you mean the tumor or something?"  
"Yeah, the tumor."  
"If you punched it, it would hurt."  
"Do you want me to punch it?"  
"Not particularly."

Conversation 6: Awkward Pause and Embrace  
*Frequency: Monthly*

My classmate grabs my shoulder.  
"Cancer..."  
He stars at me.  
"Deep man...really deep."  
He continues staring.  
"Yeah, I guess." Awkward.  
He holds me for two minutes before letting go and  
walking away without saying another word.

These conversations demonstrate a theme. People, in general, do not understand cancer and its treatment. Before cancer, I did not either. I too, thought cancer meant death. After diagnosis, I picked up a twenty-year-old medical dictionary, which did little to change my understanding. The entry for Hodgkin's disease read, "A cancer of the lymphatic system. Always fatal." Two points should be taken from this entry: 1. After ten years, medical dictionaries should be burned. 2. Cancer treatment has improved greatly in recent years.

While the treatment of cancer has improved, the public's knowledge of it has not. People still think of cancer

as a fatal disease. While certain types of cancer still have low survival rates, the number of deaths due to cancer in the United States has declined in each of the last three years. A modern dictionary might read something like, "Hodgkin's disease is a lymphoma with extremely high cure rates in low-stage disease and moderate cure rates in progressed disease."

Cancer treatment is also misunderstood. For example, chemotherapy is not a drug. There is no single chemotherapy that magically treats all cancers. Instead, there are literally hundred of drugs which are part of chemotherapeutic regimens. Most commonly, people associate chemotherapy with toxic chemicals given through an IV, which is accurate in many instances. Taking adriamycin in the form of a milkshake or an enema would result in the creation of a new coating of scar tissue throughout the body, as well as almost certain death. Still, there are chemotherapeutic drugs which can be swallowed safely, such as Prednisone and procarbazine. Making Prednisone into a shake would not cause scarring, but one disgusting beverage.

Radiation is perhaps the most misunderstood treatment, and for good reason. Radiation is weird. Take an art class and a microwave and put them into a blender, and the result is somewhat similar to radiation.

When I arrived at Central Arkansas Radiation Treatment Institute for my first radiation therapy, I half expected to be stuffed with enough uranium to make North Korea jealous.

"Ethan Helm," the radiation tech called out.

I walked toward him.

"Follow me," he replied.

Eventually, we arrived at NASA headquarters. Within the room, there were two compartments. To the left, the control center contained a plethora of monitors, levers, and buttons. I never became much acquainted with the control center, but it helped me imagine myself as an astronaut. In the main room, or the spacecraft as I thought of it, a gurney lay in the center of the room. Above the gurney and towards the head of the bed lay a machine with a big cylindrical head-like projection.

"Ethan, do you need to go to the bathroom?"

"No, sir."

"If you will, please take off all your clothes, and put on this gown. Make sure to take off all jewelry or metal."

I put on the space suit.

"Now, if you will please lie down."

Three radiation technicians, each wielding a sharpie, looked down upon my naked chest. They began to mark it as if it was parchment paper and they were expert cartographers. Carefully and precisely, they touched the cold marker against my flesh. Each stroke tickled. It is common knowledge that astronauts are not ticklish. I remained stoic.

When they finished, they glanced at a document, likely the doctor's notes, and compared it to their masterpiece. They added a few strokes here and there, and delicately erased errant marks with a damp cloth.

"Looks good."

They fastened me onto the gurney, and placed radiation shields around the border of the areas that did not need radiation.

"Alright, now we are going to orientate the machine. This will take a few minutes. Please be as still as possible."

The radiation techs went to the control center. Moments later, the head of the machine began to rotate around me in a noisy and annoying fashion. For fifteen

minutes, the machine rotated and beeped, and by then, I was asleep.

One of the techs spoke to me through an intercom, "Are you comfortable?"

"Yeah, I'm great." I yawned. Great is a relative term. Obviously, being strapped to a bed with some sort of mysterious art covering my chest and a huge intimidating machine rotating around me is somewhat alarming. Still, it was not alarming enough to keep me awake.

"We will now begin treatment."

I'm not sure what happens during radiation. I know the machine makes a few noises and moves slightly, but I spent the majority of treatment asleep. Perhaps radiation involves a circus with elephants and clowns. If so, it was a quiet circus, and fortunately, it did not disturb my sleep.

Radiation proved to be much less problematic for me than it was for the plastic army men I experimented on as a child. For those poor childhood toys, radiation via microwave meant melting and falling over. Radiation gave me slight burns and a warning to not go outside in the sun too much. The burns were relatively insignificant, as in I've had more painful sunburns.

My experience cannot be universalized amongst radiation patients. Chemotherapy took care of most of my cancer, so instead of having one month of high-dose radiation, I received only three weeks of low-dose radiation. Moreover, all the cancer in my abdomen had already been eradicated, so only a small section of my left lung was radiated. As a result, radiation seemed more like a game than therapy. Whereas chemotherapy was boot camp, radiation was art class.

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"What seems to be the problem today?" said Dr. Stine.

"Well, actually, we don't have any complaints today. I just wanted to see if you could write a prescription for a HEPA filter so our insurance could pay for it."

Weeks before my diagnosis, a girl from my hometown died from cancer. I grew up with Anna, and I talked to her on occasion, although I did not know her well. She had been fighting cancer for a long time, and she seemed to be doing well. All the reports we heard were positive, and everyone was hopeful. Unfortunately, Anna died weeks before my diagnosis.

Like many who die of cancer, the disease did not kill her. Instead, her weakened immune system allowed for a fungal infection to take over her body. The doctors tried to fight it with antibiotics. They failed. She died at the same hospital I went to, and in one of the hallways of the cancer unit, a memorial complete with pictures hung on the wall. Her death haunted Bryant, Arkansas, and in particular, children in my grade and their parents.

My mother struggled with Anna's death fearing I would die in like fashion. It would not happen on her watch. She wanted to purge our house of potentially harmful fungal and bacterial invaders through the use of a high-quality HEPA filter. If cancer is a war, Rebecca Helm was not going to take it lying down.

"Mrs. Helm, that is hardly necessary."

"What do you mean it is hardly necessary? Anna is dead." She began to cry.

"I'm not allowed to speak about other patients, but I assure you that deaths from fungi are extremely uncommon

even in patients with suppressed immune systems. You do not need a HEPA filter."

"Who are you to say what we need? My son is sick, and I'm going to do everything in my power to prevent him from dying."

"Well, you don't need a HEPA filter to do that."

"Are you honestly telling me that if your kid was sick, you would not get a HEPA filter?"

"I...I would not" he flinched.

"I don't believe you. Write the prescription," she growled. "It is your job." Mom stared at him with tears running down her face and anger seeping from her eyes. "You can't teach me how to be a mother, let me do this!"

"No."

The result of this conversation would pain the doctors at Arkansas Children's Hospital for months.

"Sorry it took so long," Dr. Saccente announced as she entered the room.

"Why do you schedule us so early if you are not even going to get to us?"

"I'm sorry, Mrs. Helm, I got to you as soon as I could. It has been a busy day."

"Every day is a busy day for you. For us, we sit around and wait, and I promise you waiting around in this place is not enjoyable."

"Mom, she can't help it. Let it go."

"Don't tell me what to do."

"I'm sorry again, Mrs. Helm."

Dr. Stine was not our regular doctor, but in the course of the conversation with my mother, he created a deep hatred within her. She hated all of the oncologists at Arkansas Children's for a time. Cancer made all of us go off about things that normally would not have bothered us. Nonetheless, getting angry at small things is much easier than getting mad at the seemingly intangible disease.

With cancer, everything seems out of control. With the cut of a knife, my family transformed from America's family to a broken group of individuals. Everything changed so fast. We were all depressed. For a time, Mom took her anger and frustration out on the doctors, and while horrible for the doctors, it allowed her to vent her pain instead of pushing it dangerously inside. When I become a doctor, I hope I remember this, and when patients lash out at me, I hope I can find a way to never fight back, but instead, to remember my mother and why she lashed out in the first place. Transference, as they call it, can be a horrible abuse to the doctor, but it is occasionally a wonderful therapy for the patient.

Mom shared her desire for a HEPA filter with everyone she met. Eventually, an old man at her church volunteered to purchase the unit for us. Truthfully, I probably would still be alive without the machine. In fact, I find it highly unlikely that the HEPA filter had much of an effect outside of the one room it resided. Still, I am glad that my mother got it, if for nothing else than her own sanity.

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As barbaric as it often is, cancer treatment can be also be hilarious, although it may take a severely deranged sense of humor. This story, which I wrote in the middle of treatment, demonstrates this.

"I have made a discovery. This discovery came to me because of one of the medications I was put on recently prevents me from eating cheese...among other things.

"This event has made me aware of the under-appreciation the average human has for cheese. Cheese is a great thing. Sure, you think, "Cheese. Why cheese?" Have you ever eaten pizza without cheese? Trust me, it just

doesn't work. Have you ever had a cheeseburger without cheese? I'm sure you have. They call them hamburgers, and they are not half as good as cheeseburgers. Rather wretched things, actually. Cheese is everywhere. I can't have it. I miss it. I love cheese. Now cheese is gone. If you could find it in your heart to thank cheese next time you see him, I'd be in your debt. Please tell him that Ethan loves him and Ethan will be back to see him shortly. Tell him Ethan has been dreaming about him and his luscious taste...OH OH...wait, enough of that.

"It doesn't end there though. You think cheese is bad enough? No caffeine. No caffeine. What is that? I'm not supposed to have much chocolate either. It could very well be a conspiracy held by the doctors to see how much a person can take before they explode. Cancer isn't enough for them, now they are making me groggy and cheeseless.

"Ok...cheese, caffeine, chocolate...you think it can't get worse, but it does. What else could they take away from you, you might ask. Anything aged. ANYTHING. Do you know how many things are aged? Nearly all meats are aged? Ham, pepperoni, all lunch meats, some beef, I'm sure there are more, but at this point I'm craving soy sauce. Wait...they took that away from me, too...and not to be outdone they took ALCOHOL. So I'm a cheeseless, droggy, SOBER cancer patient.

"This is just not right. I demand service. I'm going to go to the hospital and fake headaches so they'll give me another one of those morphine buttons.

"But do remember, say hi to cheese."

## Chapter 6: Losing the Ground

Throughout the soccer match, I warred with the ground. The ground responded by playing hide and seek and finding me repeatedly. I ran around aimlessly, as if I were blind trying to find an absent ball. As this absent ball rolled toward me, I cocked my leg, and struck out. Off balance and on one leg, I spun like a tornado as I lost the ground. During those seventy minutes, my pants got pretty dirty.

John Schellhase, our star player, ran up to me, "Are you alright?"

"Yeah." I laughed as John helped me up.

Losing the ground is an alarming feeling. After all, the ground is pretty constant. After birth, you quickly develop a relationship with the hard surface that prevents us from plummeting into oblivion or lava (for those geological purists) through crawling. Gradually, the trust builds, and you walk. As you grow older and more comfortable with the constancy of the floor, you challenge the ground to disappear through running, skipping, and dancing. At first, the ground flees from you on occasion, but only through experimentation does one truly conquer Earth's outer shell. It was presumptuous of me to think I had mastered the ground.

"Mom, can I go to the game?"

"No."

"But Mom!"

"No!"

"Dr. Saccente said it would be okay."

"I'm not losing my baby boy to some stupid game!"

Mom began leaking. I did not know how to patch her.

First attempt: failure.

My father never grew up. When he had kids, it meant he finally had partners in crime, and so we played. In one game, Dad chased us around the house pretending to be a monster. Sarah would raise her hands up in the air and scream as Dad ran toward her. He would eventually

catch her, and they would laugh and laugh as he tickled her. I never understood the game. When Dad started growling, my heart dropped, and as he charged toward me, I panicked. Instead of running away from him, I ran straight towards him, hugging his feet and begging him, "Don't eat me, Daddy." He never did.

Occasionally, my father pretended that we were pillows. He would lay his head on Sarah, and she would kick and scream trying to get up as Dad yelled, "Hold still, my pillow; pillows, don't squirm."

After a few minutes of this, Sarah would laugh, proclaiming, "Daddy, you are so silly." Yet when he got a hold of me, I'd cry and cry, "Daddy, I'm not a pillow...I'm your baby boy." My Dad did not try to terrorize us; it just came naturally. We loved him for it.

In another game, Dad feigned interest in devouring our feet. "Yum. Eat. Baby feet." He'd announce while grabbing our legs and making hideous eating noises. When he grabbed Sarah's feet she would put up a fight for a bit before bursting into laughter.

Once again, however, the joke went over my head.

"Daddy, don't eat my feet!" I'd squeal. My parents thought it was cute. Sick people my parents.

At a certain age, Dad's old games just seemed awkward. Instead of acting terrified when he tried to eat my feet, I replied, "Dad, what are you doing?" When he tried to use me as a pillow, I responded, "Geez, get off of me." And when he pretended to be a monster, I ignored him, opting instead to play video games.

Realizing his games no longer had quite the same effect, Dad adapted. At the age of six, he signed me up to play a new game. He picked soccer, because we both loved playing foosball, and he disliked the more popular American sports. At first, I remember being shy and afraid. I felt uneasy around the other kids. As soon as I began running around, this changed. Together, we fell in love with soccer.

The first season he became assistant coach, even though the only knowledge he could impart to us was "Don't use your hands!" At the age of nine, Dad became my coach. During practices, he would play with us. It must have been a sight to behold, a 30-year-old man running around with a bunch of nine-year-olds. We loved it. He loved it. It was a good time.

