

insecure
my story

natalie boonstra lilly

Contents

Introduction	9
Part One: The Origin of Insecurity	
Chapter One: One in Two Million	13
Chapter Two: When Self-Realization Is Painful	24
Chapter Three: There Is Joy in Acceptance	40
Chapter Four: Extraordinarily Rare	49
Part Two: The Hard Work in Healing	
Chapter Five: I Am Who You Say I Am	57
Chapter Six: In Good Company	68
Chapter Seven: The Power of Positive Self-Talk	85
Chapter Eight: Anxiety Is Lying to You	101
Chapter Nine: Growth, Goals, and Grace	118
Chapter Ten: What to Do When You Can't Change Your Situation	134

CHAPTER ONE

One in Two Million

Madelung's deformity of the wrist was first officially described by Otto Madelung in 1878. This deformity arises in adolescents aged 8 to 14 and is often bilateral. It is more common in females showing a 4:1 predominance and represents less than 2% of all pediatric hand deformities. . . . Unfortunately, despite its documentation in the literature, Madelung's deformity is poorly understood among clinicians and often misdiagnosed.

— Satish Babu et al, *Journal of Wrist Surgery*

*I will praise You, for I am fearfully
and wonderfully made;
Marvelous are Your works,
And that my soul knows very well.*

—Psalm 139:14

*I*f you've ever experienced a struggle of *any kind*, this book is for you. Superficially, I look different from most people, but my upbringing probably wasn't so different from yours. I was born October 22, 1999, in the small city of Oshawa, Ontario, Canada, just a few miles from the more notable Toronto.

Epigraph: Satish Babu, Joseph Turner, Sheena Seewoonarain, and Sanjay Chougule, "Madelung's Deformity of the Wrist—Current Concepts and Future Directions," *Journal of Wrist Surgery* 8, no. 3 (June 2019): 176–179, <https://doi.org/10.1055/s-0039-1685488>.

insecure

Shortly after I turned four, my dad, Shawn, took a call as speaker/director of It Is Written, a prominent Seventh-day Adventist media ministry in Simi Valley. My family moved to a neighboring suburb of Los Angeles, California. We traded our tuques (Canadian English for a wool knit cap, or what you might call a beanie) for sunshine and occasional bump-ins with Hollywood celebrities. It was surreal for our little Canadian family to join the booming Southern California lifestyle. Suddenly, everything was more accessible. My mum, shocked at how affordable avocados were, quickly learned to make delicious homemade guacamole. We frequented museums, beaches, and hiking trails with incredible views of our new home in Tinseltown.

As we glided down Sunset Boulevard, I pointed my pink Nikon camera out the window of the backseat of our family's sedan. My parents and younger sister, Naomi, poked fun at me for trying too hard to fit in with my very mid-2000s look. I was proudly sporting oversized sunglasses and a handbag that was probably closer to the size of a suitcase. What did a ten-year-old need to carry around so badly anyway? Sunset Boulevard, with its luxurious palm trees, expensive cars, and sickeningly gorgeous people, was one of the most iconic spots in the city. It was also the home of the Los Angeles Children's Hospital, where, later that year, my life would change forever.

Waiting room appointments

At the tender age of ten, I was introduced to the tiring world of waiting room appointments. I like to call them waiting room appointments because you get to know that area of the clinic best. If you're anything like me, you spend about thirty minutes to an hour flipping through outdated magazines (smartphones have since rescued us from this terrible boredom) and praying your name will be called next when that glorious swinging door opens. Or maybe you pray to have a few more minutes of blissful

One in Two Million

ignorance before the doctor wants to try a new medication that will *definitely* help symptoms this time.

“Natalie, the doctor is ready to see you now!” My stomach did a flip. Historically, getting my preadolescent self to a doctor’s office was a battle even the bravest soldiers might be a little nervous about. Luckily, my mum, Jean, was one tough warrior. In her arsenal were not guns and swords but promises of ice cream and a stroll through Target afterward. She heroically won this battle with her sixth-grader! (Remember I mentioned being an October baby? I was always the youngest in my class, and my eleventh birthday was coming up).

