Christine’s Story,

About Me

I am a Mum to two children. A teenage daughter who is 15 and currently, 'living her best life'.She's just recently got her first job and enjoys spending her free time swimming with her group of friends. She wants to be a teacher when she grows up, “but not just a normal teacher”, she told me. “I want to be a teacher who gets it.” A teacher who understands learning difficulties and differences that any single person can face in a lifetime, and, the empathy, the understanding, the flexibility, the acceptance and the love, that's needed for that person.

I also have a son Cody, who is 11 and was born deaf. He is already a teacher.

About Cody

My story begins the very millisecond the nurse turned to me, interlocking her fingers and placing her hands in her lap, she said “Unfortunately he's failed both tests.” I suspected it because he'd already failed the tests in the hospital and these were follow on tests, but the sting of her words still hit sharply. She had confirmed it. He could not hear.

My first reaction

I looked at my son, only 3 weeks old, sleeping peacefully on the hospital bed in front of me and I wondered what this meant. What does it mean to have a deaf baby? What had he heard the last three weeks since being my newest love and infatuation? What will he hear.. ever?

He will not hear me say 'peek-a-boo' when we play, he will not hear me read his sisters favourite book at bedtime. He will not hear me sing the opening song to Winnie the Pooh whenever we put it on. He will not hear his Daddy's voice or his Sisters hourly 20 questions. He will not hear me tell him to clean his room or pick up his socks. He will not hear the postman toot his horn or the birds tweet their love. He will not hear his cot mobile play or the phone ring, and just like his sister does it, he will not coming running when he hears the ice cream van as it visits our street.

No point talking to him. No point singing to him while he plays in the bath. No point telling his sister to 'shhh' while he naps or turning the tv down so it doesn't wake him. No point whispering while his little eyes close during his midnight feeds and no point playing peek-a-boo, he won't know what I'm saying.

There was no point in any of it, he couldn't hear me anyway. He will not hear me say 'I love you.'

The waves of emotion

Hearing that my baby, my very newborn baby, had no hearing, hurt something inside me. I suddenly felt a wave of emotions I didn't know how to carry.

I felt confused. I felt sad. I felt the walls closing in and I felt broken inside.

I felt to blame. I felt like I'd failed him.

I felt useless and more to the point, I felt like there was no point.

As time slowly ticked by and we shared the news with our family and neighbours and my strength grew to eventually telling strangers that stopped to breath in the 'new-baby awe' in the grocery aisles, I began to learn that other peoples reactions to disabilities weren't always good ones, as one elderly lady in the fruit aisle proved one day, as she pulled her hand away from his and immediately stopped her 'ooh-ing and ahh-ing' over his little features and tiny toes, the moment I mentioned he was deaf.

I wasn't sure exactly how to do this part - telling the world that my 'normal-looking' baby, actually isn't 'normal'. I'd never been here before. This was entirely new territory. I never had to tell the world anything about my daughter – she quite easily told them herself!

My insides began to turn and I could feel a heaviness in my chest.

Was I supposed to tell strangers? Would it better if I didn't? How will they know if I don't? Do I tell everyone who tries to talk to him or not?

"Oh." She said. Just one single word. The she left. I stayed, stuck motionless in the middle of the vegetable aisle with my deaf baby, while the rest of the world continued to buzz on around me. Did I do that right? I didn't know why at the time, and even though she was a complete stranger, her leaving, felt crushing. That lonely-left-in-the-grocery-aisle-feeling stayed with me for a very long time.

Trying to 'Fix' Him

As time moved on, something inside me made me feel it wasn't real. That this was just something he would 'get through' or, grow out of and I suddenly felt an urge to 'fix' him. To do what I could to make him hear. I found myself 'testing' his hearing all the time.

I turned up the tv up to see his reaction. I banged the pots and pans together as I was cooking dinner. I clapped my hands near the side of his head. In some situations he would hear the noise. Other times, nothing.

The Diagnosis

Sometime in the weeks between appointments, I received his diagnosis letter in the mail.