We fell in love with the game together. I knew he'd let me go.

"Dad, can we go to the game?"

"What kind of question is that? Of course we can."

Second attempt: success.

My Dad taught me that the person who cares the least always wins an argument. My mother, in appearance, cared more about everything. Unable to detach herself emotionally, she rarely won debates with my father.

"Where are you guys going?"

"To the game," my father replied.

"No, you are not."

I grimaced.

"He has to get on with life...he can't just sit inside all day."

"Actually, I could do that quite well," I thought.

"But he just got out of the hospital yesterday...chemo was just a few days ago. His immune system is shot, he is anemic, and he is likely to vomit all over the place."

"He has not vomited in a few days, and besides, Dr. Saccente said it would be a good idea. Rebecca, he needs to see his friends."

I sat silently.

"Just don't let him play," she wept.

Truthfully, I had no intention to play, even though I wanted to. I still felt pretty horrible, and I feared barfing all over the field. Sure, everyone would understand, but the game would go on with a new obstacle: the Ethan factor. I did not want that. Nobody wanted that.

For the previous two years, I had been a part of "Major Pain." Our coach named the team after an immature movie aimed at preteens. The name embarrassed us, but nobody had the heart to tell coach. We were perfectly mediocre. We won as much as we lost, but not much more. I started at forward my first season on the team, I moved back to midfield the second, and by the third I spent most of my time playing defense. When we scored, I let out a trademark roar. Fully grown at thirteen, my voice was deep, enabling me to yell menacingly. So I did. I ran up to the player who scored yelling and beating my chest as we celebrated. My team knew it was all a façade. Ethan Helm has never been menacing. The opposition was further thrown off when I began singing, "Sunny day, sweeping the clouds away, on my way to where the air is sweet. Can you tell me how to get, how to get to Sesame Street," during set pieces. I did not sing the song to seem psychotic, but because I enjoyed the confused looks on the faces of the overly competitive kids around me. Sadly, nobody ever told me "how to get to Sesame Street."

As we approached the field, I noticed something different. Everyone on our team had dyed hair. Green, red, blue, the "Major Pain" were a regular cornucopia of colors. Upon spotting me, the team ripped off their jerseys exposing shirts which read, "Get well soon Thor."

My nickname, "Thor," came about through pragmatism. At the age of 11, I needed a nickname for my email address. My previous nickname, "Shithead," did not seem appropriate (thanks, Dad). Mythology interested me, especially Norse mythology as it was more obscure than Greek or Roman mythology. Thor then became the foundation of my new nickname, but alone, it was too mundane. I then moved on to DictatorThor, but what would I dictate? After much thought, I decided against New York or California. They were too obvious. Ohio, however, was deceptively large, and no one would ever expect it. And so Thor, the future dictator of Ohio, was born. I wrote "Thor" around the collar of my undershirts. When we scored a goal, I pulled my jersey's collar down, revealing my nickname. I then proceeded to roar.

The team huddled around me bombarding me with questions.

"How do you feel?"

"Alright, I guess."

"Are you going to play?"

"Nah, I better not."

"Why not?"

"Mom would kill me."

"Well, we only have ten players."

"Umm...."

"I brought your cleats and shin guards!" My Dad skipped jubilantly to the car.

Nothing kept me off the soccer field. In one tournament, I played two games with a deep bone bruise in my ankle. If walking is possible, there is no reason to miss a soccer match. I knew this. It was the Helm way. I was a man. Men play soccer. Moms do not stop men from playing soccer. I had to play.

My Dad returned with the equipment.



"Thanks Dad. You are awesome."

"Don't mention it," he winked at me.

My heart wanted to recapture some element of normalcy. My father's heart agreed. As much as I loved playing soccer, my Dad loved watching me. We did not know if I would be alive in a year, but on the soccer pitch, we could forget about that.

I tightened my cleats and stepped onto the field.

Playing proved to be much more difficult than I anticipated. I was severely anemic, which means that my red blood cell count was low. Red blood cells carry oxygen throughout the body, and lack of oxygen can make a person extremely dizzy. Anemia should not be confused with nausea. While nausea causes vomiting, anemia makes one feel as if they are stuck in a dryer. Additionally, an anemic person may have trouble with blood clotting since they have fewer platelets. As such, if I began bleeding, it would have been difficult to stop the blood loss.

With no substitutes and an ineffective whirling dervish wandering around the field, the "Major Pain" lost the game 1 to 0. I managed to avoid major blood loss, and I did not decorate the field with my last meal. I laughed before, during, and after the game, in which time my teammates again surrounded me and gave me hugs. While we had lost the game, I did not feel like a loser.

After treatment, I returned to my team. Someone had informed coach of the lameness of "Major Pain," and we took the name "Westside YMCA." After the first game, I wrote this:

"Today I finally realized that it's over. I was on the soccer field, which alone is something I never thought I would do again. The ball came to me, and I noticed that nobody was near me. I cocked my left foot (I'm right footed), and from well outside the box I chipped the ball over the goalie's head.

"How does this relate to cancer? How does it make me feel better?"

"In the past year I've spent a lot of time lying around wondering if I'd make it, if I'd even be alive in a year. I thought about never seeing my hair long again, I thought about never scoring again. I thought about all these things and much more.

"After the game, all I could think about was how it was over. Granny will never come back to me, but I looked in the mirror. My hair is back, almost 3 inches long now. Then I thought about the game, and it happened. I scored again. I had waited over a year, but it finally happened. I almost played like I used to when I was 40 pounds lighter, and the weight is coming off. I went to my room and closed the door. Then I cried, laughed, and prayed. I thank God, because he gave me this opportunity- one that many don't get given my situation. It was an interesting notion. Crying with a smile, I hope I never have it any other way again."

## Chapter 7: Childhood

### Kindergarten:

Adam Carlisle's parents loved Star Trek. So did Adam. Repeatedly he belted my stegosaurus with his mighty triumphant triceratops. When I tried to hit back he proclaimed, "You can't do that! Mine has a force field."

"What is that?" I queried with a defeated look upon my face.

"An electromagnetic field that repels attacks...impenetrable."

Baffled, I stared at Adam. I had no clue what he meant, and I doubt that he did either. Yet I believed him, and as a result, everyday during recess, he pounded my stegosaurus as I sat in awe. I hated recess.

Two girls at my kindergarten completely matured by the age of 5. They each stood six-feet tall and benched 300 lbs. Terrifying. The giants teamed up with the devil girl, who either had severe A.D.D. or an early speed addiction, to ruin my life. I remember little about devil girl beyond the fact that she was constantly running around and she loved sugar. Devil girl and the giants were a formidable team. Once, the giants decided to teach me about kung-fu. One began kicking toward me, so to avoid her, I turned to run. There was the other giant kicking. So I turned again, only to find devil girl glaring at me. I quickly found a hole in the crowd and fled from them. The girls, content on picking on another poor soul, left me alone as I spent the rest of recess paranoid, attempting to avoid trouble. I hated recess.

Devil girl never slept. In fact, she did not understand the concept of sleep. She viewed sleep as the Soviet Government viewed religion. It was not to be allowed. I like sleep. I always have. Devil girl had noticed this. A few minutes after nap time began, she would begin throwing objects at my head, hoping to blind or kill me. Bouncy balls were her favorite weapon, because after she hit me once, it came back, and she could do it again. I hated nap time.

My Aunt Pam worked at the kindergarten. Thus, I knew if I got in trouble, my parents would know. This meant that teachers were a powerful force; they had the power to force me into double jeopardy (and not the game show version). Perhaps because of this, I behaved well. I feared punishment. Yet, I also feared the bathroom. Kindergartners are gross. This led to many long days of saving my wastes for my preferred toilet.

One day I decided to follow the bad kids. I'm not sure why I did it. Possibly, I thought the experience might train me to deal with the Giantesses and devil girl. For whatever reason, I walked a bit off the playground and observed. The bad kids stood fifteen yards apart and began to bombard each other with rocks. They were not angry or malicious, no, not these kids...they were just bad. And I sat, watching them in their badness until Ms. Butzloff found us. Ms. Butzloff was an angry woman. I discovered this as she interrogated me in the hallway. "Did you throw any rocks!?"

"No, I didn't." A halo formed above my head.

"But I saw you!" Fire shot from her nostrils.

"No, you didn't." The halo glistened.

"Don't you lie to me!" Horns sprouted on her head, and a pitchfork appeared in her left hand.

"I'm not lying," I pled. Angels sang as I spoke.

The argument proceeded for ten minutes with Ms. Butzloff making a series of threats. Yet, I knew the truth. I had not lied, and despite my trembling and weeping, I was not going to give up. I did not throw any rocks. Fortunately, Ms. Butzloff never told my Aunt or my parents about the incident, but on the ride home, I awaited for another brutal interrogation that never occurred. The angels had apparently hung around to protect me from the demonic kindergarten teacher.

### 2<sup>nd</sup> Grade

People are not blue. They are black, brown, white, tan, or some color in between. Blue is not in between these colors. I realized this. I was cunning. Yet many of my seven-year-old peers colored people all sorts of ridiculous colors, and it bothered me. The song "Jesus loves me" goes, "Red and yellow, black and white." Not, "Teal and chartreuse, gold, and fuchsia." I never complained aloud, but every time I saw a green family, I gnashed my teeth. Eventually, I lost faith in coloring. Most teachers did not

care. Coloring was more of a time killer than anything else. Yet, Ms. Jacobs, my 2<sup>nd</sup> grade teacher, did. She grew tired of my reckless monochrome artistic endeavors in which nothing was in the lines. The hell if I cared. After all, blue people and white people are the same to the artistic plebeians who teach at public elementary schools! This did not save me from detention, and although I did as my teacher asked without complaint, I did not do so happily. If people can be blue, why can't they be amoebic?

#### 4<sup>th</sup> Grade

Ms. Cozart was unconventional. She had a zoo consisting of hamsters, mice, guinea pigs, and fourth graders. The students, the kings of her jungle, took care of the animals during the week, and we got paid for it via the classroom economy. The economy had its own Monopoly-like currency. It included a bank, and the high point of each day was the auction at which students could sell parts of their lunch, toys, books, or anything else not deemed contraband. The economy rewarded the smart and well-behaved, as those with good grades and behavior got paid, too. Most students used their money frivolously, buying candy, cheap toys, or crappy books. I had bigger plans. I wanted to control the economy, and soon, I would. Without my parents knowing, I sold my huge set of Legos at school and became a tycoon like Donald Trump without being an enormous asshole (I was nine, and incapable of being as big of an ass as Mr. Trump). Once my mother discovered I sold the Legos for fake money, she exploded.

"How could you do that?! I spent so much on those!" I did not care. I was the king of 4<sup>th</sup> grade.

#### Middle School

In middle school, I tried to blend in as much as possible. I was not very good at it. My Mom bought all my clothes. She did my hair in a way to ensure that I looked as nerdy as possible, and she did a good job. Despite being one of the biggest kids in my class, nobody feared me. I was soft, literally and figuratively.

Kids sense weakness and smell fear. While my size and benign personality warded off some predators, the braver bullies gravitated toward me.

One time, I bumped into a bully inadvertently. He looked at me menacingly and stood up with his chin in the air. Certain that he would soon attack, I told him, "I know you can beat me in a fight...we can please just avoid it."

"Okay, pussy, I won't break you this time, but watch yourself."

I walked away briskly.

At the age of 11, I fell in love with a popular girl, a horrible mistake. I wrote her a long love letter inviting her to the sixth-grade dance, brought her a box of candy and some flowers, and put \$20 in an envelope.

She responded in a letter which read, "I am not a prostitute, keep the money, you cannot buy my heart." This event has scared me away from girls ever since. I am only partially joking.

My childhood felt awkward. I did not know how to relate to kids outside of my family, and I had no knowledge of pop culture. Simply put, I was naïve. I did not watch the same television shows as my peers or listen to the same music. I had no interest in clothes or style. I could not hit a baseball to save my life. I had never thrown a football, and I managed to score 0 points in my first season playing basketball. My sympathetic coach said I had fast hands. He must have had a big heart. I was the worst player on a bad team. Soccer was the only sport in which I excelled, and that was likely because nobody else knew how to play it.

#### Chapter 8: Hair

I did not plan the event that changed me. It just kind of fell on my lap...or head...when I was fourteen and my sister asked me, "Ethan, would you like to dye your hair purple?"

"Do you think Mom will kill me?"

"Of course she won't."

"Are you sure?"

"No...but I don't think she will."

"Alright, let's do it."

In retrospect, I think my sister wanted to dye her own hair. Sarah has always feared our parents more than I did, and so I became the guinea pig. Fortunately, Mom did not kill me. She did scream a bit, and when she found out we stained the bathtub, her rage grew substantially, but we survived.

Our Dad is wise and handled the situation carefully.

"Rebecca, if the worst thing he ever does is dye his hair, then let him dye his hair."

Mom never received a call from the principal's office about my behavior. I made straight As almost every semester, said, "Yes, sir," and, "No, m'am," and opened doors for people. I showed disdain toward drugs and alcohol. My great transgression lied in the color of my hair.

#### September 1998- Bryant High School

"Fagot! I should kick the shit out of you," generic redneck number one bellowed.

I lowered my head and scuttled away angrily. "What does hair have to do with sexuality?" I thought. When I got to my room, I put on Metallica's "Ride the Lightning" and fed my anger.

