

# FaiTH'S JOURNEY

D e b P i p e r

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## MY NAME IS "A"

My name is Faith. As a young child, however, I thought my name was "A." That was the sound I heard when someone called my name. You see, I'm deaf. I'm able to hear some sounds—but wait. I'm getting ahead of myself. Let me explain.

Recently I was given a writing assignment in my high school communications class. The teacher, Ms. Larson, tasked us with writing our autobiographies. Only old people write autobiographies! Why would high schoolers write those? And what would a teenager, who only has a decade and a half of life experience, really have to say anyway?

Due to my deafness, my visual awareness skills are quite good, and judging by the facial expressions of my classmates, they felt the same way I did. Certainly there were better projects we could do! But the groans of the students didn't deter Ms. Larson. We would learn a lot from this project, she insisted.

We were to start on the assignment that evening. I don't know what I thought I was going to write on that first night at home, but one thing quickly became clear: to complete

the assignment successfully, I was going to have to enlist the help of my family. It turns out that all of the other students discovered the same thing.

In this age of texting and instant messaging through social media, we as a society are completely focused on the “now.” We require instantaneous responses, not something as tedious as verbal communication.

But the autobiography project started me thinking. It made me wonder how much I might be missing—not because of my deafness but because of the deafness that we’ve all created by the addiction we’ve developed to our electronic devices. We communicate with texts, emojis, cryptic strings of letters and symbols, and pictures. No one talks face to face anymore—that would take too long. Without that kind of personal, human communication, though, what have we lost?

As I considered this concept, it occurred to me that maybe my parents had been right about me needing to put down my phone once in a while and look around. In fact, they’d been complaining a lot lately about how people rarely talk to one another anymore and how the art of communication seems to have gotten lost. I hadn’t really understood what they’d been getting at. I just thought it was just parents being parents. And to be honest, I may be deaf, but I’m still a teenager—I was only half-listening.

But now it began sinking in. To complete this assignment, I was going to have to sit down with my parents and have a real, live, face-to-face conversation. And then it dawned on me that this kind of communication may have been Ms.

Larson's plan all along. She was forcing us to have an open dialogue with a human instead of an electronic device.

So that's what I did. I sat down with my parents and talked with them. I mean, I guess we didn't really *talk*. My family has learned to sign, and we're able to communicate fluently that way. But we communicated in person—actually looking at each other, not at a screen.

To say that it was awkward at first is an understatement. I couldn't remember the last time we'd sat down and talked like that! But as we warmed to the task, we started to relax. We were actually engaging in a face-to-face conversation that connected us as a family. As we shared memories and laughter, I found that many of the stories they were telling were new to me, and I realized suddenly that I was enjoying the assignment. It didn't feel like homework. It was, dare I say, fun!

With each story, my parents became more open and animated. At the same time, I was gaining a newfound respect and admiration for my parents and my siblings and all they had gone through and sacrificed for me. I knew that my birth had been challenging, not only because of the complications of my having been a premature baby but because of my deafness as well. But until that day, I'd had no idea how dramatically my whole family had been affected by all of it. No one had really talked about it.

I became aware, for the first time, that I did have a story to tell, and it begins with faith.

## BIRTH AND BABY STEPS

I should begin by telling you about my family. My mom and dad were high school sweethearts. They married not long after they graduated and started a family soon after that. They had two girls, but Dad was waiting for a boy to come along. Finally my brother was born, and they thought that the family was complete. It wasn't until some time later that I made a surprise appearance.

When I was born, I weighed a whopping 1 pound, 10 ounces and was 13 inches long. Dad said that he could fit his wedding ring over my whole foot! My mom smiled at that memory and said that she knew right away she would name me *Faith* because she had “all the faith in the world” that I would be alright, despite the challenges that I was sure to encounter as a premature baby.

What a Herculean effort it must have been to take care of me! I was in the hospital for my first 114 days. The first two months I was in the university hospital, but then I was transferred to Amplatz Children's Hospital, which was closer to where my family lived, where I spent an additional two months. Me being close by made life easier for my parents

to be with me while also caring for my sisters and brother and carrying out the ordinary tasks of their day-to-day lives.

I don't have any memories of this part of my life, but my parents seemed eager to tell me what it was like. I think they felt that I was finally old enough to understand the impact of all that happened during that time.

There were tears in my mother's eyes as she recounted not being able to touch or hold me for the first twelve days of my life. She said that that was the hardest part—not being able to hold me. My skin was so fragile and translucent that my parents weren't allowed to reach into the isolation bed where I was, even to touch or soothe me. Mom envied the parents who were able to cuddle and bond with their newborns immediately, without having to look through a glass enclosure. All of the medical equipment that was keeping me alive looked so overwhelming and scary! They had to wait until my vitals were stable before the doctors would let them handle me, and even then they could only hold me for short periods of time. “Baby steps, Faith!” my mother repeated to me every day. “Baby steps!”

