

Our Story.

My son Ollie is our only child and was born in December of 2012. Ollie is Bilaterally aided as well as assisted by a FM system.

A difficult start

He first failed his Newborn Screen at 4 days old while at the Royal Brisbane Hospital and later diagnosed with Moderate and Moderate-Severe Bilateral Sensorineural Hearing Loss. In the next couple of years, it would become amended to Moderate in both ears where it remains stable.

To understand how I felt at his diagnosis you need to know that I had an extraordinarily complex pregnancy which without going into the horrid details we were both not expected to survive, after a major medical event at 20 weeks which saw me rushed from our home at Kilcoy to Brisbane's Prince Charles Hospital and straight to ICU.

The rest of the pregnancy entailed a lot of close monitoring and a lot of medical appointments. There were concerns from various Dr's about my then unborn son's health and how my medical situation had impacted on his. My Husband and I had to understand and prepare for the supposedly inevitable medical issues he would have once he was born.

Ollie was born at 36 weeks, by Caesarean weighing just 2 kgs. Despite being small, much to everyone's surprise, he was PERFECT.

Due to my medical needs, we were at the hospital a little longer than most.... so, the newborn screen was done twice just to make sure. I remember the lady telling me to "try not to worry" as she was telling me that he had failed for the 2nd time and what was to come next. I think she was taken back when I told her I was not. My reality at that time was that if this is the worst of what we are being given then we are fortunate. My husband, Darren on the other hand was still genuinely concerned as you would expect. I think the previous 6 months had taken its toll on us both differently. Looking back after everything we had been through to that point, I personally had become quite calm and numb to situations - neither anxious or nervous, but Darren had become overly protective and did the worrying for both of us.

We of course then became caught up in the whirlwind of appointments. This is where it got quite overwhelming for me especially as I was also still requiring ongoing medical care myself. I found juggling the seemingly never-ending list of appointments exhausting. ENT, Audiology, Paediatrician It was such a bombardment of information - I just found it far too much to deal with all at once. There seemed to be no time for any joy, and I resented the "push" of it all. I understand now WHY it is imperative to move forward quickly but at the time it was a huge struggle.

Ollie was fitted with his first set of hearing aids at 3 months. I remember the day well... Up until that day life had been quite surreal but then reality hit of what all of this meant. Darren took it quite hard with the fact that his son would be wearing Hearing Aids – and I was upset that he was so upset. Questions such as "Would people stare at him" "Would kids tease him" & "how would this impact his future" came to mind. It was all so very new, and we felt helpless. This was the start of our journey, full of highs and lows all while learning along the way that there are always positives to every story.

The Early Days

In the early days, the lows for us include the feeling of inadequacy when we had not understood something fully. Ignorance from others who questioned the diagnosis as Ollie happened to turn to a noise. The genetic testing that came back negative but concluded that it was indeed my health and what had happened that solely contributed to his hearing loss. Later, during his kindy year, ignorance from educational staff who showed no interest or understanding towards Ollie. I organised a visit from a "Visiting Advisory Teacher" when I could see he was struggling... and probably the worst thing to me that comes to mind is someone who we shared our excitement with when Ollie received his FM system turned around and said "what, so why would he need that, He can hear? He turns to his name; He can't be "that deaf."

I very much understand that others don't fully comprehend something unless they have experienced it themselves but it can hurt that those close to us would not take the time to learn to understand or dismiss what we were telling them. At times we felt very alone.

Early Learning

The highs started with Ollie's enrolment at the deaf/hard of hearing programme at EDCP. We live just under an hour from the Caboolture centre, and I remember walking in there on our first day, Ollie was about 6 months old, and I was questioning whether this place was for us and if I would be happy travelling here every week. I had no idea what to expect or what the future held but I knew I had to give it a go. I found the programme invaluable to not only Ollie's development but also a massive positive influence on mine. I personally become open minded, stronger mentally, more understanding and patient of others and just all round more confident in my abilities to advocate for my son. Ollie attended in total for 4.5 years, and on his final day we left knowing that Ollie was given the BEST start to his future. We also met what will be lifelong friends, "Our Tribe" We all come from different backgrounds, the Kids all have varying degrees and types of Hearing loss, but we are all connected by our experiences. It is always amazing to watch at every meet up that the kids just pick up where they left off, so amazingly comfortable and confident around each other.

At that point we were no longer alone. We had found a circle people of we could openly discuss our fears with – all of us with remarkably similar stories. How overwhelming it was at diagnosis time. The concerns at having our child labelled as "different". The adjustments we had to all make in our lives. Support without Judgement. Friends to vent to, to swap stories with, and celebrate milestones that not many understood.