Purple hair commands attention. Anytime I went into public, I evoked scorn in the eyes of old men, curiosity in old women, and hate by new mothers. Kids my age either loved my audacity or hated my eccentricity. Older people by and large despised me. They assumed I worshipped Satan or sold drugs, but in actuality, they could not be more wrong. I loved Jesus, and drugs scared the crap out of me. I emerged as an enigma by breaking stereotypes. I found a personality and an identity. I shed the shackles of nerd-dom to form a unique niche. I was the kid who dyed his hair.

My hair began to dye after I fell in love with music. My mother is a musician, and I grew up around her giving voice and piano lessons in our house. Every morning on the way to school, she practiced opera, and in so doing did irreparable damage to my ears. It just so happens that opera singers know how to harness their inner microphones. As such, my mother has an amplifier in the back of her throat. She always told me that listening to metal would cause me to go deaf, but if opera did not do it, I didn't see how metal could.

Musically, my mother is obscenely talented. Her voice is angelic, and she glides over the piano creating an intricate and beautiful sound. She wanted my sister and me to be musical geniuses. She still claims we could have been prodigies, but learning under my mother was difficult. She wanted us to practice constantly. We wanted to run around in circles until we got dizzy. The conflict resulted in both of us quitting music and ignoring it until adolescence.

After Mom got her MA in music, she realized there is a right way to play music. Anything that has distortion is wrong. "Rock and roll is demonic, Ethan," she would say. My next-door neighbor made me listen to Nirvana one day,

and at first, I was not receptive. I could hear my Mom's voice in the back of my head screaming, "It is evil." He persisted, and to my surprise, when I heard it, I liked it. Maybe Mom was wrong about rock and roll.

My sister helped me dive into rock by convincing me to participate in Columbia House's mail order CD promotion. We were young and foolish, and twelve CDs for the price of one seemed too good to be true. It was. In actuality, we had to buy a certain number of CDs at full price. Full price happened to be twice as expensive as Best Buy's full price.

Columbia House broke our banks and introduced us to a wide variety of music. When I signed up for the deal, I did not know a lot about music. In fact, I bought Soundgarden's "A-sides" merely because I had heard their name and found it intriguing. Columbia House, ironically, became a key element of my cultural transformation, and within a year, I owned every Pearl Jam and Nirvana album. With the music came a dramatic change in appearance. I grew my hair out, wore baggy pants, and wore shirts with the logos from my favorite bands.

Music shaped my identity. I talked about it constantly and in my head, a song constantly played (and that song still plays, which is why I constantly tap my foot). I loved the angst-ridden grunge anthems. I fed off the anger, banging my head rapidly to the drums. I felt isolated, like the world was against me.

*April 1999—Bryant High School*

"Hey, fag. Nice hair," generic redneck number two yelled.

I turned and waved at him cordially before continuing on my way.

My hair screamed at them, "I don't care what you think." I did care. I wanted to be accepted, and I wished to be judged on the basis of my actions, not my appearance. Gradually, their hate motivated me. I learned to turn the other cheek and greeted their harsh words with a smile and a wave. I strove to change their irrational hatred by continuing to open doors and saying, "No, sir," and, "Yes, m'am." In a way, I became a vigilante. My hair became an intrinsic part of my identity. I loved it because of music and the positive attention it brought, but I also loved the hatred.

Mom did not approve of my musical culture.

"Why do you have to do that to your hair?" Mom yelled.

"I like it."

"Yeah, well, Nadia likes it too."

Nadia was her transsexual voice student. He was in his thirties. I was thirteen.

"Uh, that is creepy." I was serious. Nadia made me feel uncomfortable.

"I know. Why do you do it? Are you *trying* to attract gay men?"

"Ummm, no. I'm not gay, Mom. I can't believe we are having this conversation. Gay people do not hold a patent on creativity. I dye my hair because I like it."

Sarah piped in, "Actually, I dye your hair."

"Yeah, I know Sarah, I appreciate it," Mom sarcastically stated before continuing. "You know, gay men like your hair, too. By dyeing your hair you are putting a big sign on your forehead saying, 'Gay men, please hit on me.'"

"Whatever. Do you want me to wear garlic around my neck or something?"

"I am not laughing, and you are not getting out of this that easy."

"It's okay, I'm laughing," I grinned.

"Why red and black? Are you worshipping Satan? I cannot have my own son worship Satan in my house. I am

a good mother." Mom turned the melodrama up a notch and tears rolled down her cheeks.

"That is ridiculous. I do not worship Satan, and I am not gay. I'm a straight Christian, who has never gotten in trouble and makes good grades. You are being absurd."

"Don't call me absurd."

"Don't be absurd."

"What am I supposed to think? You are off to go listen to that devil music. Don't try to tell me Rob Zombie is Christian. I've not heard of any Zombies worshipping Christ, and I know about Korn, they are a sinister band, the ladies at church are always talking about them."

"The ladies at church don't know what they are talking about."

Surya, my sister's boyfriend, glanced at his watch. "I'm sorry Ms. Helm, but we really need to go if we are going to get there on time." Mom loved Surya.

"Oh, okay, Surya. What time are you guys going to get back?"

"Probably around 11:30 pm," he replied.

"Well, you guys come back right after the concert now."

"Actually, we plan on attending this big Satan worshipping party at which we will slit our wrists while sacrificing a virgin to Beelzebub and participating in a massive gay sex orgy. Can you invite Nadia?"

"That is not funny."

"Sorry, Ms. Helm, but it kind of is," Surya chuckled, and we headed out of the door.

My hair looked immaculate. When waiting in line for the concert, I realized I was not like many of the other people there. To my left, a guy hit himself in the head with a block of wood until blood covered his face. Bad idea. To the right, an old man, probably in excess of 60, adorned a tight black-leather cat suit wrapped with chains. In his left hand, he carried a whip. Scary. The differences were not all terrifying. The lead singer of Korn called for women to show their boobs. They did. Awesome. The only breasts I had ever seen in my life were my mothers. Shudder. One of Surya's classmates and friends was displayed on the massive monitor flashing her breasts. She was seventeen. Weird.

The lights shut off. Everything was black. Silence. Moments later, the arena erupted in sound and distortion, and Jonathan Davis began to sing "Blind." I jumped into the air, yelling as loud as I could as Jonathan Davis sang, "There's a place inside my mind." I ran into the mosh pit, pushing anyone and everyone in sight.

"A place I like to hide."

We thrashed together, enacting our primitive male instincts. We harnessed our anger and turned it into brotherhood. If a person fell down, we rushed to pick him up.

"You don't know the chances..."

Sweat dripped from my forehead and down over my eyes. The fresh hair dye bled, leaving my forehead and ears black and red.

"...What if I should die?"

Signs all over the stadium said, "No Smoking," an ironic mandate which most ignored. Everyone smoked inside, but few smoked tobacco. They were generous stoners, and I was asked to take several times. I declined, but nothing could prevent me from a contact high. My head blistered with pain. I felt horrible, but I did not stop. I felt euphoric. I continued moshing, jumping, and yelling until the music ceased. I considered it to be the best experience of my life.

By the time I got home, I had no voice left, although I had some sort of croaking facsimile. My head

throbbled with pain, and I ran to the toilet. Mom thought I was drunk, and I was in no mood to argue. I went to sleep, hoping the pain would go away, but the adrenaline rush would last for the rest of my life.

I feel the need to apologize for the person I used to be. This is not because of the dyed hair. If I thought I could get into medical school with it, and I had absolute proof that no hair dyes cause cancer, my hair would likely still be dyed. Instead, I feel ashamed of the type of music I listened to. Korn is a horrifically bad band. The lyrics seemed great when I was fourteen, and if written by a fourteen-year-old, they would have been pretty decent. They were written by thirty-year-olds. Their sadly immature and technically mundane songs seem to come right out of a rubric. They are the boy band of loud rock.

The bigger problem is not that I listened to a horrible band. I've listened to worse. Instead, I allowed music to hinder my relationship with God. Music became an idol to me. I got so caught up in music and its associated subculture that I stopped thinking about God. I went to music for answers instead of going to the Word of God. God's Word has more sufficient advice.

I am also ashamed of my anger. Anger is generally a ridiculous response to a situation. As a young teenager, my anger had no basis and caused a lot of damage. In one incident, I decided to use a baseball bat to demolish my favorite childhood toy, a plastic horse big enough for a small child to ride, and I used to ride it a lot. In fact, I rode it so much that it became an annoyance to my parents. As a small child, I loved Clippity Clop. As an angry adolescent, I loved hitting Clippity Clop with a baseball bat. It was a fun way of eliminating my anger. Yet, immediately after I mangled my beloved former best friend, I regretted it. Likewise, I regretted the holes I punched in my family's old abandoned shack, and the crack I made along the stairs in my house. I did not regret the actions because of punishment, although I did get punished. Instead, I knew the actions were foolish. I was ashamed of my inability to control my feelings.

I never hurt a person, and teenage rage is fairly common for young men. Perhaps it is the process of being manly that gets to us. Society has certain expectations of men, which have only been questioned on a broad scale recently. Men are supposed to be tough, emotionless, and authoritative, and while in my youth I would have argued passionately about how I hated these ideals, in many ways, I tried to embody them.

"Yeah, at least you are not a girl. Guys do not care about hair."

My response: "Yeah."

My actual feeling: "What are you talking about? Do you think I like to see the disgusting image in front of me? I look like Jabba the Hut? No, I do not find the skinhead look attractive, and my hair does mean something to me. Did you ever see my hair? It was amazing. You are not helping anything."

"Ohh, at least you look good bald."

My response: "Thank you."

My actual feeling: "You are a liar. I look like an aerodynamic albino whale beached hopelessly on the shore waiting to die a painful and slow death."

For some reason, many women initiated this conversation. I suppose they did it to try to lift my confidence. Perhaps it even works for small children who are too naïve to realize that adults lie. Or perhaps they thought I had gone blind as part of my cancer, and I could not look in the mirror. I knew I looked hideous. If someone saw me and did not realize I had cancer, they likely would

have thought, "Oh my God, what has happened to him?" In fact, some people who knew I had cancer probably shared the same sentiments.

In most instances, hair is probably more important to females than to males. For most women, hair is a part of their identity. It reflects their perceived self worth and sexuality, whereas for many guys, it is merely an annoyance. If they did not have to comb their hair to attract and keep a potential mate, they would not.

I don't think I've ever been overly vain. I never spent hours fixing my hair or staring at myself in the mirror. Yet, hair played a big part in my self-identity. It made me unique and garnered both respect and hate among those around me. My hair reflected my largest cultural influence, music. The emergence of punk rock signified an all out rebellion against society. Punks dyed their hair, pierced their ears, lips, noses, and any other flap of skin a needle could penetrate, and tattooed their bodies. Fashion was symbolic of a rebellion against society. The statement was clear: we don't have to play by the world's arbitrary rules. While I did not listen to punk, grunge and metal were both influenced heavily by punk. While these subcultures varied in minutiae, they shared many cultural practices, and I identified with this subculture. I liked the idea of rebellion against society. I valued individuality. I loved self-expression. I loved my hair.

Mirrors taunted me. Every morning I woke up to a reflection that I did not recognize. The bald, bloated face reminded me of cancer and all the pain that accompanied it. I hated mirrors. I despised them for their honesty. They were unrelenting in their truth telling, showing me as I was, and not as I wanted to be. It echoed my present and not the past I longed to remember. Every time I went to the bathroom, the mirror reminded me of my mortality. I did not see my own face, but instead cancer. When I looked into it, I saw my friends reaching into a hearse, lifting my casket in the air, and carrying it past my weeping family. I thought of the worm growing inside of me, which morphed into a serpent, constricting around my heart. I imagined the wife and kids I would never have, the college I would never attend, and the unrealized career.

The mirror lied. It did not show my face. I wore contacts not glasses. My eyes looked normal, they were not permanently dilated. My face may have had some baby fat, but it surely did not resemble a blown up puffer fish. I had one chin, not three. My skin while not bronze did not blend in with printing paper. My hair was long and red, or blue, or purple, or orange, or pink. It was not absent. I had eyebrows and stubble on my face, instead of having a perfectly aerodynamic head.

I stared at the cruel image every day in front of me transposing it with the long red, blue, or purple hair of my past. I reduced the size of my cheeks, deflating their swollen appearance, and the color of my skin returned from the pale sickly white to a subtle tan. I reflected on the previous summer, in which my sister and I would ride together in her car with the windows rolled down. We held hands as my hair flew recklessly in the air forming tangles she would later help vanquish. She got angry when I tried to brush my hair. "Start at the tips! You are ripping it out!"

I grunted. "Me man, me not know how to brush."  
"Come here!"

Early on in my disease, I discovered that Arkansas State Law permitted cancer patients to wear hats at school. I missed the attention, and I liked laughter, so I wore the most ridiculous Dr. Seuss hats, jester's caps, and huge, demonically patriotic red, white, and blue hats which also had demon horns. These hats helped replicate the

reaction my hair had received, but generally in a much more benign manner.

Twice, coaches stopped me to tell me to remove the hat.

"Son, hats are not allowed at school," Coach Chandler said.

"Well, state law dictates that cancer patients can wear hats," I replied.

"Oh, God, I'm sorry." The next time I saw Coach Chandler, which was weeks later, he handed me fifty tokens as penitence. These tokens were generally awarded for good behavior and grades and could be used to purchase candy. Coach Chandler was a nice guy who made a mistake.

The next instance was less cordial.

"Remove that hat immediately," Coach Nance roared.

"I have cancer, and Arkansas State Law permits me to wear hats."

"Prove it."

I took off the hat. "I don't really know how...I don't have to carry around a cancer card, do I?"

"What is your name? I'm going to talk to the administration about this."

I never heard about it again.