I patiently waited while the nurse recorded my height (much lower than average) and weight (very average, but please don’t ask me about it today). The X-ray technician propped both arms into a machine, and I was no longer nervous about being there but bored. This was just another doctor’s visit where they wouldn’t be able to tell us why my arms were beginning to bow.

Just a few weeks earlier, the family had been out to lunch, something we loved to do together at the local Thai place down the road. Engaging in casual conversation, I had both arms propped on the table, lying flat. Dad stopped me in the middle of my thought and said, “Hey, one moment, let me see your wrist again.” I continued chatting as he carefully examined my very prominent wrist bone.

“Hey Jean, let’s see if we can get Natalie in to see her doctor soon. Something doesn’t look quite right with her wrist bone, and I want to make sure everything is OK.” My dad was alert to this kind of issue, having had surgery for orthopedic problems in both ankles as a kid.

And so, she did. And we were referred to an orthopedic pediatrician in the area, who referred us to a surgeon, who referred us to a colleague, and so on. There was no explanation for the noticeable slope between my protruding wrist bone and hand. But then we met Dr. Murphy, and he introduced us to Madelung’s deformity.

What Madelung's deformity is

You've probably never met somebody with Madelung's deformity; in fact, I would be willing to guarantee it. The deformity is so rare that statistically, only about *one in every two million* people are likely to have it. Forget one in a million.

The deformity was first discovered by Otto Madelung in 1878. Orthopedic surgeons have since been able to narrow down who is likely to get it. The deformity usually makes itself known when a person is between the ages of eight and fourteen. It's often bilateral, meaning it affects both wrists. It's most common in females and represents *less than 2 percent* of all pediatric hand deformities. According to a study done in 2019 by the National Library of Medicine, "Madelung's deformity is poorly understood among clinicians and often misdiagnosed."¹

If not treated, Madelung's deformity results in a limited range of motion in the wrists and pain either after activity or continuously.

We know how to identify Madelung's, but there is no way to pinpoint a root cause. I think that's a question I'd like to ask God in heaven someday. Why do things happen to our bodies that we can't explain? I bet He'd have a pretty good answer for me.

Treating the deformity

If you are fortunate enough to be diagnosed before puberty, like I was, there are options to ensure pain-free usage of both arms.

During our first appointment, Dr. Murphy walked into the room with a giant textbook draped over his arm. A finger pressed gently in the middle of a page to hold his spot.

"I think I have some answers for you," he said, his reassuring nature a comfort to all of us at a time when we weren't sure if we would ever hear those words. He went on to describe Madelung's deformity and showed us a seemingly ancient X-ray of a young woman's arm that looked exactly like mine. Dr. Murphy described the difficulties that I would potentially face in my adult life if

One in Two Million

decisive action was not taken in the next year. The word *surgery* fell from his lips and immediately dropped to the pit of my stomach.

After the appointment, the air was thick as we traveled through the infamous standstill traffic out of Los Angeles on our way back to our little suburb. The operation was scheduled for the next available date, which at LA Children's Hospital meant waiting about five months for a non-life-threatening emergency.

I stayed quiet in the backseat (which was unusual for me), and we tried to talk about anything but the operation. We pointed at planes flying overhead and guessed at where they might be traveling to, joked with one another, and listened to music—anything to keep my ten-year-old head from thinking too deeply about what was going to happen to me in just a few short months.

Mum and Dad, relieved to have answers, kept the realities about the seriousness of the operation to themselves. Dr. Murphy would take the most modern and least invasive approach to provide relief. His plan was to treat me with a procedure called “ulnar-shortening osteotomy,” in which the ulna bone is shortened to level out the wrist. He also would release my Vickers ligament, which restricts medial and volar growth. This would restore alignment and prevent pain later in life. But neither of these procedures was guaranteed to fix the physical uniqueness in my arms. They could still be shorter than average, even after a successful surgery.

So, we waited, and I completely forgot about the upcoming surgery. To me, five months sounded like a lifetime. On went my normal activities of piano lessons, school, and playing with my friends.

A bad birthday gift

I loved my birthday. I still do, but for some reason, in adult society, we've all decided it's unbecoming to celebrate yourself loudly. Hopefully, I can persuade you to do so.