He had a Bi-lateral, sensorinureal hearing loss. Moderate to severe in one ear and severe to profound in the other. I had no idea what these words meant and although I had heard the nurse say them at the end of his hearing test appointment, it felt like I was seeing them for the first time.

That was when the next part of our story began. The part where researching became my newest infatuation. The part where I realised, he really, actually WAS deaf. The part where, I found out, there was no 'fixing' him. There was no changing him or making him 'better.' Or 'waiting it out' or even moving on from it.

This was it. This was us. This was real and it was no dream or mis-diagnosis. This was him.

And all there was to do, was, simply accept him.

Acceptance

I looked at him, sucking his little fist in his bassinet beside my bed. He didn't look at me, not right away. But after a minute when his little eyes spontaneously caught sight of me, he held his gaze, he dropped his fist and his eyes lit up. His little lips curled into an 'O' shape and it was as though he wanted to say something. His hands flung excitedly to the ceiling, then beside him and then back to the ceiling again. His short little legs stiffened and he threw his arms back against him once more, purposefully but involuntarily as well.

His energy lifting at the mere sight of me. Tears fell down my cheeks as I watched him look at me as though I was responsible for every single star that lit up the night sky. He looked at me like I WAS the stars. Like I was the whole sky.

He was happy. That was all I wanted.

When I was imagining the baby I thought he'd be, all I pictured was a smiling, happy boy. I didn't predict or play out any 'what ifs' when I planned on having him. I didn't forecast a disability or envision the pathway we were now walking on. All I saw was a Mama, loving her baby.

A wave of guilt washed over me. Not because I didn't love him. I absolutely loved him. But because from the reactions of people close and strangers in food aisles, I felt as though the world was telling me I SHOULDN'T love him. Because something was wrong with him.

The world doesn't love broken. The world doesn't love different. The world doesn't love wrong.

I moved myself closer to his bassinet and, standing over him, I reached out and held his little hand in mine.

“I love you” I said out loud for what felt like the first time.

He didn't react.

But boy did it feel good. I felt a sense of relief wash over me. Like I had been withholding something and I could finally breathe now that it was out in the open.

“I love you” I said again. “I love you so much, my baby boy.”

While it was still hard in the first few weeks and months to get my mind around him not being able to hear, loving him was easy.

We faced some other challenges as the timeline continued including the fear of him losing his speech and the race to get hearing aids fitted and then with that came a long list of new challenges as we battled getting him to wear those aids.

Hearing Aids

When Cody was 4 months old, he was fitted with hearing aids and the excitement that came with this was almost too much to bear. “My baby will be able to hear!” I wanted to shout it from the rooftops. I told everyone. “He will hear! He's going to be 'normal'!” I said and once again, I began envisioning and imagining the life we would surely have.

But as our little teacher taught us, life does not go to plan. HE does not go to plan.

From the minute his hearing aids were fitted at just 4 months old, he hated them. He ripped them off. He headbutted the ground beneath him. He bit himself, he cried, he screamed, he threw himself around.

The heartbreak and confusion that came with this was a lot. I tried harder. And I cried harder, too.

He refused again and again, and again. He got angrier. He even got upset at just the sight of them. He was adamant he did not like them. He shoved them deep into the couch. He buried them in his weetbix. He buried them in his sandpit. He threw them out the car window.

He threw them over the fence.

He threw them down the toilet.

He threw them at me.

He chewed them.

He hid them.

He broke them.

He wrecked them.

He did everything to them except wear them. He even refused to sit for any hearing test – in the chance that they weren't adjusted right and maybe that was the reason for his refusal – but he refused, every. Single. Time.

This continued for years. Even when he started school, “Is there another way he can learn to communicate?” I asked, completely spent.

Introducing Auslan

So in between trying to encourage him to wear his hearing aids and at the help of our mentor, we began Auslan classes. This was hard, too. But teaching him to sign and discovering his love for it was easier than trying to make him want to like his hearing aids.