The coaching incidents did not bother me near as much as the student ridiculing my hat. The coaches were, after all, just trying to do their job. Sure, Coach Nance was a bit of a jerk about it, but in my experience, most coaches were paid to be jerks. They have an inflated sense of their importance. High school athletics did not matter, and few if any of his protégés would play in college, let alone in the pros.

*November 1999- Bryant High School*

"What the fuck is that on your head you fucking queer," generic redneck number three shouted.

I clenched my fists and walked up to him. My face lit up like a candle. I was furious. I wanted to kill him. Instead, I ripped off the red and blue jester's hat revealing my bald head.

A voice inside my head told me to hit him.

Another voice said, "Your muscle has atrophied. If he hits you, you will bleed excessively due to anemia, and you are ridiculously tired. You cannot win this fight."

As I was still walking, he added, "Nice hair, baldy."

"When I had hair you made fun of it. Now, it is gone, and I can't grow it back, and you still mock me? Do you know why I am wearing this hat?"

"Because you are gay?"

"I have cancer," I turned my back and began walking away.

"Bullshit."

A student responded, "No, man, he does have cancer. My Mom teaches his class."

When redneck number three called me a "fag" because of my hat, it bothered me. His insult played on my pre-existing insecurities. I wanted my hair back badly, and I would have loved to have been insulted for my hair, but to be insulted for having cancer showed me new levels of cruelty in the world. It hurt more when I heard the person was "Christian," and thus misrepresented my religion, as well.

Later he came up to me to apologize. "I did not know you were sick man, I really didn't." He wore the remorse on his face with his head held low and a solemn frown.

"Thanks for the apology, but does it really matter? Why would you say that to someone?"

"I was just showing off to my friends. I thought they'd laugh about it. I did not mean anything by it. I swear," his voice trembled.

"Well, maybe you should get some new friends! Isn't picking on people always wrong? Do you think Christ would want that?"

"You are right man, I'm sorry."

"I forgive you."

And while my words forgave him, my heart did not. Making fun of my hair was okay. I chose it. I did not choose to have cancer.

"Thanks man, I'm praying for you."

"Thanks."

He walked off. We never spoke again.

\*\*\*

I wrote the following poem at a poetry slam a year after treatment ended. I got in front of the microphone and recited. The crowd ignited when I finished. It was the first time I spoke publicly about my disease, and it felt great. I did not win the poetry slam, and to be honest, I felt slightly cheated.

### *The Guy With Blue Hair*

I was the guy who had blue hair  
The Guy they loved  
The Guy they hated  
The Guy with blue hair

Then...it fell out  
And I became the guy who had cancer  
I  
Was the sick kid  
I was no longer called "freak"  
I was no longer called "faggot"  
I missed it  
Because I was the guy who had cancer  
I cried  
I cried a lot

But now, I am the guy who HAD cancer  
The guy they love  
The guy they hate  
But more importantly  
The guy who has blue hair

## **Chapter 9: Blackouts and Bone Explosions**

Although I went to a children's hospital, I was not the typical child. Most children do not weigh 200 pounds. With the steroids, that number swelled to 230. I was a big kid, literally. This provided nurses with a plethora of challenges. Some of them were miniscule. My bulging biceps were Herculean compared to the average pediatrics patient. The blood pressure cuff never fit my arm, causing nurses to search for the adult cuff hidden in the corridors of the basement. I never considered myself buff, but these excursions gave me confidence. Nurses also did not expect that a single human being could eliminate two liters of waste in one sitting. They can. I have done it. Respect me.

*October 6, 1999*

As the euphemism goes, size does matter, or at least it matters whenever nurses consider sitting children up after a spinal tap. Apparently, children can tolerate this with no ill effects. Adults, however, prefer to lie down flat. In fact, they prefer it so much that whenever they are sat up, their bodies actively rebel against it. The phenomenon, known as spinal leaking, is as ominous as it sounds. Nobody wants

his or her spine to leak. Spines are solid. They contain a lot of important nerves and help us walk upright. The average person would be strongly against having their spine leak. While I writing this, I asked the person next to me how she felt about "spinal leaking," and she responded, "Uhh...that sounds bad." Kind Ms. Kelly McNutt, spinal leaking *is* bad. When spinal fluid leaks, the pressure within the spinal column drops. Normally, the pressure within the spinal column is equivalent to the pressure of the fluid which surrounds the brain. These two fluids, which are separated by a membrane, exist at equilibrium pressure. Yet after a spinal leak, this is not the case. Mammoth headaches are the result.

By now, you have undoubtedly realized why I wrote all of this. After all, this is a memoir. I'm not explaining random facts to you, but instead, explaining events that occurred in my life. Thus, you already know that the nurses, who were used to dealing with children, did lift me up after my second spinal tap. You also know that this resulted in a spinal leak, and ultimately, my head felt like the victim of an overzealous jackhammer. You are both wise and astute.

Thankfully, I have very few memories from October 6, 1999 to November 10, 1999 (which is funny, because I'm sort of writing a memoir about it...you should check it out sometime...). The memories I do have consist of excessive amounts of pain and morphine. When I got home from the spinal tap, I had a headache. This headache lasted for approximately a month. For my entire life, headaches have plagued me, yet no previous headache had come close to the magnitude of this one. The presence of light made me vomit; trying to get up made me black out. I lay in bed, agonizing constantly. I groaned in vain as my head vibrated. The pain stuck like glue as my head felt like it had been the victim of a bowling ball's wrath.

"Shoot, no problem," the doctors likely thought before performing the standard procedure, a blood patch. Some doctor, likely a resident, took some of my blood. He then made me lie in a fetal position as he inserted a needle, with my own blood, back into my spine. My blood was put back inside my spinal column, theoretically equalizing the pressure. Yet, the problem remained, and I had to endure the additional pain of another needle to my spine.

Blood patches work such a high percentage of the time that back up plans are rarely considered. So my doctors got creative. They got together and decided, "This kid needs some coffee, and a lot of it." They put me on a caffeine drip.

About this time, they were giving me morphine and a lot of it. They gave me a button to push whenever the pain became unbearable. It was always unbearable, and thus, I discovered the button had a limit. If you continued pushing it, at some point, it would cease feeding you drugs. Over the course of treatment, a young resident named Fred and I became pals. I liked him because he knew how to laugh. Many of the young doctors were overly serious. In an attempt to appear professional, they erased their childhood from their memories. To them, the act of smiling became a crime and laughing seemed a peculiar cultural phenomenon which they no longer understood and scarcely tolerated.

Fred succeeded where many failed. He understood that cancer did not kill my sense of humor. In fact, he challenged me to laugh. One day, while Fred came to check in on me, I was particularly high from the morphine. He came in and stood beside my bed, and said, "How are you?"

Trembling, I stuck a finger in his general direction. Fred grabbed it to shake it, thinking I was just trying to say hello. Right when he grabbed it, I let one rip. Farts

supposedly lose comedic value after the age of thirteen. We become too sophisticated for them. Yet, with my supply of morphine coming constantly, sophistication inhibited me no longer. Fred dropped to the ground laughing. I would have as well, but I was in a bed, and the guard rails were up. I imagine Fred will remember that experience for the rest of his life. Patients don't normally fart at their doctors.

Now, even in my morphine-saturated state, the caffeine drip idea seemed a bit ridiculous. I grew up with caffeine. As a baby, my grandfather stuck his finger in his Coke and put it in my mouth. My parents scolded him in vain as he pled with him, "But he likes it." And I did.

In middle school, I took my obsession with caffeine to a new level. After school, my Mom drove us to our grocery store, Helm's Grocery and Mercantile. Some days, I stayed with Granny until Dad closed up and went to work. Other days, I would return home with my mother. While I was at the store, I filled my backpack with seven Jolt Colas, a beverage which claimed to have twice the caffeine of Coke. The next day, I hid the Jolts in my locker and tried to sell them at inflated prices, which never worked. I was too charitable for my money-making scheme, and I'd end up giving away a couple each day. In the end, I rarely even covered their prices.

Even when I had the headaches, I consumed caffeine. Whenever I felt like I could hold food down, I ate as much chocolate as possible, and as long my mouth was not actively expelling stomach acid, I downed sodas (Or "pops" or "cokes." This is not the place for such a nomenclature debate). Despite the flawed logic fueling the caffeine explanation, I did not protest. I just wanted the pain to go away, and I figured it could not hurt to try it. They tried it, and it provided absolutely no relief at all.

If at first you do not succeed, try something ridiculous. When that does not work, try the first thing again, and see if the second attempt, by some sort of weird luck, works. The doctors seemed to have adopted this methodology when treating my headaches, and after the caffeine drip failed, they decided to try another blood patch. Fortunately for me, before they did this, someone had a revelation. Adults can become physically addicted to steroids. Children do not. Adults need to be tapered off steroids. Children do not. Prednisone, a steroid, was a key element of my chemotherapy. It works by breaking down inflammations, and in my case, the inflammations were tumors. I ceased taking Prednisone about the same time as the spinal tap. The combination of these two things caused my brain to swell, which perpetuated the pressure difference between my brain and the spinal fluid, and prevented the blood patch from equalizing out the pressure. The solution came in the form of an orange tablet, which, if not swallowed rapidly, left an unforgettable and unfortunate taste in one's mouth. The little pill knocked the jackhammers out of my skull. I could sit up again.

Tapering Prednisone became an important part of my therapy. At first, we cut the tablets in half, and then into quarters. Mom took care of this out of fear that I would cut myself. She never let me have any fun. From there, I began taking cute little tablets of Prednisone. Most likely, the tablets were not as cute as I perceived them to be. Orange is a particularly hideous color. By my estimations, it is the most hideous color humans can perceive. It does not have the vibrant joy of yellow or the emotional extremities (love and hate) of red. Orange is a wretched excuse for a color, but the tiny jackhammer-destroyers saved me from pain, making them adorable in my book (drum roll).

With cancer, pain is normal. It is not extraordinary. You get used to hurting. You also get used to

feeling dizzy and lethargic. The treatment is ridiculously hard and the side effects are persistent. The headaches were extraordinarily painful, but after the headaches, I discovered another sort of pain that turned out to be worse than anything I could have ever imagined.

Bone pain is a very rare side effect of Neupogen. In fact, only around 1% of all patients experience it. Through my diagnosis, seizures, headaches, and now bone pain, cancer taught me one important lesson: I am a statistical anomaly.

Chemotherapy compromises the immune system. It strikes down tumor cells along with any other fast dividing cells. It is for this reason that cancer patients are hairless, anemic, and neutropenic. Many cancer patients are killed by opportunistic infections which normally would have little to no effect on a healthy person. This occurs because neutrophils, the most common type of white blood cell, are also destroyed by chemotherapy, causing neutropenia.

When my white blood cell counts became too low, the doctors decided to give me Neupogen, a protein that stimulates white blood cell production. As such, Neupogen is a quick immune boost. The protein is given through subcutaneous shots in the muscle. My mother took up the task of administering these shots when we were home. I suspected that she loved it. For the first time in her life she could stab me without fear of legal recourse. She treasured every shot.

*November 18, 1999*

At three in the morning, I woke up to a morbid sensation. A nuclear war erupted inside my skeletal system. It was a world war in which my body was the world. A bomb exploded inside my clavicle. Another one sent shrapnel flying within my patella. Explosives blasted my pelvis, and a mushroom cloud formed within my spine. I tried to ignore the pain, passing it off as a nightmare. The bombardment continued as all my bones were attacked simultaneously. Shaking, I threw myself out of bed. The pain rendered walking impossible, so I crawled to my parents' rooms on my knees. Overwhelmed, I opened my mouth, trembling as I yelped, "Help," in a barely audible voice. Somehow, my mother heard me.

"Oh, God, what is it honey?"

"It...hurts."

"What hurts?"

Silence.

"What hurts Ethan?"

"Everything..."

My Mom proceeded to interrogate me, but I had no answers. I did not understand the pain and discussing it did not make me feel any better.

My Dad picked me up, which was not an easy task as I had swelled to 230 pounds, and carried me to the car. Yet, when I arrived at the emergency room, the doctors did nothing. I sat in the room for four hours, gyrating as the war continued.

"Mom, help."

"I'm trying to help, baby."

"Nurse, he needs morphine! Get him some relief."

Her pleas were in vain, and she became convinced that I had to talk to the nurses.

A nurse entered the room. "Ethan, how are you feeling?"

Still shaking, the question seemed obvious. I hurt. I had to look like I was hurting. Yet, I'm not good at complaining to strangers, and instead of telling the truth, I replied lethargically, "I'm fine."

"Ethan, that is not what you told to me a moment ago! Tell the truth."

"It hurts so bad..."

"I'll see what I can do," the nurse responded. We did not hear back from her for another hour.

I am not sure why I lied to the nurse. Maybe I wanted to be polite, and I did not feel like imposing my pain on others. Or maybe, I thought she realized my pain from my body language. More likely, however, I did it because I was a complete idiot. My idiocy frustrated my mother endlessly. It still does.

It likely would not have helped one way or another. The emergency room doctor claimed I was experiencing morphine withdrawals. I shook because of morphine, and not the pain I experienced. He thought I wanted a quick fix. I did. I wanted the excruciating pain in my body to be fixed.

When Dr. Saccante arrived to work, she realized the problem immediately. She berated the attending doctor and ordered some painkillers. Unlike the other doctors, she knew the side effects of Neupogen. The painkillers gradually extinguished the war in my bones through tedious diplomacy. When it was over, I felt exhausted. I experienced what I later found to be bone pain three times in all. Fortunately, the magnitude of the pain never again matched the first bout of bone pain, and nothing in my life before or after this event has come close to matching the pain of the nuclear war fought inside my bones.