My birthday was treated as a national holiday in our household.

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As an October baby, I got to celebrate with my family *and* celebrate at school, plus a birthday party at my house. I started planning in August—only because my mum would not let me start any sooner. I made a guest list and a detailed plan for the decor. There were chocolate cupcakes, pink streamers, and a dress code for my very best friends, who arrived with presents their mothers picked out for me.

I celebrated with friends, family, and even some of my parent's coworkers. I felt truly loved, and the upcoming surgery was a distant thought. But just a few days later, I was thrown a curveball when my parents picked me up from school. I always wished they wouldn't be so prompt with pick-up times so I could spend a few more moments giggling with friends and playing in the autumnal leaves. I threw my backpack down in the seat beside me—wasting no time chatting them up with the latest elementary school news. They waited patiently to share their own news.

“Natalie, honey, we have some news for you from Dr. Murphy's office,” my dad said gently. I knew this wasn't going to be something I wanted to hear based on his cautious tone. “They had to cancel a surgery, and we can actually go for your appointment next week!”

I was not pleased. There was no way I was ready to face this. Mum and Dad reassured me that if I was going to have the procedure done, it was best to get it out of the way. They had prayed diligently for their little girl and believed God was guiding us closely through this process.

Midnight pizza

On October 27, 2010, we dropped Naomi off at a family friend's house and made our way to Los Angeles. Mum and Dad did their best to distract me from what would happen the next day. We packed my favorite blanket and stuffed animal, and I sported a new outfit from my birthday wish list.

One in Two Million

Staying in a hotel right on Sunset Boulevard normally would have felt like a luxurious vacation—but that night, it felt like a prison sentence. I had learned at a young age through my parent’s example what showing up for someone you love looks like. Nothing else mattered that day except how I was feeling. Rules were broken, and requests, granted.

As is standard practice before most operations, I wasn’t supposed to eat twelve hours before. We all sat up well past my normal nine o’clock bedtime, watching movies and talking through what tomorrow would look like for me. Suddenly, Dad sprang up from the bed.

“OK, kiddo, get your shoes on! We’re going on an adventure,” he said with a twinkle in his eye.

“But Dad, it’s midnight already! Where can we even go at midnight?” I was naive to the bustling nightlife in the city.

I laughed as we hurried out the door and down the street to a local pizza place. “No way! I’ve never been to a restaurant this late at night! Look, Dad, they even have pineapple left,” I squealed delightedly.

My dad had a special plan for me that night. He invited me to trust him and enjoy some fun before entering the hard weeks ahead. That night, I knew there was somebody on my team rooting for me to win, no matter what.

Love is a powerful force. Do you recall a time when somebody showed you immeasurable love? Have you ever been shown kindness with no expectations from the other party to return it? That warmth and safety is not something you can’t replicate artificially—though many try. Dr. David Viscott is credited with saying, “To love and to be loved is to feel the sun from both sides.”

Sometimes earthly fathers do a wonderful job of reflecting the character of the heavenly Father. Other times, their own struggles get in the way of being good to their children. Sometimes people cause us a lot of pain that we didn’t ask for and can do nothing

insecure

to change. Situations beyond our control can affect our ability to see the goodness of God, much less believe in Him.

Because I'm a Christian and I operate from that worldview, I believe in God. I believe that the Bible paints a picture of a God who is loving, somebody who would do *anything* for a hurting child. Love is the driving force behind God's character and motives.

And so we know and rely on the love God has for us.

God is love. Whoever lives in love lives in God, and God in them (1 John 4:16, NIV).

Though the author of the above epistle never identifies himself, it can be deduced that it was written by John the apostle. First John is one of three letters most likely written to the seven churches in the vicinity of Ephesus. He wrote to encourage the congregations to love each other and keep up the good faith. Meanwhile, John was exiled to the island of Patmos, a desolate, rocky island in the Aegean Sea. This place was usually home to the harshest of Roman criminals.

Love got John through the loneliest time of his life. Love got me through the scariest night of my adolescent years. And God's love *will* get you through the tough moments you face.