But just when it seemed that I was gaining ground, I started having extreme blood pressure problems, which required heart surgery to address. I was just two and a half weeks old. After surgery, I needed to breathe with the assistance of a machine and then oxygen. That continued until I was three months old.

And still my mom kept up the mantra of “Baby steps!” Every day was a baby step—one step forward, but sometimes a giant step backward, too, because there were other hurdles to overcome. During my first four months, I battled lung

issues as I learned to suck, swallow, and breathe. Apparently, sometimes when I would try to suck or swallow, I would forget to breathe. But when I would try to breathe, I would start choking as I tried to swallow. These are behaviors that come naturally to healthy newborns, but I had to be taught them—slowly and with great care.

It was a frightening and stressful time, my mom explained. But, she told me, “I only had to hold your little hand, and my worry and frustration would disappear. The sleepless nights, the constant indecision—it all faded away.”

As a family, my mom, dad, sisters, and brother celebrated each new milestone, no matter how small. It brought us closer together as a family.



# MERRY CHRISTMAS!

Homecoming! Finally! My mom described it as the best Christmas present ever. After countless setbacks and challenges, I was coming home. At last I could be physically close to my parents and siblings. They no longer needed surgical masks, gowns, and gloves to be with me. We could hug one another with no barriers between us. I could be normal, and I could finally discover the world outside of the hospital!

Until I was able to come home, my world had been one of machines of all shapes and sizes and people poking and prodding me, their faces covered by masks. But suddenly my world was alight with bright colors, new smells, and laughter. What better time for a new beginning than Christmas! Everyone was eager for me to experience home and what it felt like to be a normal family.

Although I was too young to understand the excitement around me, I do remember exploring my sense of smell. The scent of hospital antiseptic cleaners was replaced with cinnamon and peppermint and evergreen. It was wonderful!

More important than that, however, was something else: I could finally sense the bond of love between mother and father and family—freely and without restrictions. It truly was a new beginning for me. I was home.

# DEAFNESS

A few weeks after I came home, my family finally began developing a normal routine. My mom called it “loving chaos.” At last my parents and siblings could begin to lead a normal family life.

Like with all families, especially those with siblings, there were arguments—for example, fights over favorite toys that ultimately had to be resolved by a parent. It was boisterous and loud at times. It was after one of these occasions, however, that my mother began to notice that something didn’t seem quite right with me. Noise didn’t seem to bother me, no matter how loud. In fact, I showed no reaction to noises at all. Mom decided to start experimenting, calling my name from different directions in the room to see if I would respond to her voice. I didn’t.

At first my mom thought that maybe she was just being overprotective, over-analyzing everything about me and my behaviors because of all I’d been through. But finally my lack of response to sounds couldn’t be ignored. There was something wrong, and my mom was determined to find out what it was.

I'd had frequent ear infections, and initially doctors diagnosed my problem as nothing more than a side effect of those infections. With medication and time, they said, it would get better. But Mom wasn't convinced, and as the weeks turned into months, she grew more concerned. I still was not reacting to loud noises. In fact, if someone called my name, I didn't respond unless the person was directly in front of me and I could see his or her face.

But I did seem to hear some sounds. I would respond to the *a* sound in my name, but I was not hearing the sounds around it—the *f* at the beginning and the *th* at the end. Those sounds were indistinguishable to me. Because I was clearly hearing some sounds, my parents continued to wait to see if the doctors were correct that I would begin behaving as a baby with normal hearing would. Unfortunately, that didn't happen.

Enough! It was time to do something! My parents were on a mission to find answers. Back we went to the children's hospital, where still today I can remember the smell and the activity as soon as I walk through the doors. In fact, that may be my first memory—maybe not as much as a memory as a sense.

When we met with the doctors, they said they believed that my problem was related to my being born premature, and again they insisted that things would improve with time. So my parents, who wanted so badly for them to be right, decided to trust their judgment. But my mother continued to monitor my response to sounds and randomly tested me to see how I reacted to different noises.

Eventually, after three sets of tubes in each of my ears and no change in my condition, my parents were determined to get some answers. They took me to an ENT (ear, nose, and throat) specialist. I was only sixteen months old and too young to be tested by normal procedures used with children. The doctors decided that I would have an ABR scan, which is a brain response test that measures hearing nerve responses to different sounds. That's when everything changed. With the results of that test, the doctors concluded that I had moderate to profound hearing loss that was degenerative, meaning that it could get worse over time.

My mom remembers laughing when they told her that. The doctors probably thought she was crazy. "Of course we didn't want you to have hearing loss," she told me, "but finally we had some answers, and we could move forward." After so many months of doctor visits and testing, it was a relief to confirm at last what my parents had known for some time. Now we could begin to address the new challenges that awaited me.