At around age 2-3, following regular assessments it was found Ollie did have the need for Speech Therapy. Fast forward to now, his speech and language is on par with hearing Children. Although Ollie still sees an OT regularly that assists him in other areas of his life, I sometimes jokingly refer to Ollie as "the poster boy that proves Early Intervention DOES work" whenever someone mentions how well he is doing, but in all seriousness, I consider ourselves incredibly blessed that Ollie has had these supports and opportunities as I do not believe he would be where he is now without them.

At age 4 he was diagnosed ASD which entails a whole other story 😊

TOP 5 CHALLENGES being a Parent raising my Hard of Hearing Child

1. Not knowing what to expect. The uncertainty of what his future held. The concern if he was meeting Milestones, especially as he is our only child and as we did not have experiences with many children, so we had no comparison.

2. Hearing Aids. Keeping the Hearing Aids on him as a baby is one of the biggest challenges that we faced early on, that and the whistling coming from the aids as he grew so quickly. Now, as he heads towards his teen years it is knowing exactly when he is using his hearing loss as an excuse to not “listen” when asked to do something.! LOL

3. Insecurity. My own issues of insecurity that left me feeling judged and scrutinised. Asking myself of I was doing enough. Do I fully understand his needs? Have I done enough to disperse that bloody ear wax? (This one still makes me so incredibly anxious every time someone wants to look in his ears.)

4. The weight of responsibility. Needing to be more deliberate in our communication so Ollie can understand exactly what is being said. Along with the worry that he is keeping up both at school and socially.

5. Unsolicited advice. Dealing with the unsolicited advice that comes through messenger from a parent you have just met. They think that they have all the answers, but really, they have no clue, experience, or knowledge to back up their advice. Gritting my teeth and being “nice” back when they are telling you to “try this that or the other thing” when it came to dealing with problematic behaviours.

Based on my own Experiences Top 5 Tips for Newly diagnosed Families.

1. Breath. Take a big deep breath, get in and do what needs to be done but most importantly do not forget the exhale part. When we are all under stress this is the bit that locks in our concerns and worry but whatever you are feeling just know while you cannot see it yet, you are very capable, and your child will be fine. Know that everything always seems impossible right before any massive change in our lives, the positives are always right around the corner.

2. Surround yourself with the Best People. This is something you cannot force – it takes time, but just know they are out there, and you will learn to recognise who they are along the way. Association is everything. Positive Involvement with others forms an important aspect of life. We all need to feel supported to succeed. You will come across ignorance. Understand that not everyone will be beneficial to you or your child’s journey. It is ok to walk away.

3. Read to your child, right from the very beginning. Immerse them in language. Whether that is Auslan or spoken English. It is so important to communicate even if you think they cannot hear you. Make that connection. One of the best pieces of advice I was given early on is “if it does not go in, it cannot come out” This comes in many forms, even facial expressions are equally as important.

4. Early Intervention. Take the time to find the right fit for your family. One of the most important gifts you can give to your child is the support you all will be given by attending.

5. Fear is normal. Getting everything right is something we all fear and is very normal. I remember being terrified of his devices, scared I was going to break them, scared they would get lost, Scared I would look like an idiot for not understanding how they were to work.... Scared I was being judged by choosing the clear / nude options for his very first set of Aids and moulds when everyone else chose colours. So just remember that you are “not the only one” who can feel that way.

Five Strengths I see in my Family Unit.

- 1. Appreciation.** Our Life together is not taken for granted. This appreciation has developed with the challenges we have faced together. We are all safe and know that we are loved.
- 2. Honesty.** There is no pretence. We tell it like it is. Strengths and Weaknesses. It is about being real and showing it. Nothing nor nobody is perfect. Mistakes are ok. That is how you learn.
- 3. Dependability and Reliability.** Doing “our bit” It is all about just knowing that ultimately, we have each other to rely on. We are fortunate that this is strengthened by others around us, extended Family, Friends, and our community.
- 4. Humour.** To us it is an expression of warmth. It enables us to be at ease, reduce stresses and opens communication. Having a positive outlook ultimately gives us the resilience to meet all of life’s challenges.
- 5. One-on-one time.** I also see that Ollie has benefited by being an only child – it has its negatives of course but ultimately; he has benefited due the fact that I can give him more time. One on one time that enables me to concentrate on his needs.

