

Ask that Your Way be Long

When I chose to have children, I had it all planned. They would nurse, eat healthy food, be as free-range as possible, live carefree lives, go to public school, which I would supplement with nature, art, hiking, and reading volumes of Laura Ingalls Wilder and *The Lion, the Witch and the Wardrobe*. My children would learn to notice the world with insightful eyes. I would engage in their lives while letting them gain as much independence as necessary to survive in this world.

I had already moved to rural New Hampshire from Boston so that they could live in an environment similar to the one I experienced. As the breadwinner of my family, my staunch belief that babies should stay home with their mothers had already been shattered, but at least I had chosen the right profession. As a teacher, I could spend vacations with them when they started school. I was excited about sending them to public school where they would meet people from diverse backgrounds, unlike me, who had spent my elementary school years in private school. From there, their opportunities would multiply as they approached high school and graduated to college and beyond. My children would have it all.

I found out that life isn't so predictable when William was born with Trisomy-21.

William's entry into the world took all night—as if the universe was deciding whether to let him in or let him go. When he entered this world, he didn't cry. He flopped over his folded legs as he would for most of the transitions he made later in his life before feeling ready for what came next. A pause hung in the air a little longer than felt right as if to say, "Wait a second. I need to think about this." If I had known William as I do now, I would have expected this. I would have been the first one to breathe.

Suddenly, everything became medical, and after some whisking, scooping, and juttering about, William started to breathe. The obstetrician's shoulders sagged with the relief of having finished with his obstetrics. Nurses fluttered like fireflies stuck in a jar before they took William from me to inspect him and give him a shot of vitamin K. Even though the 8:30 morning sunlight should have broken through the dusting of snow we had that morning, the room was dim.

I am no different than any other mother who recognizes that raising children is the most challenging thing a woman can face. Children bring out an extraordinary emotion that touches the core of a mother's spirit and body. William was no different from his sisters, Kate and Claire, in that way. Each child presented me with the challenges children do for working mothers—daycare, the perils of middle school, chickenpox, facing an animal's death. William's trials took more oomph on my part—hospitals, advocating for the best education he could get, and transitioning out of school into the world. I have grown used to the stares and outlandish statements following us around as if William is a curiosity. I may not have skirted the obstacles I had to face for William with grace, but I learned how to navigate the journey as each one presented itself.

Welcome to Holland

Emily Kingsley, once a writer for *Sesame Street*, has a son with Trisomy-21, which is the term I use for Down syndrome. In her 1987 essay, "Welcome to Holland," she compares his birth and her shifting expectations to landing in Holland when she thought she was going to Italy. In Italy, you would see Rome, the Leaning Tower of Pisa, the Sistine Chapel, and paintings by Michelangelo. Holland is flat, and all you can see are miles and miles of tulips and windmills.

When I was pregnant with William, I expected to land in Italy too. When he was born, and I realized he had Trisomy-21, I knew I was in for a long and arduous journey. On a bike, the headwind would be fierce, I didn't speak the language, and other than that, I knew nothing about Holland. I resisted the journey even though the plane had landed.

But I couldn't leave. William was William, not Trisomy-21. As I fell in love with him, I started to see things from a new perspective. Even though arriving in Italy was what had I expected—what I planned on—I had it all wrong. It took me some time to realize it, but landing in Holland was going to be okay. Certainly, there were some bumps along the way. William had heart surgery and an aortic repair before he was eight weeks old. The bureaucracies I would have to face spoke a different language. With William's birth, I had entered a new culture beyond the one I had lived in before. I learned a new language and saw life through a different lens. Still, after William was born, I started to notice a plethora of red, yellow, and pink tulips growing around us, and the windmills spinning through the day and night. I was, and am, meant to be right where I am with my beautiful child, who has given me far more than Italy ever could.

When you have a baby, any baby, especially your first one, all expectations fly out the window. Today, I embrace Holland. I see farther there than I see in Italy. In Holland, I watch windmills whir endlessly over fields of tulips of all different and extraordinary colors.

