

Kate and Phil's five year old son Levi was born with condition called congenital Cytomegalovirus (CMV) . Here Kate tells the story of how she and husband Phil, who live in regional Victoria, came to learn about Levi's needs and challenges, and how they made the decision about cochlear implantation.

Introducing Levi

“Levi is a happy, placid five year old boy. He has piercing blue eyes, a beautiful smile and a contagious laugh. He attends a local kindergarten and will start school next year. If you watch Levi for a while you may notice his face may involuntarily contort, he may bite down hard on his hand, flap his arms or clap his hands for no reason. He may even mouth something within his reach or lick the wall. Levi might also avoid eye contact or be overly friendly with you even though you just met.

He doesn't talk but makes a lot of moaning and grunting noises. He wears a hearing aid in his left ear and has a cochlear implant sound processor on his right ear. Levi has an intellectual disability, autism and hearing loss. This is a result of me contracting Cytomegalovirus (CMV) in the early stages of my pregnancy, although I did not realise it at the time.

A diagnosis has been confirmed for Levi only recently. It has been a long journey over the last few years until we could establish an explanation and understanding of it all. There were so many times of confusion, questioning, frustration, denial, sadness, grief, acceptance to get to where we are now.

Levi was born on 31st July, 2009. He is the first child for my husband, Phil and I, and was born at Wodonga Hospital. He was a healthy, happy, placid baby who brought so much joy to us and his grandparents. He was the first grandchild for my parents, who lived in Melbourne. They would come and visit every couple of weeks. I would take photos of Levi every day and give mum a running commentary of everything he did via text message. I was enjoying been a first time mum and Levi was my whole world.

A slower start

I was taking Levi to all of his maternal & child health appointments and started to express concern when he wasn't rolling at the appropriate age; he didn't seem to be very strong in his core strength and couldn't hold his head up. The nurse didn't seem too concerned, but recommended we start physiotherapy to try and work on Levi's strength. Little did I know that this was the start of so many appointments with various doctors and specialists.

Our concern for Levi escalated, as he continued not to reach milestones and was displaying some unusual behaviours, such as staring at ceiling fans, throwing his head back when being held, and favouring one side. We started seeing a paediatrician who confirmed Levi had a global development delay. We wanted answers, so we were referred to other specialists and commenced a whirlwind of appointments that still continue today.

One of the many tests was a hearing test, which Levi had at 16 months of age. He was totally uncooperative, so they suggested we come back in a few months. I wasn't too concerned about his hearing at this stage, and he had passed his newborn screening. We had commenced early intervention and speech therapy and Levi started attending day care two days a week and weekly swimming lessons. I was now at the stage where I had to explain his development to everyone but all I could say is that he is delayed and we didn't know why.

Levi was still developing at his own pace which was slow, but I was sort of hoping he would just “catch up”. This notion was abruptly extinguished by our paediatrician one day when he told me Levi would always have difficulties in life. I felt the news was delivered insensitively and I was upset. I decided to change paediatricians, but looking back perhaps it was the wake-up call I needed. I had followed up on the hearing test and once again the results were inconclusive. We tried going to Australian Hearing rather than the

previous audiologist we were going to, to get a second opinion. It was then discovered that Levi had fluid in his ears and we saw an ENT who suggested grommets.

Levi was now two years old and still delayed, not walking and not talking. We were using basic signs as suggested through early intervention. Autistic behaviour was also becoming quite evident. Levi got his grommets a couple of months after he turned two, and the difference was amazing. His balance got a lot better and he was a lot steadier on his feet and seemed to be responding to some sounds that he wasn't before. We were so happy thinking this was the answer to some of the problems.

Levi started walking two weeks before Christmas of 2011, which was the best present ever, as we were wondering if it would ever happen. By this stage we had had our second child, a boy called Joel. It was so difficult having a baby and a two year old who couldn't walk. Meanwhile the hearing loss was now so apparent that staff at day care agreed with my thoughts - I was positive that Levi couldn't hear much at all.

I went to my GP who I had a good relationship with, and just said "Levi can't hear and something has to be done". I think he could see my frustration and he has always said he takes a mother's opinion seriously. So he made a call and sent me straight back to the ENT who did Levi's grommets, who sent us to his own audiologist for testing. As I suspected, there were a lot of sounds he just wasn't responding to. I felt glad that he was co-operating and relief that I could now prove what I had suspected for so long. The audiologists were explaining the audiogram to me because Levi had a sloping hearing loss and I found it quite hard to understand at that initial appointment. It was all a bit overwhelming. I found the pamphlet with the decibel levels with the pictures the easiest to understand and it helped me get my head around it. The audiologist explained that Levi would need to be fitted for hearing aids and it would happen as soon as possible.

Levi got his hearing aids one week before he turned three. We noticed a difference straight away. As soon as we walked out of Australian Hearing he was looking around in awe and staring at the cars going past. A bus went past and he just stopped and looked at it in amazement. Levi pulled his hearing aids out sometimes, but was surprisingly good at wearing them. There was another child at our early intervention play group with hearing loss and her mother was very helpful with advice. I ended up contacting Aurora school who came to see us two weeks later. They explained their early intervention and other services to me. I was so impressed I made up my mind straight away that they would be an asset to us. They provided me with a DVD called "Understanding Deafness" and that's when it really hit home to me that this whole new world is going to be a part of us forever.

A candidate for cochlear implantation

We continued to have hearing tests through Australian Hearing, and we realised that Levi would be a candidate for the cochlear implant, in his right ear.

Levi had an MRI in November 2012, which showed two things: firstly his cochlear was compatible to receive the implant and secondly that there were abnormalities in his brain. The neurologist suggested these abnormalities would cause Levi learning, speech and behaviour difficulties, though to what extent, she couldn't say. She suggested these brain abnormalities and the fact that Levi had hearing loss seemed were consistent with the effects of CMV.

