

I am sharing my story as a parent of a child that is hard of hearing. There are many challenges that a parent is faced with when having a child that has a hearing impairment. Over the years I will be honest it hasn't been easy many tears and many frustrations and not to mention the feeling that there must be more I can do to help my daughter.... Let's keep in mind also living in a rural community in Northern BC where there is very limited care, resources and no specialists.

My daughter was 5 years old talking on the phone to her grandma like any other normal child when she said "grandma can you hold on I need to switch ears I can't hear you". Right then I knew that wasn't normal I then took her to our family doctor who referred us to the local audiologist at Northern Health. She was great she did a hearing test on my daughter and confirmed yes her hearing in her right ear is low and that we will need to continue to monitor it. Six months had passed we had seen the audiologist for tests and seen visiting specialists (ENT) all we knew was that my daughter had fluctuating hearing and the recommendation was to remove her tonsils and adenoids. Following her surgery of removing her tonsils and adenoids nothing had changed her hearing never went back to normal.

Continuous hearing tests with Northern Health it was finally confirmed that her hearing has stopped fluctuating and she is able to be aided now. Although this felt like a relief in some ways cause now my daughter will have what she needs to be able to learn in school and hear normally day to day this however brought on many other concerns. How will this affect her being different than others, why has she lost hearing and what steps do I take next to help her?

Months and years had passed with so many questions and no answers until she was 12 and she got a bad ear infection in her left ear over the Christmas Holiday's instant panic set in and I took her to a nearby walk in clinic and seen a GP who confirmed my daughter does have an ear infection but felt the healing process with or without antibiotics are the same. I had strongly voiced my concerns with her hearing loss and I don't want her to lose hearing in her left ear as well. Despite my concerns we were sent on our way with no treatment to only find ourselves at our family clinic the following day with my daughter in so much pain and receiving treatment from our family doctor. The following days my daughter's infection had cleared and she was feeling better. Only to wake up New Years day with a wringing in her left ear.... Not knowing what it was I said "oh that means someone is talking about you".

Well eat my words my daughter woke the next morning not able to hear out of her left ear now... I will never forget the fear that was going through her and the panic that hit both of us and the feeling of not knowing what to do it was devastating. I immediately contacted Northern Health leaving a message of what has happening. They contacted me first thing in the morning getting her in for a test and yes confirming hearing loss now in her left ear. I had also booked an appointment with our family doctor as well.

We had then been referred to Prince George to see a specialist to find out why and what to do however following our visit there we still had no answers only told there is no answer or reason and it could come back one day or not. Let's keep in mind my daughter is aided on one side and not on the other now trying to compensate for this loss in school with no help or resources provided. I went back to our family doctor demanding a referral to a specialist that deals in these types of problems. I received a referral for

her to Edmonton and what a relief. We arrived there a few weeks later the specialist was very concerned and ran numerous tests including blood work, CT scans, MRI he assured me he would find answers and he did. She was diagnosed with Enlarged Vestibular Aqueduct Syndrome. Sitting down with us he provided us with information regarding the condition and how it works and can impact her life. Now with this diagnosis and my daughter being an avid competitive figure skater and being told a blow to the head can result in complete loss created more questions and concerns. I felt life is too short I told her "do what you love and enjoy life". Following our visit there and the diagnoses she received her second hearing aid.

Months had passed with great difficulty and fear! Imagine as a parent having in the back of your mind forever that your child could have complete loss of hearing one day or may not! Imagine your child dealing with the lingering thought in the back of her mind as she tries to move forward and live a normal life. The fear is real and no one to turn to in the Medical system for help and answers. She was faced with struggling in school only hearing some of what was being said around her resulting in not understanding a lot and falling behind. The teacher for the deaf and hard of hearing started to work with her and got her set up with an FM system to help her hear the teacher in class which sounds great! However it's NOT as she was missing out on group discussions only hearing the teacher not her peers and also this started to impact her self esteem as well. However there were no other options for her. Now as a teenager and the lack of options over the years and lack of resources by Northern Health and Interior Health she has many anxieties now from the years of not having the resources or the technology that it isn't available through the BC Medical System.

As a mother with a child that is hearing impaired my daughter was provided with the resources that our Ministry of Health recommends which is very little and very costly. After relocating to Kelowna to have better care for my daughter and the doctors and specialists nearby we have learned so much. There were minimal resources or options through interior health which made us seek out other options bringing us to Ossicle Hearing. They were able to offer different solutions and equipment options that can meet my daughter's needs and wishes; they were caring she was no longer just a number in the health system with lengthily waits to be seen even during emergencies. There needs to be more support and resources offered to the deaf and hard of hearing children. The medical system in BC is underfunded for the deaf and hard of hearing as well as under staffed resulting in high costs for families and lack of care for our hard of hearing children. There is nothing more frustrating than having a normal healthy child that is falling through the cracks educationally because of their hearing. There is lots of technology that could be available to our children that we weren't aware of and let's not forget it's very costly and these costs are on the parents with no government grants.

My daughter and I after years of turmoil and frustration have finally found help with Ossicle Hearing they are understanding and provide options for the costs of the equipment that my child requires to lead a normal life and succeed in school and the sport she loves. MarKus being a qualified doctor not just an audiologist is able to understand her condition and provide her with help and options she needs. As well as providing support when there are equipment failures by providing loaner hearing aids so she can still go to school and live life. Upon our first visit with Ossicle hearing my daughter was very distraught and scared as she has had so many bad experiences with in the medical system the fear just

over comes her. They were very understanding and did everything to calm her and assure her that they are there to help her. We learned during our first visit that her hearing aids had been programmed incorrectly and that there were things that should been done over the course of the years for her hearing going from a small child to a young teenager that hadn't been done through the medical system. My daughter no longer is being seen by Northern health/Interior Health as they aren't able to provide the care she needs.

I want to thank Ossicle Hearing staff, Rachel and Dr. Markus Hilbert for the care they have provided to my daughter and always being available to her even after hours or during school when she text's Rachel for when she is needing help. I feel that more parents need the care and resources that Ossicle Hearing is able to provide. I want to be open with our experiences as there are parents out there that are starting the journey of having a child that is being diagnosed with being deaf or hard of hearing so that they too don't have to go through the journey we had to go through for years. There is help out there and it needs to be provided to all children suffering!

Thank you for allowing me to share my journey.....

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