Unwrapped Packages

Trisomy-21 enters our lives like a gift packaged in brown paper. The paper is stiff, unyielding, and challenging to fold. Everyone unwraps the package differently. Perhaps with wonder. Maybe not knowing whether to laugh or cry, console or worry, send a sad note, or sing praises. More people than you would think aren't ready to unwrap the stigmas. Some people don't know where to put them once they open them. It is human nature to keep people in

categories. Thus, extraordinary people are fit into the world in a particular way so that others can feel comfortable.

No one mentioned that William might have Trisomy-21 on February 22, 1989, the day he was born. Doctors and nurses skirted around us, focusing on his jaundice, and my inability to nurse him. Meanwhile, other mothers popped out pink baby girls and boys with healthy hearts who seemed to grow during their short overnight stays. People from my birthing class bounced in and out of the hospital. One mother concerned her daughter's ears might stick out too much, taped them down with Scotch tape.

William and I stayed in the hospital for days. I, still ignorant of the semantics, was sure he was a Mongoloid, an archaic term I am ashamed to write on this page. It took a whole day for me to gather the courage to admit the truth to William's pediatrician. When I did, she raised her eyes—perhaps because I was the one who said it first—as if I had opened the window and let in the fresh air.

Declaring my suspicion made it real.

Having a newborn son different from any child I expected to have, tore me apart. Guilt for not being elated, for feeling resentful and cheated seeped through my skin. Doubt wouldn't let me fathom how to make it through the next day, let alone the future. Devastation wrapped my heart. In the shower, I cried until my skin turned red. William was a mystery. He was also my son, which trumped everything, the doctors, my mother, Italy, guilt, fear, and doubt.

God and Angels

When people used God and William in the same sentence, it used to fill me with resentment. I brushed it away, but it resonated and fed my doubts about whether or not there is a God. A friend told me it was okay to be mad at God, which comforted me. It allowed me to be

angry at something besides myself. Maybe God does choose specific people to raise children with disabilities.

A few days after William's birth, my Aunt Phoebe, whose daughter Susie has Trisomy-21, wrote, "God has sent an angel to you in William." Why would any god pick *me* for this job? From my perspective, the only thing God had done was send me a child I was incapable of raising. I was a first-time 31-year-old mother with a lifetime of nurturing an extraordinary child ahead of me. Perhaps if I had known then what I know now, Aunt Phoebe's words would have resonated with me.

I wonder about God. I almost refuse to believe in him. Contradictorily, when things get rough, I blame Him, ask Him why he made me his new version of Job. Perhaps my formative years sitting on cushioned pews inside St. Matthew's Episcopal Church in Bedford, New York, molded these feelings. Even then, it felt uncomfortable praying to something as intangible as a God sitting in heaven with his flowing white beard.

Peering into the Future

When William was still recovering from jaundice in the hospital, I drove to town to take a break. I saw a man with Trisomy-21 riding his bike and weaving through the traffic. He was going places. Why didn't this man infuse me with hope? Instead, what lay ahead daunted me. How was I going to get William from where he was to where the man on his bike was?

I kept to myself because I was mourning for the baby I didn't have. During these times, I couldn't bring myself to call the women from my childbirth classes whose babies were going to

go to daycare, pre-school, elementary school, and eventually college. Beyond that, their opportunities were endless. I wasn't sure that it would be that way for William.

When William entered the world, I felt as if we did not belong. One day after our prolonged stay in the hospital, I gave a ride to a colleague. She peered at William in his car seat. I felt compelled, as I always did, to explain he had Trisomy-21. She stopped me and said, "I know. He's beautiful."

She got it. She knew William shed light on what he held for us. We do belong here. I may feel alone in this world most of the time, but every once in a while, someone reassures me with their understanding and compassion.

Home

William arrived at our first house on Starrett Row in Bennington, New Hampshire, after spending his first week of life in the hospital with jaundice. Tom, my ex-husband, and I did not have the money to buy anything but this fixer-upper, with light pea-green vinyl siding, a one woodstove house. You could stand in front of a window on one side of it, and blow out a candle on the other side in one breath.

We hadn't finished turning the house from a shack into a home. Tom had built our bed and moved it to the second floor, which now had electricity and a crib for William. While I was pregnant, people used to ask me if I had decorated the baby's room yet. "Well," I would reply, "we put up the sheetrock this weekend, but we need to install the rest of the electrical sockets."