Struggling for breath

On the morning of October 28, 2010, the Los Angeles Children's Hospital was unlike the cold and scary hospitals I'd seen on TV. Rather than a sterile environment, I was delighted to be met with coloring books on tables and friendly cartoon characters plastered on walls.

The nurses, highly trained to be optimistic around patients, gently guided me through each step of the pre-op process. Dad took pictures and videos to update our family and friends about

One in Two Million

each of those steps. I had an awesome community praying for me.

Eventually, it was almost noon—almost time to begin. Dr. Murphy pulled back the seafoam green curtain to my pre-op waiting room. I asked him how many surgeries he'd performed before this one. He laughed and reassured me that he was “the best” and could do the procedure with his eyes closed. Although he'd previously never treated Madelung's deformity, Dr. Murphy was an expert in orthopedic surgery. He was confident that it would be fairly routine, and he promised to keep his eyes open.

The nurses wheeled me back to the operating room. It was the longest hallway I'd ever traveled. I chose the grape soda scent to be pumped into my mask with the anesthetic—a luxury awarded only to patients under eighteen. I counted down from ten, and the next thing I knew, I was starting to wake up.

My arms felt heavy. So did my eyelids.

This is just like the movies. I can hear everyone in the hospital running around and the machines beeping. This is so cool. Am I awake? Or is this just part of my dream? Can you dream during surgery? My mouth is kind of dry; I hope they'll let me eat when I wake up. Maybe somebody can get me some ice cream.

“Natalie!”

Who's bothering me? I'm so tired; I wish I could just keep sleeping.

“Natalie! Are you awake, honey?”

Can't these people just leave me alone? That sounds like Mum's voice, though; I bet she's worried. I should try to respond.

With all my might, I peeled my eyelids up and offered the most enthusiastic smile I could muster.

“I'm awake! You don't need to worry! I can't lift my arms, though; they feel heavy.”

I looked down and saw both forearms wrapped in casts, propped on two pillows for blood flow. I would not be able to move them easily for several days and would be in casts for about ten weeks.

The hours passed calmly. The anesthetic and pain medication

insecure

slowly wore off. Soon, I began to feel the seriousness of what actually happened. I started to cry as the pain got worse. It was time for my next dose of medication, but my oxygen levels weren't high enough to administer it safely. The nurses tried everything to help me calm down and raise my oxygen. We tried cold and hot compresses, breathing exercises, and moving my arms to new positions.

Mum and Dad walked me through more breathing exercises and asked me to tell them a story to get my mind off the pain. But nothing could totally distract us from the low oxygen levels and desperate need for some relief.

"Nat, we haven't tried something. We haven't tried praying and asking Jesus to raise your oxygen," Dad said hopefully.

Unable to hold my hands, my family placed their hands on my shoulders, and we bowed our heads. We asked our heavenly Father to hear a child in need of comfort. Before we could finish the word *Amen*, my oxygen levels spiked! The nurses all looked at each other in disbelief—they thought it would be hours before my breathing would be more regular.

God wants to hear you, too. He wants to be your relief when the painful moments are too much to bear. Your condition probably doesn't look the same as mine, but we all have something we wish we could change.

Maybe your mental health is preventing you from experiencing life's joys. A loss of a loved one. A sexual assault. Unbearable guilt from past actions before you knew better. I don't know what it is you're dealing with—but it doesn't define your worth—not in God's eyes.

In Psalm 139:14, the psalmist writes,

I will praise You, for I am fearfully and wonderfully made;
Marvelous are Your works,
And that my soul knows very well.

One in Two Million

He didn't leave a line open for exceptions. You are not fearfully and wonderfully made unless this happens or that changes. No, you are fearfully and wonderfully made, *period*.

Dig deeper

Discuss the following questions with a small group, or reflect independently:

1. What was your first encounter with insecurity? Was there a specific event or incident that caused you to question yourself?
2. How do you believe God views you?
3. Think about a typical week. How many decisions are focused on pleasing other people and doubting yourself? How can you make adjustments?
4. Why or how do you know God loves you?

1. Babu, Turner, Seewoonarain, and Chougule, 176.