I'm not entirely sure what the doctor would have lost by giving me morphine. My records indicated I had cancer with bone involvement. Clearly, I did not come to the emergency room from the streets just to get high. I had been to the hospital frequently in the last few months for blood patches, chemotherapy, and spinal taps. Junkies do not get chemotherapy. Even if I had been lying, with morphine, I would have been a high cancer patient. If I told the truth, I'd be a hurting cancer patient. Of the two options, an honest patient hurting because of a distrustful physician is more injustice than a lying patient laughing a lot because of a trusting physician.

## **Chapter 10: Manhood**

Cancer picked away at every last ounce of my dignity. It started when the doctor checked my testicles to check for abnormalities. Surely, boys like the idea of people touching their testicles. Even with my disdain for premarital sex already in place, the idea seemed good in theory. In practice, the appeal dissipated for a number of reasons. First of all, frequently, a male performed the groping. Appeal lost. When not done by a man, an older female prodded at my manhood. Appeal still absent. Secondly, the presupposition that the cancer had spread to my junk made the probing necessary, a terrifying possibility.

There is nothing romantic about a doctor's exam. The relationship does not begin with flirting; there is no invitation for coffee, and afterward, nobody smokes a cigarette (which is good, I hear they cause cancer.)

Despite this, I lost a bit of my innocence every time I dropped my shorts for the fondling. After all, beyond my mother, no women had ever expressed in interest in seeing my balls before cancer, and with my mother, it was not exactly interest. It was more of a, "Damn, he shit himself again," reaction that caused her to rip off my diapers.

One of the less obvious fears of testicular exams involves a rush of blood. Teenage boys get erections constantly. Often, the erections pop up randomly without any warning.

In sixth grade, I got called on to do a math problem on the board. I got up and worked out the problem flawlessly. My math created more problems than it solved. In the middle of working the problem, I became erect. I did not want to have an erection, and I most certainly did not find mathematics arousing, even if it was my favorite subject. I

stood at the blackboard and thought of solutions to the problem. There were none. I hunched down as I shuffled briskly to my desk. Nobody commented about the situation afterward. No awkward laughter ensued. Perhaps my escapade went unnoticed, but I doubt it. Every guy who had seen my erratic behavior knew what happened. Instead of laughing, they empathized. It could have easily been them, and at some point in their young life, it probably was.

Establishing the fact that the adolescent penis is a ticking time bomb, you may understand the trepidation I felt every time my testicles were checked. What if I got an erection? If the doctor was male, he would get the wrong impression, and if the doctor was female, she would get the wrong impression. Even worse, I had no clue what would come of it. Would they yell at me? Would I be known as the pervert with cancer? Would they let my parents know? Fortunately, it never happened, and I avoided that potential embarrassment.

No man wants to have a small penis. There is no advantage to having a minute prick. People do not give sympathy for tiny phalluses. Miniscule dicks are not cute. The reward for having a small cock is insipid laughter. This laughter is feared by men all over the world because at some point, history decided that penis size accurately indicated manhood.

At the age of fifteen, I never would have admitted I cared about my manhood. I prided myself in being different, and I felt no need to prove myself. Yet, largely, this was just a façade. I wanted to be stronger, bolder, and tougher. I enjoyed hitting things, watching sports, and cutting meat. I longed to grow a beard.

Taking your clothes off in front of a stranger is nerve-wracking. Hospital exam rooms are cold. Penises panic in these conditions. They curl up inside the body, like a bear strolling into a cave preparing for hibernation. Shrinkage, as it is known, made exams worse by denying my manhood and showing the entire world that I was only a boy. Most of the time with cancer, I certainly felt like one.

When my mother found out I had cancer, she asked the doctor every question imaginable.... multiple times. She is a good mother, after all. After some research she asked a doctor, "So will this make Ethan sterile?"

"It could."

Great idea, likely thought my father. He wants grandchildren, but not from me. He says that it isn't safe for the universe or something. He hopes that my wife adopts or has an affair, or that my sister has around 20 kids, just as long as my genes do not survive.

My mother, however, wants the universe to be destroyed. She wanted me to visit a sperm bank. At first, this seemed a great idea. I thought, "I masturbate all the time anyway, right? At the sperm bank they will have lots of 'pretty' magazines for me to look at."

My initial reaction was ill-conceived. As we walked into the door of the sperm bank, I realized the disturbing nature of my mother's proposal.

Mothers are not supposed to ask their sons to masturbate. If they do, it is generally considered sexual abuse and requires years of therapy. It reeks of incest, which while legal in 20 states (seriously), is surprisingly illegal in Arkansas.

Now, to understand the extent of the repugnance (which, by the way, is not a legitimate word) of this situation, I must introduce you a little more to my mother and my childhood (which are not the same but are strongly correlated). Before anything else, I must state that my mother has been amazing throughout my life. However, she

can be a tad ridiculous at times. During much of my childhood, my mother prescribed to the psychotic ideas held by the Southern Baptist Convention. Southern Baptists have an acute sense of evil. They smell it. Mom smelled evil in the weirdest of places.

Television, in particular, made constant attempts to drag my sister and me into the fires of Hell. Mom, like Arnold Schwarzenegger rescuing the world in *Terminator 2*, had to save her known universe: her children. She did this through a strict regimen of fascist censorship. Shows not to be watched included: *Married with Children*, *The Smurfs*, *G.I. Joe*, *Care Bears*, and *He-Man*. I mention *Married with Children* to contrast it with the other shows. I would not want my hypothetical children to watch Al Bundy's constant references to sex, alcohol, and displeasure. In contrast, the Smurfs wandered around trying not to be destroyed by Gargamel. My Mom pointed out that there was only one female, Smurfette, as if to accuse the Smurfs of participating in gay orgies or sharing Smurfette. Unbeknownst to my mother, the Smurfs are not real. They do not actually need to reproduce. As long as the color blue exists, more Smurfs can be created.

My father did not agree with my mother's demands, but he realized it was a battle he did not want to fight. Instead, he took a diplomatic route, which frequently got him into trouble. When hearing our complaints, he would simply advise us to watch the cartoons at our grandmother's house.

My father took a much more active approach to protecting the television programming he viewed as important. This created a strange world of contradictions. While we could not watch the Smurfs struggle to survive against Gargamel, we were forced to watch Homer Simpson develop a new alcoholic drink, "The Flaming Homer." We could not watch the Care Bear stare, but we were required to tape a marathon of *The Ren and Stimpy Show* for our Dad who had to work. In one episode of this show, the demented dog and cat duo sold rubber nipples door to door. As a child, Mr. Horse's eagerness to purchase the rubber nipples did not disturb me. It should have. Instead, though, I just thought Mr. Horse was silly.

While my mother railed against a plethora of television shows, we watched some of the most controversial cartoons of the early 90s as a family. Partly because of our mother's consternation, my sister and I loved *The Simpsons* and *Ren and Stimpy* the most. We grew up to share our father's demented sense of humor, a mark of what it is to be a Helm.

"Ethan?"

"Yes, Dad."

"Your mother wanted me to talk to you."

"I'm fine Dad."

"I know, I know. She wanted me to ask you if you knew how to..."

"How to what?"

"Masturbate." Dad blushed.

"Um...what?" I looked at him in disbelief.

He stared at the ground. "Do you?"

"Yeah."

"I thought so...but, well...she wanted to make sure you understood what you'd be doing at the sperm bank."

"Dad, let's never talk about this again."

"Agreed."

The actual sperm bank did little to ease my nerves. After filling out some paperwork, a short, stump-like man with slicked-back hair and thick glasses called my name. He stood in front of me with a clipboard and a face



dressed with an eerie smile. He looked like a mix between a used car salesman and a mole, an unholy alliance.

"Come this way," the creepy little man said.

"You may sit here."

Mom and I took our seat, and a nurse came to collect some of my blood.

Moments later, Creeper returned with his perpetual grin intact, "Ms. Helm, you can stay here. Ethan, follow me."

"I hope it's not too hard," my mother cackled. The little man did as well.

My face turned bright red. "Thanks, Mom. I'm not nervous or anything."

Apparently, Mom had been hiding her demented Helm humor from me for the last fifteen years. If only it had stayed hidden for another moment.

I escaped Mom's maniacal laughter by following the goofy fellow into what I perceived to be his home. The room contained thick stacks of masturbatory material including an archive of around forty years of Playboys. It was the dream of every teenage male. The masturbatorium destroyed my imagination that day. While I should have been in awe of the room, the goofy bastard offset this. Easily in his 30s, the man had an irrational love for his job. He jumped around and danced while giving me a brief tour.

"Well, the magazines are here," he pointed. "And also here," he pointed again. "And here, as well." One more point. "This one is nice. Yeooowwhh!"

Uncomfortable.

"You can sit on the chair, the toilet, the bed, or the couch. Feel comfortable."

Not likely. Thousands of people had masturbated in this room. Disgusting.

"To use the cup, you want to aim down into it. This leads to a maximum yield. I'm going to leave now, but if you need anything, let me know."

He spoke rhythmically as if he were practicing a bizarre scene from a musical without the music. A pirouette here, a chassé there. The goofy fellow bastard glided across the floor like a ballerina. It was obvious to me that goofy bastard was a virgin. Moreover, it seemed quite likely that he would remain a virgin unless he resorted to farm animals. I became convinced that goofy bastard lived in the room, sleeping on the couch every night.

"Remember to fill out this label, and put it on the container. Then slide your container in the opening when you are done. Fill her up!" After another quick pirouette, he was gone.

I sat down on the chair and thought, "Hell. My mom is waiting for me to masturbate."

I delayed the inevitable. Walking around the room, checking it to make sure there were no hidden cameras or peepholes. I locked the door and considered barricading it before returning to the chair.

Naturally, my precious was reluctant to rise up, but eventually it did and I got to have sex with a plastic cup. While cup sex does not disqualify one from virginity, it was and is the closest I have come from leaving the realm of innocence.

I put the cup inside the fridge, and left the room. As I walked up to my mother, she said, "Did everything CUM out alright?"

"Oh, God." I thought. My crime had been acknowledged.

"You did not expect me to say that did you...hahaha," she said as we walked back to the car.

"No," I blushed. "No, I didn't."

One night, as my parents lay in their bed; I burst into their room completely naked and announced, "It's big!"

"Well, it is bigger...yes," my Dad remarked.

"I'm going to go show Sissy."

"Noooo," my Mom laughed.

"But it's big!"

My first erection was memorable, even if my parents did not let me show it off to my sister. (P.S.: Thanks, Mom and Dad. I owe you one).

Apparently, my nerves affected my performance. Two days after my visit to the sperm bank, we were informed that my sperm count was low. I had to go back.

"Dad, please take me. I don't want to go with her."

Dad chuckled, "I can't take you Ethan, I have to be at the store."

"But Dad!"

"I'll see what I can do."

We compromised. This time, Mom dropped me off at the sperm bank and then left for a while to go shopping.

With Mom out of the way, even the creepy bastard could not bother me. I was so comfortable that I stayed in the masturbatorium for two hours and filled the cup. I wouldn't have ever left if they hadn't made me. The room included a sink for water, and with as much fat as I had stored, I could probably live there for at least two years without having any problems.

While that's at least a slight exaggeration, the second visit to the fertility clinic went much more smoothly. The moral of this story is clear. Don't get cancer, because if you do, you may have to masturbate in a cup for your mother.

A year after my treatment, I returned to the sperm bank to see if chemotherapy rendered me sterile. It did. I could, still hypothetically, have children. Somewhere in my tank a few sperm still swim around, just like the days of old. As a fertility counselor at the clinic explained, "The chances that you will ever get someone pregnant are one in a million." In which case, if my future wife wants children the old-fashioned way, we will have a lot of work to do. I'm up to the challenge.

To many college-aged males, sterility is seen as a blessing. In fact, a friend of mine got a vasectomy to support his gargantuan sexual appetite. I do not need a vasectomy. I've gotten the effect for free. Yet, I do not need the effect, as I'm waiting for marriage to have sex. A former roommate put it this way, "Dude, it's too perfect. If I were you, I'd be banging chicks all the time. Seriously, why couldn't it be me? You obviously do not appreciate your disease!"

Few conversations revolve around masturbation, and when they do, humor is typically involved. Masturbation is rarely taken seriously. In fact, the few instances where it is tend to involve individuals such as Pee-Wee Herman or George Michael being asked, "Are you seriously masturbating?"

My view of masturbation has changed immensely since chemotherapy. At the age of fifteen, I loved masturbation. Most fifteen-year-olds do. Now I've become a bit more conservative in my views of masturbation. In other words, I do it, but I'm not proud of it. In part, this is because I view masturbation as a sin. I always have. When I was younger, I excused it with little thought, but now I actively acknowledge it as sin. Masturbation is a way of enacting lust, which according to both the New Testament and the Hebrew Bible is a sin. As a Christian, I hold both of these collections of books with quite some esteem, as in they have more moral authority than I do. Thus, I no longer masturbate with glee, but instead, masturbation has become a reminder to me of the grace of God. I, as a sinner, am very much in need of forgiveness.

This is not to say that I have given up on stopping masturbating. Philippians 4:13 reads, "I can do everything through him who gives me strength." Through my continued failures, I have become convinced that I need to be married. Paul wrote in 1 Corinthians 6:8, "Now to the unmarried and the widows I say: It is good for them to stay unmarried, as I am. But if they cannot control themselves, they should marry, for it is better to marry than to burn with passion." I need a wife.

Most fifteen-year-old boys would die for the opportunity to have seven women crowded around their crotch. Not this boy, not these circumstances, and not these women.