I was new to marriage, to homeownership, to making it from one paycheck to the next, to New Hampshire, and to parenting. I didn't know about the trials I would face over the next two decades, or that twenty years later, Tom and I would be divorced.

After William's birth, the depression I had lived with all of my life found an ample opportunity to surface and compound with the hormones and emotions wreaking havoc on me already. Depression creeps into me when life sneaks up on me unawares. It's exhausting. If I am not in the throes of it, I am in the throes of holding it back.

I grew up in a family of five. Three of us were and are bipolar. This led to my brother's death in his 50s. The three of us were sandwiched between a brother, who was seven years older than me and a sister who was seven years younger. Maybe it was birth order, perhaps it was me, but my parents didn't have the time or wherewithal to deal with another needy child, so I was the one who had to be strong. Falling apart was a sign of weakness. If any of us were sick, we kept quiet and went to school. I don't think I ever cried in front of my mother. I played sports with a vengeance and spent as much time as possible outside. As a child and an adult, I have sought refuge in nature and the woods to face my world. I worked hard to keep my lack of trust, my depression, and my vulnerability in check.

Cocoon Days

I was not new to feeling alone. I had spent a lifetime as a sole warrior, fighting my own battles and trying to understand how to live in a world that didn't make sense to me. However, with William, it was a different kind of alone and misunderstanding. After William and I settled

into our house on Starrett Row, I spent most of my time alone—the kind of alone that comes with snowy New Hampshire cloudy days. Winter cold. Winter alone.

With William, I welcomed the quiet. I embraced the time I had to focus on him for days on end in all of the newness surrounding me. I pretended we didn't need to face the outside world. The heat from the woodstove curled through the dining room and found me in the rocking chair, holding William and falling in love. The heat was sparse, but enough to wrap us in the warmth of what was happening inside, where I could disregard the threats and realities of the outside world knocking on my front door. We weren't ready to metamorphose and fly headlong into the unknown. Now was the time to stay inside and rock, avoiding the cold raw days ahead.

The road passing by the house looked as grey and bleak as the sky. The neighbors weren't home, and the aloneness settled in like a quiet leaky storm spitting out specks of snow, silencing the birds in the eaves, and filling the house with loud, hollow reticence. In our house, I settled into my cocoon, where the grey February light streamed through the single window in William's room, leaving a small patch of warmth on the floor. The rocking chair sat in the corner. I could not afford to reupholster it, so I covered the worn, ripped, brown corduroy with a bedspread from my college days. It felt as if I was piecing my life together with the past because it was all I had.

William and I swaddled in the comfort of our nest. The snow still hugged the new March ground. Together we nursed, tucked under cover, protecting and loving more than I knew I was capable. Under the eaves, next to our nursing chair, a mother bird also made her nest. It was with her I came to know William. I wondered about the mother bird's experience. Perhaps, she was a Bluebird, or a House Finch, or a Song Sparrow. We had the same job to do. Both of us were protecting our young from the outside until they were ready to fly from the nest. I nestled into

my cocoon trying to nurse William, while Mother Bird kept a pulse on the outside world, foraging for food.

I listened to her chirping chicks when she flew away to find food for them. William mostly slept and rarely cried. When Mother Bird braved the cold for her chicks, they kept each other warm in the nest. She would fly back and rustle in to satiate their cries for her and the food she brought. They stayed there with William and me, growing and becoming a part of our small world.

None of us was ready to leave the nest. While Mother Bird cuddled her chicks, I rocked myself trying to get William to nurse, my old college blanket scratching my back with warm comfort. Compared to the chicks, William was silent, his skin soft, almost blue. I tucked his loose limbs into his blanket as I tried to feed him, not knowing I was barely keeping him alive. William slept more than he ate, and his breathing was labored. He was becoming more transparent each day.

Even though I didn't have to gather worms as Mother Bird did, I knew I would have to venture out of the nest too. I would have to step out of the house and lay a path for William, find a place for him to get healthy, and the right people to support him when I went back to work. A series of unknowns awaited both of us. But I knew the stories of baby birds falling out of the nest and never learning to fly.