After years of trying, and falling down and stumbling and starting over, eventually, we gave up on the hearing aids. The guilt ate me up, a lot. Again, I felt like I was failing him. I felt as though I was ensuring he would be missing a very great and big part of life. And I was scared for his future.

“What now?” I thought.

He loves to sign. He gets so much joy out of him signing and other people signing to him. He loves the gestures, he loves the expressions, he loves the movement and he even loves the learning part.

Cody uses a variety of Auslan, key-word sign and spoken-english sign. He also makes up his own signs, which, is always fun to try and decipher.

He knows a lot of signs, he can sign colours, animals, greetings, family members, emotions and countless objects. His favourite sign right now is a begging sign when he asks for a second serving of icecream or some extra chocolate biscuits.

He also very clearly likes to sign 'go away' to his big sister when she is annoying him.

Further Diagnosis

Cody was later diagnosed with Microcephaly, a triplication of Chromosome 14, developmental delay, Epilepsy, CHARGE-like syndrome, ASD, ADHD, PDA, sleep OSA, heart and eye defects, perthes disease, short stature, and he is also non-verbal.

Throughout the next years and as each letter of diagnosis fell upon our feet, the same sinking feeling would hit. 'Something is wrong with him' I felt the words reach out of the paper and slap me. Again came feelings and 'what if' and 'how' questions. Again came confusion and a little heartbreak and sadness. Not sadness for me though, sadness for him.

Sad he would not have the same life as every other little boy.

Sad he would not do things the same as every other little boy.

Sad he would not know the world like every other little boy.

And sad he would need more than every other little boy.

But as the years in my new role very quickly taught me, I was right.

A happy life

I was right to believe he would not have the same life, or world or experiences as other children, but I had no reason to feel sadness for him because of it.

For, while he has needed so much more than any other child, and while our days, and routines and life all over, has looked very different from other little boys his age, and while I have had to give so much more than any other Mother or parent I know, and while we've experienced struggles and hards and tears that we never knew we would, and, while his journey looks very different to the one I pictured, he is happy.

He is living a life that is full.

It's full of help, no matter what struggles he faces, we are there beside him. It's full of encouragement, no matter how many times he can't do it the same as others, he is encouraged to do it his way.

It's full of belief

It's full of bravery

It's full of learning

It's full of guidance

It's full of adventures

And it's full of love.

And, slowly, as the days unravelled and the pressure of forcing him was lifted and life just kind of.. went on, I soon discovered that our little teacher was still giving lessons. He was still teaching us and guiding us and showing us the way.

One of the things that I struggled with in the early days of our journey was, the entirety of it all.

The weight of the whole thing, and it strangely felt as though I was carrying it on my own. It felt lonely. It was a very isolating, worry-some and heavy road. There was not a single person we knew, who was going through this too. It felt strangely as though, the world was happening around us and in front of us, but not with us or along side us, and that's a really hard pull to navigate away from.

We were different. Nobody else was different.

But the question that hit me the hardest, especially in the moments of extreme hard and isolation, was, WHY do WE have to be different?

Why us?

Why him?

Why can't we just be like everybody else?

And while we have faced many bumpy struggles along our journey including behaviour, understanding, communication and acceptance and, over the years, with the struggle he has faced to have his voice heard by others, I have learnt to BE his voice while encouraging him, and helping him to strengthen his own.

I have learnt that while 'different' can be uncomfortable for many, it isn't for me. I have learnt that, this world wasn't built for disabilities but, every little thing we do to fight that, changes things. I have learnt that, letting go of the picture in my head of how I think things will go, or play out and happen, is valuable for accepting how things ARE while simultaneously creating so much space to enjoy what you have.

And now, I one thousand and twenty percent, do know that, the answers to all of those WHY questions is because, the path I dreamt up, was never actually for me. It quite literally was just a dream and this path that I'm walking, this journey I'm on right now, is what's real.

I was always going to be, the Mama that loves that little boy who can't hear or talk but has taught us all the importance and the need to be 'a teacher who gets it.'

Christine x