The headaches were so strong I could hardly move, and as such, I approached showers casually, in that I rarely had them. Perhaps due to this, something began growing on me. Literally.

My night sweats served as a Petri dish for microorganisms, and with morphine, I did not really care. Most of my hours were spent sleeping. In the rare instance that I did notice the dampness, I never spoke about it. Good patients complain; I was not a good patient. So instead, I lay contently in my bed, the pond, until my mother or a nurse discovered my disgusting swimming pool.

"Time to change the sheets," my mother announced.

This meant I had to get up. "Boo!"

I got up and put one hand on the wall and the other on my head, which pulsed with pain as my mother and a nurse changed the sheets.

"All done," Mom announced.

I collapsed onto the bed. Just before I pulled the covers over myself, my mother pointed at my crotch and asked, "What is that?"

I laughed. Morphine has that effect on me.

The nurse came over to investigate. She pulled gently at my pants exposing my inner thigh. "Oh, my God. Wendy, come quick, you have to see this."

Wendy then called in a few more friends, and before long, the entire nursing staff huddled around me, gawking at my manhood.

"Gross," my Mom announced.

"Thanks, Mom. I knew something had been itching"

"You should have," one of the nurses responded.

I shut my eyes, trying to ignore the newfound attention my crotch caused.

The fungus had grown like a garden of beautiful flowers all over my crotch. Four inches from my testicles on either side, a thick yellowish rash had bloomed. Unfortunately, the garden itched horribly, and responded to my scratching by producing a mixture of blood, puss, and skin flakes.

A young resident came in to join the party. "Looks like a yeast infection."

"I told them we needed a HEPA-filter," Mom added bitterly.

"Mom, I've been in the hospital. I don't think it would have helped that much."

The resident ignored us. "Don't worry about this too much. The infection should be little more than an inconvenience."

It was an inconvenience. After watering the garden with an anti-biotic ointment, the plants needed sunlight. Naked, I spread my legs, while a large hot light shined brightly. Uncomfortable and embarrassed, I lay on my back as light scorched my manhood and everything around it.

The actual point of this diatribe on manhood is thus: I'm a 23-years-old, single virgin, and I need to get married. Interested females may call 501-837-3863.

### Chapter 11: An Irrational Desire to Wear Pants

After hour upon hour of waiting for doctors who like to make appointments but never keep them, I can attest that cancer is a boring disease. Barely being able to leave the house because of a weakened immune system from the toxic goop the doctors gave me didn't add to the excitement, and spending weeks in the hospital where the most entertaining thing you can do is sleep also didn't spice up my life. Cancer is dull. In some ways though, boring is all you want when you become cancerous. Diagnosis is exciting, but not in the "hurray, let's have a party" type of way. It's more closely related to the excitement and horror of, "Oh, crap, my house is on fire" or, more accurately, "Great, my body's systematically killing itself."

So there I was in the hospital, again, after receiving my 2<sup>nd</sup> regimen of chemotherapy, receiving massive amounts of fluids to prevent dehydration. Despite not having food for 48 hours, I managed to find a way to vomit. Puking was not exciting. In fact, I had become quite good at it and had my own style in which I held my neck as far from my body as possible and let it flow. I even considered going pro, but couldn't make contact with the circuit. The Pro-Pukers Tour doesn't have a website.

Besides the continual reemergence of nurses, everything was perfectly boring. The channel button on the remote stuck, making watching TV an impossible event. Sure, I could take my chances and see which channel it landed on when the adhesion came undone, but this quickly lost its allure after landing on two different home shopping channels consecutively. As alluring as a 2-in-1 shampoo and facial cleanser may be to some, it hardly ranked high on my priorities. I tried to read *The Hitchhiker's Guide to the Galaxy*, but the words kept moving around, and as a last resort, I tried talking to my mother. Then it occurred to me that I really didn't feel like doing anything. With no other options available, I slept.

I woke up at three in the morning with a strange desire to put on my pants. Normally, I slept in my boxers. Pajamas are not good for night sweats, and I've never liked pajamas, anyway. My mother bought them because she thought they'd be nice in the hospital. Yet, even in the hospital, I saw pajamas as just another layer blocking my skin from the feeling of sheets. That particular night my boxers must have bored me. I wanted pants.

I got up, rolled my IV over to my bag, and began searching.

"Can I help you, son?" My mother's words sounded faint in the background, and I promptly ignored them.

Trembling, I slowly stuck my left foot in, and my right followed. The process was much more difficult than it should have been. As I pulled my pants to my knees, I lost control. I teetered back and forth like a metronome before I plummeted towards the ground. I fell out of consciousness head first.

The next morning I awoke feeling sore and even worse than I had the previous day. My mother's hand covered mine. She looked at me with bags under her eyes, and said, almost as if rehearsed, "I thought I had lost you." Unfortunately, I was not bored.

"You had a seizure, and you hit the floor so hard. Your pants were in the way and they just anchored you to the ground. Blood was coming from your mouth and from

your head, and you stopped breathing. I was so scared Ethan."

She continued on for a while, but I was lost in the words. What did this mean? Hodgkin's disease is not supposed to cause seizures. Had it spread to my brain? Why did it happen? This, too, was exciting. My house, which was already on fire, collapse, and I was still inside. Boring houses are better than smoldering ones.

Before I had very long to think about it, a man in a light blue coat entered the room armed with a clipboard and an engraved pen.

"I'm here to schedule the surgery."

My Mom's eyes opened wide as if she were an agitated predator about to kill. "What surgery!?"

"I'm a neurosurgeon. I'm here to schedule an appointment," he said smugly. The doctor was young and clean-shaven. He looked like he was still in medical school, and he had not found a way to curve his confidence. We were not confident in him.

"What!"

"I guess nobody talked to you about this." The surgeon was astute.

"No!"

"Well, I'll be on my way then."

Mom quickly pushed the help button, and yelled, "Nurse!" to begin the interrogation.

A minute later, a nurse entered the room, and began a large round of apologies. Deftly, she evaded my mother's wrath by explaining the surgeon was mistaken. The doctors did not know what to do. They had no record of this happening previously.

In response to my new vibrating skills, the doctor's ran every test in the book. The only result came from the MRI, which showed something significantly smaller than a dime. They ran the MRI a few times over the next few weeks to see if there was any growth; there wasn't. This left the doctor's in a position they don't like to be in at all; they were clueless.

From my perspective, there was no resolution and no real explanation of what happened. In fact, it seemed that their only answer to the problem was prescribing yet another pill for me to take everyday. When you have something go dramatically wrong with your body, and doctors say, "Uh, I don't know, here take this," it is not reassuring. In fact, it's completely terrifying. My house which was now just a flaming ball of rubble was now being probed cautiously to make sure all of it burned.

My mother, who was slightly paranoid and more than slightly stressed without dealing with this seizure nonsense, thought the doctors were ignoring the problem.

Dr. Saccente walked into the room. "Hey, guys, I got your EEG back, and it looks clear, which is good news."

"Good news? He had a seizure! How is that good news?"

"He is doing fine now, Ms. Helm. We are trying to figure out what went wrong. None of us have ever seen a Hodgkin's patient have seizures."

"Listen, earlier today a surgeon came in to schedule us for brain surgery. We don't know what is going on, and I don't feel like you guys are telling us everything."

"I'm sorry about that Ms. Helm. There was some miscommunication. We had talked about doing a biopsy, but decided against it. It is a dangerous surgery, and the irregularity on his skull is very small. There is no reason to cut."

"So for now, we should just sit around?"

"I'm afraid that's all you can do."

Sometimes, Mom seemed to blame Dr. Saccente for my illness. She treated her bitterly and rudely. Dr.

Saccente always remained professional and kind, though, and eventually, this kindness won my mother over.

In reality, there wasn't much Dr. Saccente could do. She had two options. 1. Order a dangerous operation based on a small irregularity found on one scan. The operation would be risky for a normal individual but with my weakened immune system and anemia, the risks were heightened. The cut could become infected, and once I started bleeding, it would be hard to stop it. 2. Prescribe some anti-seizure medications and hope that the problem goes away. The second option included fewer risks.

Emotionally, I was a wreck before the seizure. After it, things were even worse. If I did have a brain tumor, I'd have to have radiation to my head, which would kill brain cells as well as cancerous cells. Never in my life have I consumed drugs, and while I've had sips of alcohol, I've only been drunk once. I abstained from these mind-enhancing implements because I value brain cells. I take the ability to think seriously. The seizure medication made it hard to concentrate on anything. It made me feel like an idiot. Radiation could make the feeling permanent. It scared the crap out of me.

"Mom, they cook the rum out of rum cake right?"

"I think so Ethan."

"I don't think they do," replied Sarah.

"It's okay, honey, they boil it out. Trust me."

And Mom went up the stairs to go to sleep.

Sarah and I stayed up playing canasta. She always won, taking advantage of her poor little brother's inability to concentrate. I dealt the cards.

"This cake is good," I announced.

"Have another piece?"

Not only did I have one other piece, I had two. I blame my slothfulness on the steroids. They made me perpetually hungry.

"Soooo, Sarah, yourrrr beating me, pretty baddd," I laughed.

"Are you drunk?"

I laughed some more.

"Mom was wrong about the rum cake."

"I...lick it...like it. Yum yum yum yummy yum."

"I can tell."

"More?" I smiled and held out my plate.

"No, definitely not, I have another idea...how do you feel about bed?"

"I lick bed."

"I hope not. Come on, let's go."

She grabbed my arm, led me up the stairs, and tucked me into bed.

I laughed the entire time.

Prednisone enhances the effects of alcohol. Rum is poured in the cake after it is cooked. So, the only time I've been drunk in my life was due to cake and chemo.

"We need to talk about school."

"We are talking about school."

"We are?"

"You mentioned it didn't you?"

"I guess I did."

"Well, what do you want to talk about?"

"I think you should finish the year."

"Why?"

"Because you want to graduate with your classmates don't you?"

"I don't care. I'm going to ASMS anyway."

"Yeah, but you will be a year behind..."

"Mom, I think cancer is enough right now without me worrying about school. Besides, I have trouble concentrating enough to read a lot of time due to the seizure

medication, and as easy as Bryant is, it is not easy to pass a class without being able to read."

"But you can do it Ethan."

"I know I can, but I don't want to. I have enough stress just trying to survive. I don't need to worry about getting As on classes I rarely attend."

"Well, it is your decision."

"Thank you."

Arkansas School for Mathematics and Science (ASMS) is a public boarding school for nerds. Most of the professors at the school have PhDs, and the course schedule includes microbiology, biomedical physics, multivariable calculus, and number theory. My sister went to ASMS and excelled. She scored higher than anyone at the school on the Arkansas State High School Math Examination (ASHME), a test all students are required to take.

More importantly, she loved it. When she came back home for the weekends, she told stories of flaming footballs, students playing slip and slide in the hallways, and her entourage breaking into old bathhouses. My Dad subsequently deemed the school, "Arkansas School for Misfits and Shitheads." He said, "Kids at ASMS are creative enough to be dangerous and smart enough not to be caught." I longed for it. I applied while I was sick knowing I would have to defer. Eventually, I reaped the benefit, and for two years, I discovered the splendor my sister once shared with me.

My motivation for deferring my sophomore year stemmed from my desire to attend ASMS. Missing class for an entire month made learning difficult, and the seizure medications Trileptin and Dilatin made concentrating extremely difficult. In summary, cancer threatened my grade point average. I feared rejection. Cancer would not ruin my educational plans.

After my conversation with Mom, I decided to take two courses and audit the other two. I only agreed to take the two classes (word processing and world history) because I knew that they were jokes. I type extremely fast. In junior high, I won the district FBLA typing contest by thirty words per minute. Now, I am able to type at around 100 wpm. Although I rarely came to class, I finished Word Processing with the highest grade in the class, and I did minimal work outside of class. I completed four days of assignments in a single class period.

World history should be a serious class. Yet, the teacher of my class, Ms. Johnson, somehow knew less about history than I did. She continually made mistakes. One day, she stated that Hitler killed more people than anyone in history. When I suggested that Stalin and Mao Ze-Dong killed more, she supported her argument by stating, "You do not have a degree." And while I did not have a piece of paper certifying me, I doubt that the 50 million killed by Mao or the 15 million by Stalin will soon be forgotten. She taught with a southern belle swagger, and pretentiously read word for word from the textbook. More of the class discussion revolved around her personal life and pop-culture than history. I did not want to have to take the course again.

During one of my rare appearances at school, Ms. Johnson, with her sub-hamburger mental capacity, gave me a make-up test. She sent me to a desk in the hallway, and I began. The test seemed surprisingly difficult as the words danced around the page. They did not move linearly either, but instead they were doing circles, 360s, and assorted other inverted aerial maneuvers. In vain, I tried to follow them as they floated around the page. Needless to say, each question took much longer than it should have. My muscles began following the words, and I performed an impression of a bobble head doll. When I woke up with people all around

me, I felt no fear. With blood gushing from my mouth, I tried to wave at two childhood friends who stared at me crying. My hands did not respond. Excited to see them, I was not worried about the men carrying me away in the stretcher. It felt familiar.

The next few days they repeated all the tests from the previous seizures. MRIs, EEGs, and CAT scans galore. The doctors still had no clue. The tests were not entertaining. I slept through most of them. Fortunately, the growth on my skull had not grown. The oncologists had no explanation. Realizing they weren't equipped to handle the problem, they made an appointment with the head neurologist.

She explained, "Everyone has the tendency to have seizures; something just has to trigger that tendency. Chemotherapy, for you, seems to have the ability to trigger these seizures. The growth on your skull is nothing to worry about, though. It appears to be a vein that pushes slightly into your bone, which is not a health threat in the slightest."