I didn't have a chance to stop hearing Mother Bird's chicks chirping or when their chirping may have turned into song. I don't know when they started to fly from the nest or if any of them didn't make it. Maybe I stole away before she and her chicks did when I took William to Children's Hospital one day and didn't come back until the black flies were biting with a

vengeance, the sun was high in the June sky, and her bird children swooped and dipped over the surface of lakes to satiate themselves without her.

THOSE WERE THE FIRST PAGES. WHAT FOLLOWS ARE THE END PAGES

New Year

The weather was kind when I took William for his follow-up visit with the neurologist. I don't know why we were going back. We had proof of another fainting episode and knew he did not have epilepsy. I was prepared to wean him off the Keppra the minute I stepped into the neurologist's office when he arrived two hours late.

When the neurologist settled into his chair and pulled up William's chart on the screen, he went into a frenzy. "What is this? This can't be right," he ranted as William and I, terrified, watched him clicking the keyboard as if to make the screen say something else.

I managed to sputter, "What's wrong?"

"But this can't be true." The neurologist stammered. "It's inaccurate. He was having seizures. This is a misreading."

William's eyes darted from one of us to the next.

"What?" I said, standing up to read the screen.

"It says here that William's heart stopped beating for 30 seconds on December twenty-fourth at 5:30 am." It was now January fifth.

After a series of frantic calls, we paged Dr. Flanagan, who once again came to our rescue. He said he needed to research the issue and would get back to me the next day. True to his word, Dr. Flanagan called at three the following afternoon. After about ten minutes of medical speak, I said, "So if William's heart *did* stop beating for 30 seconds on December twenty-fourth while he was sleeping, what does this mean?"

“It means,” Dr. Flanagan’s steady voice said, “you need to come up here right away. If his heart stops beating again, it may not start up again as it has before.”

I mulled it over for a minute. I was tired from crying all day. William would be rattled by this. I didn’t want to rush and create panic for either one of us. It was my turn to pause. I paused because I knew that the tension of driving to the hospital right away was not worth the stress it would put on William and me. Besides, I knew well enough it would be best to stay at home while the hospital found William a bed before we trudged up there and sat in the waiting room until they did. This time the call for action was to be calm. William had been having these episodes for one year, maybe more in his sleep, and another night wouldn’t hurt. We both needed to gear up for this one.

“I’ll be there in the morning.”

Dear William,

On the EKG, your heart was a series of squiggles that weren’t squiggling the way they should. Instead, they lay flat for 30 long seconds in the middle of the night, or while you fell to the ground as you loaded the truck with wood, or accorded to the barn floor while you tended the cows. But something inside of you woke up your heart each time. Something inside you said, “I am not stopping here.”

Yesterday, they fixed the electricity in your heart. You were mad about the giant bandage that had to sit on your chest all week. The wires would be there forever. You could feel the pacemaker underneath your skin living inside of you and sending your heart’s electrical signals north every day.

After they inserted your pacemaker, your chest was swollen. There was something unreal inside of you. When you got home, you didn't eat your plateful of food. Your eyes were like dark hollow tunnels traveling to the root of the pain. Your furrowed brow knitted the anxiety swirling inside of you. Your husky voice yelled, "It hurts! No! Don't! Don't touch. It hurts." I held you as I held you when you were a child. We rocked. "I know it hurts. I am sorry it hurts. Things hurt sometimes." Solving problems hurts.

That night as I started to leave, someone asked you to thank me for all I do for you. "Tell her how much you love her," she coaxed.

Express the nonverbal with words.

"Mom." You called me back.

"Mom," you said, and you waited.

I waited and leaned into you.

We touched foreheads.

You didn't need to say a word.

Reconnecting

I expected a routine check-up. The kind when you drive an hour and a half so a technician can tell you the pacemaker was working. It wasn't. The wire in the lower ventricle had not adhered to tissue and settled the way it should have. It takes six weeks for the wires to adhere to the heart. As long as you don't lift your hands over your shoulders or do any heavy lifting. William sleeps with his hands under his head. He puts his coat on by laying it on the floor, putting his hands into the sleeves, and whipping it over his head. Perhaps, I hadn't emphasized how essential it was that William not do this.