I spent the trip home from Melbourne to Wodonga googling CMV on my phone, as I had never heard of it and feeling a bit numb because as much as we wanted answers this wasn't the greatest news.

The decision

We headed to the cochlear implant clinic in mid January of 2013 and started the ball rolling for Levi's implant. We felt that due to his intellectual disability, he required as much assistance as possible to cope

with life. I read books and did a lot of online searches, although there wasn't much information about children getting cochlear implants who had additional needs. It was hard to compare to the stories of other children when I knew their situation was nothing like Levi's.

The neurologist confirmed the diagnosis of congenital CMV in April 2013. I had also started an Auslan course at TAFE that year and learnt so much about Deaf culture, met a lot of Deaf people and just gained a greater understanding of what it's like to be Deaf. I learnt about how some Deaf people don't agree with cochlear implants and I can understand their point of view. I can see how a lot of Deaf people can function perfectly as they are and how Auslan is a great way of communicating. It has been so hard trying to sign to Levi though, because he would avoid eye contact due to his autism and he just didn't have the cognitive ability to learn more than basic signs. If Levi was just deaf and did not have additional needs I would have found the decision so much harder, and I really don't know whether I would have got him implanted. I really feel for parents trying to make that decision for their child when they are too young to make their own choice.

The surgery – the first time

We were booked for surgery on 1st October 2013 and I couldn't believe that after 9 and a half months since our first appointment the implant was going to finally happen. We were excited but also nervous. Levi had now been to hospital and had an anaesthetic about 6 times previously, so we were probably not as apprehensive as we would have been if it was the first time. We booked into a motel near the hospital and went down to Melbourne the day before as we had to be at the hospital at 7am. I really didn't sleep that well that night just thinking about it. I wasn't having second thoughts at all but I was just a bit nervous.

The next morning Levi was in surgery by 8am. They told me to go off for a few hours and they would ring me when they were ready, but it would probably be about 4 hours. I went back to our hotel room for a few hours but got too restless and went back to the hospital and waited in the café. Finally my phone rang and it was the surgeon telling me they had to abort the procedure due to discovering inflammation in Levi's ear.

I went up to see Levi and he was all bandaged up and we had to stay overnight. There was just one thing missing; the implant. I had so many people ringing to see how it went and I had to tell everyone that it didn't happen. I was so disappointed. The surgeon told us they probably wouldn't try again until for at least 3 or 4 months.

We returned to the hospital one month after his post operative appointment and I was wondering what the point of the appointment was when the surgeon said he wanted to attempt surgery again on 17th December. I was shocked and nervous that they would face troubles again, but hoped for the best.

The surgery – the second time

So we went through it all over again, the trip to Melbourne, arrival at hospital first thing, wheeling him into surgery, and the hours of waiting. Then, we got the call that the implant was in! I went to see Levi and he seemed a lot more subdued than last time. He was very quiet, pale and tired.

Levi recovered well and we were excited about the switch on but really not expecting a huge reaction out of Levi. I really didn't want to set my expectations too high. I felt that if the implant only allowed Levi to hear enough to provide him with a bit more awareness of his surroundings, even if it was just to provide a bit more safety for him that would be enough. Levi lives in such a closed off world, I was hoping the implant would just give him a bit more, and open up the world for him.

Switch on and getting used to the implant

We went down to Melbourne for switch on and Levi had some sounds transmitted through to his sound processor. He paused a little from his activities and his eyes looked around a bit, but that was all the

reaction. We had to go back to the clinic on a regular basis so they could slowly turn the processor up and get Levi used to it. We went off home to see how Levi coped with it in his every day environment. This is when we faced a hurdle I was not expecting. He just would not wear the sound processor!

He pulled it off constantly. I was frantic, after waiting so long for the implant, and now he wouldn't wear it. I turned to a Facebook group I'm in and asked for some help. I had a lot of helpful advice, but everyone said this was a common occurrence and to persist, but that it might continue like this for a long time, perhaps years!

Levi had had his implant for about six months when they spoke to me at the clinic about how long he was wearing it. The can track on their computer the time he is wearing it (something I wasn't aware of), and they said he wasn't wearing it enough. I felt a little bit reprimanded and I thought, "Right, I'm going to just try harder."

So then the real battle began. I just wasn't going to give up. Previously if Levi pulled it off, I would take it off him for a while, thinking he really doesn't want it on. Now I would put it back on every time. Some days I was putting it back on 30 times or more. The beeping on the remote assist nearly drove me mad!

The improvement

This went on for about 6 weeks, then one day he just seemed to click, and didn't pull it off as much. He would wear it for hours. I think he was finally realising that this thing was actually helping him. Now that he was wearing it we could really see the improvement. He seemed more aware of his surroundings, and he was starting to turn to his name being called. He looked up in the sky after hearing an aeroplane fly overhead. He was looking around when he heard a car alarm go off. Life is so much easier now that I can just call his name and he turns.

The implant has changed his life and I would say it's been a success. I do have hopes that he is going to continue with his development in ways that he wouldn't have without the implant. He is starting to recognise basic words in speech. I still sign to him but speak the words as well. I'm hoping over time he will understand more and more. It is a constant battle to get him to cooperate with speech therapy and him speaking seems a long way away, but prior to the implant I would have said it was impossible.

Advice to other parents

I would say to parents considering an implant for their child: you know your child better than anyone so this is only a guide to help make the right decision. If I had a child without additional needs I would find it extremely hard to make a decision. Having a child with other disabilities I felt like I had to give him every chance possible. We felt like we had nothing to lose."