Interestingly enough, my seizure caused my high school to make two administrative decisions. First of all, the school instituted the Ethan Helm rule, which prohibited students from taking tests alone. Apparently, the school's lawyers thought we would have had a good case if we had sued. We did not sue. Money lost.

Secondly, I could no longer have classes upstairs. The administrators feared I would seize while walking up or down the stairs. The fear seemed irrational. My family did not move out of our house which had two flights of stairs. The decision stemmed from a paranoid lawyer's idea of potential for a lawsuit. My family hates lawyers, but he did not know this. The decision allowed for me to escape from the idiot's class. They did not tell me I would be joining the class of idiots. The first floor included only one history class: remedial world history. I knew many of the kids in the class, most of them weren't stupid; in fact, I knew one of them to be a genius. The kids in the classroom hated school. They did not want to be there. They were bored. Soon after I joined them, I decided I didn't want to do work either. Ironically, the remedial class required more work than Ms. Johnson's story time, and I did not try to catch up. I preferred boredom.

In American culture, we strive for excitement. We want action. We desire new experiences. Our culture teaches us to desire. We want an extravagant house, a nice car, a big family, a nice paying job. But how often do we stop to realize how great what we have already is? Most people in the world wish they were American. In America, you do not have to worry about finding food each day or finding a place to sleep. You can worship whatever god you want to worship, and say whatever you want to say. Before cancer, I used to get angry when I got bored. I felt antsy and useless. Cancer helped me appreciate boredom as a sign of stability. In the middle of the seizures, I would have loved to have been bored. In that respect, boredom is often a luxury.

## Chapter 12: The Funeral

My father's mother, "Granny," as I knew her, loved me. She loved all of her grandkids, and according to my Dad, we saved her life. When my Dad was in high school, Granny lost one of her breasts to cancer. The surgery changed her. She suffered from immense depression and manic/depressive behavior. She constantly fought with anyone she could. Her huge mood swings caused her two children to avoid her. Whether these actions were an early symptom of Pick's disease, the disease she would suffer from at the end of her life, or whether they stemmed from the emotional trauma from losing her breast and the symbolic

womanhood which she associated with it, we will never know. We know how she reacted to having grandchildren: jubilantly. Sarah, Tom, Jim, and I stayed at Granny's house all the time. We loved it there. At Granny's, we watched cartoons until our hearts were content. We ate one chicken nugget and one piece of apple for lunch, and the rest of our meal could be chocolate bars (which became the source of our obesity, except Jim, who has the metabolism of a small bird). At Granny's, we drank Coca-Colas all day, and we played together. She spoiled us, and we loved her for it.

But the best part of Granny's was Granny, who played an active role in many of our endeavors. When we played games, she played games. She let us win, too. We beat her at Hungry Hungry Hippos, checkers, Kerplunk, and Candy Land. For along time, we thought Granny wasn't very smart. After all, she could not even beat children. Unbeknownst to us, she did not play to win. Instead, she played to see the smiles on our faces as we beat the mighty Granny. When we were tired, she would rock us to sleep on her lap, and then carry us to bed. She loved to sing, and her voice, although never trained, was like that of an angel. She did not mind that I loved making my own songs, even though the songs were horrible. She did not mind when I demanded, "I feed myself," when I was very small, only to successfully throw food all over my face and the floor. She encouraged my creativity, teaching me to make picture books from which I could tell my stories. At Granny's, I played in huge paper towel boxes or placed huge sheets over the air vents, creating a bubble world.

There were times when we angered Granny. When we ran around inside or wrestled, she'd tell us, "Go roughhouse outside!" Our proximity to the television was another sore spot. "You're sitting too close to the television, you are going to go blind!" Once we found a can of paint and decided to paint the old store. In actuality, we painted only our bodies. We each got spanked and bathed in gasoline for that one.

Granny nourished better than she punished. She got the thorns out of my butt the time I fell on the prickly pear, and she held my head as I vomited out Halloween (I really liked candy corns). As we got older, the love remained, and while our visits changed, they were still frequent and entertaining. Instead of Candy Land, we watched *Jeopardy* or *Wheel of Fortune*. For many years, I'd visit her every night, and we held hands while watching the shows. Granny was an intelligent woman. The valedictorian of her high school during WWII, she could have prospered in college, but she never had a chance. Few women went to college in those days. So instead, she played the role of a housewife, mother, and grandmother, and she did all three brilliantly.

Slowly, she began to forget things. At times, she was still sharp as a tack, but at other times, she lacked the ability to reason. The doctor's diagnosed her with Pick's disease, a neurodegenerative disease quite similar to Alzheimer's. The disease rendered her irrational. While most of the time she was fine, on occasion, she became overly obsessive. Frequently, she obsessed over her medicine. The first time this happened, she took all the Percocets in the house. My father found her on the ground with an empty bottle next to her. He rushed her to the emergency room, and they pumped her stomach. After that, Papa administered the medicine.

After my diagnosis, she had a new obsession named Ethan. Every day, she would call me ten, twenty, even thirty times. Sometimes, she called minutes after we hung up, because she had forgotten we just talked. It drove my mother crazy, but I loved it. She had a way of inducing me into conversation. When my mother tried to talk to me, I rarely said anything. Frankly, I was a jerk. I did not want to

have to be taken care of, and frequently, I took this out on her. Mom, who has never been known for her patience, learned to be patient with me. My grandmother, however, could get me talking about anything, and spoke at long lengths about the Arkansas Razorbacks, *Jeopardy*, and Bill Clinton. She had the gift of gab; I was under her spell.

Six days before my sixteenth birthday, I received a call, not from Granny, but about her. She had had a stroke. At first, Dad sounded hopeful. Dad is always hopeful. When we went to the hospital to see her, the hope dissipated. She did not look like the grandmother I loved, just as I did not look like the grandson she helped raise. Wires and tubes came out of her body, and a trach tube came out of her mouth. There was no life in her eyes. On January 28<sup>th</sup>, 2000, Vaciell Ermadine Helm left this world. Two days later, I was officially 16 years old. Bald, swollen from steroids, cancerous, and mourning my beloved grandmother, I found a new low.

And in this low, I chose seclusion over company. Instead of going to the viewing with the rest of my family, I stayed home. Most assuredly, I did not feel good, but I never felt good. Highly toxic chemicals ran through my veins wreaking havoc on my body. High dosages of seizure medications frequently made me dizzy. On that night, I felt better than most. Like a coward, I hid behind my illness. There were many reasons for my cowardice. I hated attention. Everyone asked me how I was doing, and I lied, "Fine, fine." I'd say. In my mind, I yelled at them, "How do you think I'm doing? My grandmother just died, and I might not last the year!"

I did not want to feel that way. Nor did I want to see her distorted figure again. As I stared at her in the hospital a day before she died, I could not stop thinking, "This is not Granny." I did not want this misshapen, discolored image of my grandmother to be the last one I had. Most importantly, I did not want to let go. The viewing would make her death seem more real, and I hated reality. So instead, I spent the night alone and crying. Immediately, I felt guilty. I should have been there for my family. We had all lost someone we loved, but they had to face it, while I hid my head in the sand.

At the funeral, I lifted my head from the sand and joined my family. I don't remember the details of the room, or the types of flowers we put around her. I don't remember the Bible verses on the funeral card or the pastor's sermon. I remember my family. I remember my grandfather's cry of agony as the funeral began. I got up, walked next to him, knelt down besides him, put my arm around him, and we wept together.

After my grandmother died, I felt guilty. It is common knowledge that strokes can be caused by stress. Nothing in Granny's life stressed her out more than the knowledge that one of her babies might die. The stress caused her stroke. In other words, I killed Granny.

It is hard to write about this, largely because I now realize the absurdity of my former mindset. I did not ask for cancer. I did not want to cause my grandmother stress, and I do not know why she had the stroke.

Just the same, I remember my emotions. They were real. I cannot deny them. I seriously felt like I had killed my grandmother, and I hated myself. It did not help that a month before she died, I snapped at her.

One day, my grandmother tried to explain to me the pain she felt when she lost her breast to cancer. "I understand what you are going through, Ethan."

"No, you don't," I snapped back coldly.

She looked at me as if I had just threatened to kill her. She turned away from me, and with her back turned to me, her voice quivered, "I understand better than you will ever know."

My grandmother did understand. She understood more than anyone with whom I had spoken up to that point. She lost a breast to cancer, a psychologically grueling process which I cannot come close to comprehending. At the time of her diagnosis, cancer treatment was primitive, and she did not have the luxury to know if the cancer was completely gone, or if it would ever comeback. She understood my fear, but instead of accepting her advice and listening to her wisdom, I denied it.

As soon as I spoke, I knew I was wrong, but I did nothing to make amends for my heartless actions. I just sat in the chair feeling sorry for myself. As I left for the night, I hugged her and apologized, but she never tried to empathize with me again.

### Chapter 13: Speech Impediments and Struggling with God

"Ethie, come here."

"Coming, Daddy!" I yelled.

When I rounded the corner, I saw a behemoth of a man standing next to my father. The man easily weighed over three-hundred pounds, and Green Peace rioted to ensure he did not shave his monstrous beard for fear that several endangered species might be eradicated. Despite being immensely obese, he was strangely flexible. Once, he showed my father and me his unique ability by placing one foot on the floor and the other on the ceiling, while standing. The man was my father's best friend. I loved him and his tricks.

"Uncle Spencew!" I jumped at the bear of a man, who caught me, put me above his head, shook me gently, and put me down.

"How are you, Ethan?"

"I'm good."

"Ethan, what do pirates sound like?"

"Awwwwwwwww, matey!"

"Ohhh, the sympathetic pirate!"

I crossed my arms on my chest, lowered my head, and walked away. I hated the letter R.

"Mommy, how do I let Jesus into my heawt?"

My mother's eyes widened (they are already huge). She paused for a moment. "What?" She clearly had not expected her four-year-old child to be asking her about God.

"I wanna let Jesus into my heawt."

Mom beamed with pride. "Well, someday, you will ask Jesus to be your boss because you know that you do bad things, and you need Jesus as your boss so you can be forgiven. And when you accept Jesus as your boss, he will come into your heart."

"How do I ask him to be my boss?"

"You just pray, honey."

And I did. I lowered my head, placed my tiny hands together, and said, "Deaw God, Thank you for sending Youw son to die on the cwoos fow my sins. Jesus, come into my heawt and become my boss. Help stop me from being bad. In Chwist's name I pray, Amen."

"Amen."

#### *A year and a half later*

"Pastow, I want to be baptized."

"Why do you want to be baptized son?" Pastor Owens attempted to hide his concern, which worked quite well. Six-year-olds do not read faces well.

"I want my sins to be washed away by Jesus," I declared joyfully.

"That is a good reason, Ethan, but not this week. Ask me again next week." He patted me on the head, and I

stared back with a dejected expression on my face.

Pastor Owens walked over to my dad. He squinted his eyes and spoke softly, "Brother Helm, are you telling Ethan to get baptized?"

"No, we decided he needed to decide when he should be baptized. He actually prayed for Christ to enter his heart over a year ago. We did not expect it at all, and we were not certain he understood it all."

Pastor Owens nodded.

"Last week, he began talking about getting baptized. Honestly, he won't shut up about it now. We told him to talk to you about it...he seems so young. It is exciting and concerning as well, you know?"

"Yeah, I've never baptized anyone as young as him. It is great that he's interested, but I'm not sure if he gets it, either. He seemed to understand baptism, though. At any rate, I think it is best to wait a while."

"Well, we will be here." The two men shook hands.

The next Sunday came, and I spoke with him again.

"Come back next week, Ethan."

And I came back seven days later, and he replied, "Next week, Ethan."

I returned to him a fourth time, and he told me to wait once more.

I grew frustrated and complained about it to my parents, who, frankly, were tired of hearing my talk about baptism.

On my fifth attempt, Pastor Owens agreed to baptize me. Secretly, he made plans with my mother, who brought a change of clothes.

I remember feeling confused when they told me to change. I wanted to dive in to the water; changing clothes seemed an unnecessary waste of time. I wrongly assumed I would be baptized in the same clothes I wore to church. Churches are considerate of the fact that water and church clothes do not always interact positively. Pastor Owens' effort not only cleansed my soul, but also saved my parent some cash.

Pastor Owens got in the water first, and read from the scriptures. He whispered to me, "Join me, son."

I got into the water and waded toward him.

He then turned to me and asked, "Are you a sinner Ethan?"

"Yes, sir." I shivered as I spoke, not because of fear, but instead because the water was unreasonably cold.

"Do you accept that Christ died to forgive you of your sins?"

"Yes sir."

I do not remember the next words he said, because in the middle of them, he dunked me into the water. Expecting another question, I did not hold my breath, and I inhaled water. When I came up, I coughed, before smiling and hugging the Pastor tightly. Baptism hurt more than I expected, but I loved it anyway.

#### *2 A.M.*

For the past six hours, I've lodged myself between the computer and the television. I've eaten two grilled pepperoni, ham, and cheddar sandwiches topped with my favorite lettuce substitute, flaming hot Cheetos. For dinner, I ate three chicken-fried steaks for dinner, two servings of mashed potatoes, and two servings of green beans. Green beans became a staple of my diet once I discovered that they taste about as good coming out as they do coming in. I consumed four cans of Cherry Coke, watched two hours of television, and spent four hours playing Diablo. I had just become a level 46 legit sorcerer, and I could beat the game at every difficulty level alone. My fireball evaporated my

enemies, my chain lightning left only ashes. After a long night's work, even the mightiest warriors need rest. I climbed up the stairs from the basement, ate a bowl or two of Lucky Charms, and then went to my room to face my demons. I opened the door to my forest green painted walls, grabbed my Bible, crawled on my bed, and pled to God.