William would have to go through another surgery to reconnect the wire from his pacemaker to his heart again. It was more straightforward this time because they only had to reattach one wire, and the pacemaker was already in place. The surgeon didn't have to trace William's complicated mass of blood vessels to his heart again; he reattached the dangling wires. This time William got to go right home, and the device that read his heart was tucked and secure under his bureau. There would be no repeat performance of the disappearing heart monitor.

Weeks later, the hospital called me to ask if William was undergoing intense exercise because the reading on his monitor was sending messages that his heart was racing. He wasn't. Even if he had been, it wouldn't have pushed his resting pulse to 170. William had called me the night before complaining of a stomach ache, which wasn't typical for him, so I had an inkling something was wrong. After William got into my car to make another trip to the hospital, I asked him where his stomach ache hurt. He pointed to his chest. He didn't look well.

We drove to the tunes of *The Music Man* and *Raffi* as a sense of fear settled into the car. It is never a good thing when the hospital tells you to get there on the double. This time a pause was not an option. I could see his heart fluttering against his T-shirt. We arrived at 5:00 on a Friday afternoon after most of the doctors left, and the staff was at a minimum. Friday is the worst time to get to the hospital when you need immediate care, which William did.

There was too much silence as the doctor tried to override William's tachycardia with his pacemaker. If the pacemaker could force his lower ventricle to catch up to his upper ventricle's 360 pulses per minute, it could override it. Then the rhythm of William's heart could readjust. When that didn't happen, it was the doctor's turn to readjust. It didn't take long to admit William to the ER and recharge his heart. In the old days, they would have used paddles and said "clear" the way they do on *Grey's Anatomy*. Now they use oversized rectangular patches—one patch

sticks on the front and another one on the back. That was all I knew because I couldn't stay for the five minutes it took to stop and restart his heart.

One of the doctors, who seemed to be in charge of the recharge, told us we would go home that night. Others weren't so sure. William was adamant. "I am not spending the night." We spent hours in that state. "I'm not staying here. I'm not sleeping here. I'm going home." On the page, his words sound gentle, but they were dark and hollow.

I wasn't sure what to say to William until one doctor on his team confirmed we were leaving. The nurse unplugged the wires attaching William to the EKG, his pulse, his oxygen, and heart monitor. I was relieved I didn't have to explain anything to William, and we could put an end to the visit and head home. However, my relief was premature.

An hour later, a different doctor came in to tell us William wasn't going anywhere—for the next four days. It is not uncommon for one person on a medical team to say one thing and another person to say something else. William was furious, and I felt the gravity of the situation leak onto the floor. He needed close monitoring to make sure the new medicine worked and that his heart would keep beating at a reasonable pace.

When we left four days later, it didn't feel as if I had put an end to the medical troubles William will have to face as an adult. Life is catching up to William and me. For now, he is well; his heart beats steadily under his shirt. He has a new bike, a new scar, and more medicine to add to his repertoire for hypothyroidism and high blood pressure. I discovered that we did not have to store the monitor under his bed. I had been misinformed. He needs to be close to it 20 minutes a day, so it sits in the dining room without drawing notice, so that it can send William's heartbeats north every day.

Do They *All* Look the Same?

I would love to think William's story is not necessary. Almost every day someone reminds me with a stare, a question, or comment, that perspectives on Trisomy-21 haven't changed much since William was born. I am not sure why. People with Trisomy-21 were liberated from institutions almost 30 years ago. They live longer, go to school, reside at home, and later in vibrant communities. Many people still lack the awareness of how different people with Trisomy-21 are from each other. Their capabilities vary, and, like all of us, their intellect is as broad as the typical population. It seems people sometimes forget that they are human.

Friends and members of the community continue to mistake William for another man with Trisomy-21 who lives in our town. This man is five years younger than William. He dresses well, and he never looks like he has been working on a farm, as William does. This man has chosen to live independently, and he plays a drum and chants to its beat in various places around town.

It's not okay for people to mistake two people because they have similar traits. I can think of many racist remarks starting with "I can't tell those (fill in the race) apart. They all look the same to me." It's the same thing with Trisomy-21.