Five Strengths I see in myself as a Parent

I have learnt along the way to trust myself and my instincts. Be assertive when I need to be but at the same time respect the process. To listen and learn but most importantly to stay humble in the face of frustration. My five key strengths are:

- 1. Patience.** Knowing that things can take time, nothing good comes out of rushing anything It is about progress instead of perfection. I can handle difficult situations with greater perspective now, Calmly and without negativity. But I am not perfect, I can feel stressed and can lose my cool, but I will show my remorse and apologize. I endeavour to be a positive role model.
- 2. Security.** Ollie knows he is very much loved and cherished. While it is very much said I believe it is just as important to show him – I keep promises, am reliable and trustworthy. He knows I will be there for him. I understand his need for structure and routine.
- 3. An open mind and positive outlook.** I know not everything is black and white. There are two sides to every story, to every decision. We are all included in what affects us all. I am an advocate for possibilities for the future not the negatives of the past. Showing I can, instead of I cannot.
- 4. Encourage independence.** This has been something that has been one of my main struggles but also something I am very much aware of the need for. We have had our fair share of difficulties due to his anxieties with his ASD personality as well as his hearing. I have had to know when to push and when to not... Something I think I now have a good grasp on with small steps and building his confidence by backing away slowly and when he is ready.
- 5. My Village.** I am extremely fortunate to of built a solid foundation of people around us who are a positive influence, can offer a sense of belonging and will interact with Ollie as if he were their own. My friends in my local community have taken the time to understand how his FM works/know how to pop his hearing aids back in/ know that his equipment needs to come home from school with him should they pick him up from school instead of me. I recognise I cannot do it on my own.

Ollie today.

Ollie currently attends Year Three at our small local School. The school has approximately 120 students enrolled, and Ollie is supported very well. While there were initial transitioning issues and days where I sat by the phone waiting to be told “what he had done” which usually ended with me in tears as I hung up the phone, upset that this was my fault and how was I going to help him. We are fortunate that our School provides an inclusive environment. Every Teacher that he is now engaged with understands that his FM system makes a huge impact on how he learns. Not only is he not missing out on valuable class time he is no longer exhausted trying to listen. This was a big Issue with his behavioural patterns. He is now thriving, well engaged, tenacious - He knows exactly what he wants and how he is going to make it happen. He loves to learn and has big plans for his own future, he aspires to be “The Prime Minister” one day or apparently the backup plan is teaching? Basically, he just wants to make the all the rules. He can also be very funny and cheeky.

When I look back on some of our initial fears at the start of this journey especially with how his peers would see him, I now know that he is not defined by his Hearing Aids. His friends and classmates see him no differently because of them. They are just a part of who he is. Smart, funny, and full of life. He is proud when choosing the brightest red for his aids and moulds. We have come a long way and I am especially proud of how he views the world around him.

A final word.

There was never really any choice in the beginning as to whether I would be at home with him and not continue working – that had already been taken away from me before he was born with Doctor’s advice being that I was not to continue working for the foreseeable future. As time evolved, again, there was no choice... he needed consistency and routine and for me to continue being there for him.

My hope for Ollie is that he will see himself positively and not that he is “different” Even though he has a strong understanding of the benefits of his hearing Aids and the FM (He very much recognises himself that he needs them). I do worry that when he comes to me questioning WHY he the only one at his school that wears Hearing Aids and WHY don’t his ears work properly, all I can do is remind him that we are all different – I will then point out some of those differences and that the world would be a boring place if we were all the same. For now, he is very accepting of my explanations, but I know as he eventually heads towards his teenage years there will be more influences coming from outside our home, I hope all his interactions remain positive.

What I want most and yes it’s a Cliché - but is for him to be happy within himself. Happy to know that he is enough. Happy with his purpose in life. Happy with who he is.

Hard work, determination a deep understanding that his best is good enough but to never stop learning or trying.

To inspire others, Be resilient, honest with his dealings. Understanding. Loyal....and respected for being himself.

I think probably the biggest concern I have for Ollie is the limits I have on our future together. As we are older parents, and that he is our only child I need him to remain surrounded by people who love, support, and understand him. I am not a huge worrier about the future, “sort of a work it out as we get there” type of person, but I do know all of our lives are a cycle and that If I can set a good example for him my actions now will hopefully continue to guide him throughout his life.

As for his future as a man living with hearing loss. I can see that the world has changed considerably since I first entered the workforce myself over 30 years ago and it continues to change rapidly. There is so much more awareness about people's differences and abilities. We are a more inclusive society. This makes my fears minimal. However, I am not naive and understand that prejudice does still exist, but as long as he can see himself not as a lesser person because of his Hearing OR his ASD he will ultimately triumph. We are often our own worst enemy and critic. If he can walk away from ignorance with his head held high and see his own strengths so will the rest of the world.