"Why me, God? What have I done?"

Demons surrounded me.

Head under water.

"How can a loving God permit suffering?" I thought of small bald children coughing in the waiting room, their parents staring at them, uncertain of whether their child would live or die. "What crime has a two-year-old committed? What crime have I committed? Where is justice?"

I ran out of mana; I could cast no more spells.  
Head under water.

I gripped my bible and breathed deeply. "I don't have to believe in You."

I paused.

"There is no God!" I said with immediate regret.

The demons attacked. Defenseless, they hit me, and my life bar drained. Soon I would die.

Head under water.

I burst out of the water.

"God, I love you. Forgive me."

Eyes swollen and exhausted, I escaped from the demons with only a bit of water up my nose.

Almost every night, I fell into this pattern. After hours of killing demons and consuming massive quantities of food, I'd run out of mana. Water covered my head as I wrestled with God. I never beat God, and He never left me, although sometimes it felt like He had.

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"Hey-uh-uh, Ethan, how-uh, are you doing?" Greg's stutter, like my speech impediment, sounded cuter than it did awkward. Social workers should be gentle, and Greg was an excellent social worker.

"Hey, Greg, I'm doing pretty well...I mean, I could be doing better, but you know, I'm okay."

"Yeah-uh, I know what you mean...well-uh, I actually came with good-uh news. Dr. Saccente nominated you to participate-uh, in the-uh, Sunshine Kids trip to New Orleans."

"What are the Sunshine Kids?" I squinted slightly, uncertain as to why I would want to participate. Teenagers do not want to be called kids, and the term Sunshine scared me. It seemed optimistic. I hated overt optimism.

"The Sunshine Kids bring kids with-uh cancer together from all over-uh the country. The trip is all expenses paid, and it lasts-uh a week. I really highly-uh recommend it."

"Greg, that is awesome. Thank you so much, he will gladly participate." My mother asserted, realizing my ingratitude.

I stared at her menacingly, "Yeah, it sounds cool." It did not sound cool. I had never flown or spent time away from my parents, and the organization's name terrified me.

"Great, well, I'll send you paper-uh work about it all soon."

The trip almost never occurred. I received chemotherapy three days before departing, and my blood counts were low. I needed a blood transfusion.

Dr. Saccente stood in front of us, clearly concerned. "At this point, I don't know if you should go to New Orleans, Ethan. The trip would be really good for you, but your health comes first. We will give you some platelets in a moment. We need you to come back tomorrow, then

we will reevaluate your status."

"Okay," I said, doing my best to look distraught, as I rejoiced silently.

The next morning, my counts were better, but still bad. After talking to my mother, Dr. Saccente decided it was worth the risk. I would go to New Orleans wearing a mask to prevent infection. Speaking of which, cloth microbe filtering masks feel disgusting. They quickly become saturated with sweat, spit, and water loss from respiration, causing one's skin to feel dirty and clammy, while ensuring that sick people look ridiculous. Sure, the benefit of not dying outweighs these vanities, and while I appreciated their lifesaving capacity, I hated them for their lack of aesthetic value.

As I stepped off the plane, a huge mob wearing yellow, green, and purple greeted us. They gave us ridiculous jester hats and Mardi Gras beads while marching around us, dancing, cheering, and singing. It seemed surreal. We were still in the airport.

I stood unimpressed. I did not share their exuberance. Shy and afraid, and I meekly marched toward the bus. Upon arrival, I sat down, and for the first time, conversed with adolescent cancer survivors. We started with icebreakers.

"Where are you from?"

"What did you have?"

"How long has it been?"

"What? You still have cancer?" Andrew said.

"Yeah."

"Right on, you'll make it. I mean, look at us."

And I did. They all had hair and color in their face. For the first time, survival became a legitimate possibility. Some of the kids had extremely rare cancers with little survival chance. They beat the odds. I could, too.

From that moment on, I danced when they danced, I sang when they sang, and I spoke, even when nobody else spoke. Having been locked away from society in relative isolation, I rarely encountered people around my own age. I felt empowered. On the bus, I grabbed the microphone and began telling jokes.

"Why did the monkey fall out of the tree?"

A few people shouted some answers.

"Actually, it was dead."

I continued with the theme.

"Why did the monkey fall out of the tree?"

"It was dead!" They shouted.

"It got too close to the power lines. Remember children, don't monkey around power lines."

They roared in laughter, and I grew in confidence. Before long, I became the unofficial Sunshine Kids spokesman for the trip. They asked me to thank restaurants for hosting us, an easy job since all the food we had was incredible.

In our short week together, the Sunshine kids grew into a family. Yet, one member of our family remained silent. He spoke softly and preferred the company of adults. He seemed to be having a good time, but he did not become fully involved like the other kids.

And I wanted to change that. I felt compelled to talk to Martin. So while the other kids went around running amok through the hotel, we sat down and chatted in his hotel room.

Four years ago, he had been diagnosed with a rare cancer. The prognosis was bad. He had only a five percent chance of living.

"We did not give up," he proclaimed. "We called everyone we knew together, and we prayed together. They prayed over me, and we asked God to spare me. So far He has."

His path to survival made mine seem luxurious.  
"At one point, I lay unconscious in the hospital for about a month. When I woke up, I had a catheter. After some rehab, the doctors took the catheter out." He began to sob.

"As I went to pee, I looked down..."

"It is okay," I put my hand on his back.

"My right testicle was gone. Nobody had even told me...it was just gone. My cancer spread, and they had to remove it, but I was unconscious. So they did not tell me, and they did not tell me when I woke up. And it was gone..." His words were muffled by tears.

"It is okay man, you are alive."

"Yeah, I am. I've never told this to anyone. Thank you," he smile

"Thank you," I replied.

And at that point, I also had never spoken to anyone about my experience. Martin became the first to hear it.

When I spoke of my quarrel with God, Martin spoke boldly and powerfully. "God is more amazing than cancer is bad." I agreed. He then advised me, "Ethan, you can't do this without God. You need Him. You might not understand why things are happening, and that is okay, but you need to put your faith in Him. He will take care of you in one way or another."

These words changed me. Instead of focusing on my anger with God, I put my faith in Him. I knew I could not do it without Him. Understanding, He does not require, but faith, He loves.

And after I did this, everything went better. My attitude, health, and confidence all improved. I had seen kids who had survived. I had heard their stories...many of them were literally miracles. They survived, and I could, too, but only with God.

*July 10<sup>th</sup>, 2007- Arkansas Children's Hospital*

"Ethan Helm, you are in remission! Congratulations!" Dr. Saccente announced.

I smiled and hugged my mother.

As we walked out, Mom asked, "So what kind of cake do you want for the party?"

"What party?"

"You want to have a party, don't you?"

"Not really."

"Why?"

"Well, I never had an 'I don't have cancer' party before I was sick. I don't feel the need to have one now."

"Well, I guess that makes sense."

Remission does not mean cure. Instead, it simply means physicians cannot detect any cancerous cells at the moment. After five years of remission, doctors arbitrarily declare you to be cured, but cancer can still comeback, especially if the problem is rooted in some bigger genetic problem.

For almost seven years, I have been in remission. After five, I still did not feel the urge to party because I was "cured." Right now, I am alive. I am able to serve my Lord on Earth. I do not know what the future holds as life can change in a moment.

Understanding this has given me some urgency. I feel the need to change the world. I want to help the orphans and the widows while demonstrating the love and compassion of Jesus Christ. I want to help alleviate suffering, as I once suffered.

For three years after cancer, I questioned the meaning of suffering in Epicurean fashion. How could God allow 1/4 of Cambodia to be eradicated by the Khmer Rouge? How were one million Rwandans killed in 100 days? Why

did I have cancer? Why did others die from it? Many Christians claimed my disease came from God. "It's all part of His plan," they would say. I could not accept this. God's plan was not for me to go through excruciating pain. Was it God's plan for one million Rwandans to die? Was it His plan for parents to have to bury their small children? No! Christians claim that everything was part of God's plan. I could not accept this. God did not kill 1/4 of Cambodia, one million Rwandans, or give me cancer. Of this, I felt sure. Why didn't God stop it? I could not answer this question.

And during high school, I did not try to answer it. I remained faithful. I prayed, read the Bible occasionally, and I tried to follow God's word, but subconsciously my anger held me back from investigating the issue of suffering in the Bible. I feared what I would find.

When I arrived at Lake Forest College, I felt isolated and alone. Unlike most students, I did not care about sex, drugs, or alcohol. My roommates joked, "So what are you going to do this weekend, read the Bible?"

"Probably," I smiled.

The debauchery of college pushed me toward the Word. After seven months, I had read the entire Bible, and my study has continued ever since.

Now, before I go on with the Bible, I must be honest about my perspective. I believe the Bible is true, and God inspired. Proverbs 3:5 reads, "Trust in the Lord with all your heart and lean not on your own understanding." God is a greater source of authority than I am, and I try to take head to the Word he has left us.

During cancer, I felt like Job. Constantly, I felt tired and sore. I vomited, seized, grew fungus on my crotch, bombs exploded within my bones, and I couldn't even eat cheese. Death seemed a real possibility, and at times, I saw it as relief. In the middle of my suffering, the comforter of my childhood, my beloved grandmother, passed away. Financially, my family struggled. The store I grew up on was failing. My father often went weeks without pay.

And like Job, I searched for an answer for my suffering. After all, I never drank or did drugs. Sex terrified me. I opened doors for old ladies. I said, "Yes, m'am," and, "No, sir." I loved God.

Based on this, I struggled to understand how a loving God could allow me to suffer. I wanted to know what I had done wrong. So I turned to the book of Job, trying to understand my suffering. I read the book forward and backward. The book seemed to pose more questions than it answered. While Job's friends claimed Job's suffering was his fault, Job defended himself, claiming he had done nothing wrong. Toward the end of the book, God weighs in (38:32-36):

Can you bring forth the constellations in their seasons or lead out the Bear with its cubs? Do you know the laws of the heavens? Can you set up God's dominion over the earth? Can you raise your voice to the clouds and cover yourself with a flood of water? Do you send the lightning bolts on their way? Do they report to you, "Here we are?"

The point of God's response is this: God is so powerful that man cannot understand Him. Moreover, men have no authority to judge God. God's response did not answer why suffering exists, but upon hearing God speak, Job felt satisfied, saying, "...Surely I spoke of things I did not understand, things too wonderful for me to know" (Job 42:3).

Job convinced me that cancer was not my fault, but I still did not understand why God allowed me to hurt. After my encounter with Marcus, I put this question on the backburner, and instead, focused on faith.

As I read through the Bible in college, I again tried to understand suffering. I found the book of Ecclesiastes



particularly interesting. In the book, Solomon, the wisest man who ever lived, reflects on his life. Ecclesiastes 2:11 demonstrates the general theme of the book, "Yet when I surveyed all that my hands had done and what I had toiled to achieve, everything was meaningless, a chasing after the wind; nothing was gained under the sun." Solomon sticks with this theme by claiming wealth, pleasure, wisdom, and even toil are all meaningless. The book ends with the answer to the question of the meaning of life, "Now all has been heard; here is the conclusion of the matter: Fear God and keep his commandments, for this is the whole duty of man" (12:13). This message struck my heart by helping me understand the meaning of salvation.

Christ died on the cross, a sinless man, to eradicate the sins of world. Most people in the United States have heard this at one point or another. Christian churches proclaim it every week, but the meaning of this is often "Left Behind." Christ himself said, "I have told you these things, so that in me you may have peace. In this world you will have trouble. But take heart! I have overcome the world" (John 16:33). The Apostle John also wrote, "For everyone born of God overcomes the world. This is the victory that has overcome the world, even our faith. Who is it that overcomes the world? Only he who believes that Jesus is the Son of God." (1 John 5:4-5).

Overcoming the world is a concept that is hard to grasp. I like to phrase it this way. Once a person accepts Christ, they have won at life. Now they have a new purpose, to serve God with all their hearts and all their minds. And to serve God, we are "to act justly and to love mercy and to walk humbly with [our] God" (Micah 6:8). Christ told us blatantly, we will "have trouble" in this world. Yet, God has given us the opportunity to overcome the world and all our troubles. Once Christ is accepted, we have defeated our suffering, even when we are in the middle of it.

People come up to me all the time and say, "Ethan, you are blessed. You are so lucky to be alive. Praise God! He has healed you."

And I agree with them. I am very blessed. Everyone who accepts Jesus Christ as their savior is blessed. God has healed me. God may or may not have healed me of cancer. Yet, I know Christ healed me when I accepted Christ as my savior. From that point on, I had won at life. It took me three years after treatment to finally realize that salvation means that I never had to worry. I had already overcome the world.

At the age of twenty-three, I frequently state that cancer is the second best thing that has ever happened to me. I learned so much from the disease. Romans 8:28 reads, "And we know that in all things God works for the good of those who love him, who have been called according to his purpose." This does not say that God causes suffering, but it says God can turn it to good by helping us grow. Cancer taught me how to smile. It gave me an urgency to get out and to actively love people. It inspired me to pursue medicine, and most importantly, it has helped me realize the true meaning of salvation. While I do not think God caused my suffering, I thank Him for it everyday. If tomorrow I relapse and discover I will die in a month, this will not change.

As for the best thing that has ever happened to me, it occurred in a car, when I was four years old, and I couldn't say my Rs.

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