One day, William was playing with the Temple Band as the rain thrummed on an unsteady green and white striped tent. A woman, neither of us knew, started calling "JOSIAH, JOSIAH." William didn't turn around because he isn't Josiah. Besides, he was performing. William looked like Josiah because Josiah has Trisomy-21. Maybe if I weren't still in the throes of depression or recovering from a year of almost losing my son, I would have made this a teachable moment. But even that was a stretch. So, instead, I lost it. "He is not Josiah. He doesn't know Josiah."

"Oh, but he looks just like Josiah," she beamed as if I must be mistaken. "Josiah just graduated from high school, and everyone loves him so much," she gushed.

"His name is William, and he is turning 30," I snarled. "You know *they* are not all the same because *they* have Trisomy-21." I turned my back to close the conversation and stewed, not at the woman, but at myself. I was ashamed of myself for reacting to an innocent woman. She didn't know how many times this happened to William. She didn't know this was a sore subject for people who have the traits of Trisomy-21, but still have different hair, different smiles, different clothes, and everything else that makes someone unique. Finally, I got up and sidled through the soggy crowd to find the woman. I got to her eye level and said, "I am sorry. I was way out of line speaking to you in that tone. It is common for people to mistake William for other people with Trisomy-21, and this time it got to me."

"Oh, that's okay," she chortled. "He is just like Josiah though. . ."

"I am really sorry," I said and walked away.

Do you Know?

William,

Do you know
that you touch people like the morning dew?
I know what I know.

You bring light
as if you were skimming by the opposing team at the end of a soccer game
slapping hands sideways with each opposing player.

as if you were a time-lapse of city lights spreading across the world

until the whole earth filled with the light of you

as if you were the force of the sun making a shadow of the tip of a mountain disappear at sunrise when everyone reaches the top but you.

Did you let yourself happen—
opening up like a human flower
not as graceful
when you refused to grow like one.

Someone once told me God sent you to me.
She didn't mean God.
She meant something that sends angels to troubled souls
To teach them what you taught me.

Puttering

William pulls back my throttle until I settle into his pace. He steers me away toward vigilant, compassionate, and mindful waters where we putter along with the current. His world is timeless. Today, he measures time by what day he stacks the wood, when he works in the barn, what night is music night, or what day one of his co-workers has off. William's way of moving through life is to taste it, chew it, ponder it, and absorb it before he digests it.

Renewal

Experts say William will die before I do. It's a reality they try to make me believe. So anytime you consider asking, "don't people like William have short lifespans?" Remember that my heart sinks. I want to ask, "Are you human?"

Your heart is tangled with its many repairs Still, it holds all that you share with the world.
And I am a simple tangled mom.

Yesterday, I walked through the woods and up to Mt. Skatutakee on the same path I used to carry William up on my back. My naked Vibram soles slid up the mountainside. My microspikes dangled and clattered outside of my pack, reminding me that if I put them on, it would make the trip easier. I refused their clanking suggestions. I wanted to slip and slide—defying the gravity of challenges.

Every time I looked up, the woods, the woods, echoed in my head. “What happened to you?” I asked them on this post-winter day. “You are grey, gloomy, and cold.” Deadwood and rotten debris crisscrossed in jumbled dark and gray piles on the snow. The winter’s destruction was natural, blameless, part of the life cycle. Tiny handprints of lost possums gave me the hope that something so small could make something so safe and sure. I kept my eyes riveted to their delicate handprints. I thought, are they looking at me looking for them? Are the squirrels chattering at me because what I see are not possum prints at all?

Everything dies. There is always renewal in the spring. William may not be renewed someday. His life has been a complicated crisscross of joy, confusion, and systems set up like tiny boxing rings. Sometimes a clatter of negative challenges added to an already heavy burden, and the pain of sliding down a slippery slope taught me how to manage what is most valuable in life’s cycle.

I am always ahead of William’s tracks, treading a path to make it easier for him to follow. No one knows the joy hidden underneath the path. The millions of times those who cleared the way trod it, along with those who may have been reluctant. I am a mountain climber, a woman of the woods. It is what I do. None of William’s life has been a sacrifice for me. William is the part of the climb I hope will never end as long as I am on this earth.