THE SUNDAY TIMES

What it feels like... to have a deaf child

Oliver Dennis was devastated when his daughter was born profoundly deaf. But with the help of 'bionic' ear implants, she can now hear

Oliver Dennis Published: 15 April 2012


Oliver Dennis, Hope and Becky (Vicki Couchman)

We do *not* deserve this. That was my first thought when I discovered that our baby was deaf. Not that anyone deserves to have a child born with a disability. But my own personal sense of injustice was fuelled by the fact that my wife, Becky, and I had already gone through so much heartbreak in order to have a child: four miscarriages and an ectopic pregnancy that required surgical intervention. So I stupidly assumed that we'd more than exhausted our quota of bad luck. Weren't we, of all people, entitled to be blessed with a normal, healthy baby?

When our daughter, Hope, arrived in September 2010, it seemed that our wish had been granted.

Sure, she failed the newborn hearing test, but we'd been warned that, as infants' ears are so full of gunk (I think the technical term is vernix), a negative result is not uncommon and no immediate cause for alarm.

Four weeks later, Hope was rescreened at the Nuffield Speech and Language Centre. When the audiologist told us the results, for a moment it was my own hearing I questioned: it sounded like we had just been told that our little girl was profoundly deaf. That couldn't be right? And then I picked up something about her being measured for hearing aids, but that it was unlikely this would allow Hope to access conversational speech, given the severity of her hearing loss. Hang on, what? I simply couldn't process this. But then, finally, it was explained in a way that I could comprehend: if a jumbo jet landed right beside Hope, the chances are that she wouldn't even bat an eyelid.

The next thing I remember was trying to hail a cab in a King's Cross Friday-afternoon rush hour, standing silent, shell-shocked and soaking in the pouring rain, clutching an assortment of NHS pamphlets, trying to hold it together until we could get home. I broke down on our doorstep. It's a cliché but, truly, it felt like the world was ending. I cried pretty much nonstop for a week. I bawled down the phone to every name in my address book; collapsed into the arms of every neighbour. I didn't want to do anything other than sleep, a means of fleeing this nightmare, but an infant allows only short bursts of escape. So every two hours she awoke, and every two hours I did, too, only to face that moment of painful recall, over and over again. It was utter torture. And for those few days, I'm ashamed to admit that every time I looked at Hope's face, I no longer saw a blessing, but a curse.

Eventually, it was time to stop wallowing in self-pity. I had to let go of the future I was grieving for and embrace the new reality. It was time to get up. To read up. And to man up. The first step was to discover the cause of the hearing loss. An analysis of our DNA revealed that my wife and I both carry the same recessive gene: connexin 26. As a result of both of us giving our faulty gene to Hope, she had been born with none of the thousands of hairs that most of us have in our inner ear, hairs that allow the processing of sound. On the plus side, we were assured that deafness was the only complication that connexin 26 caused.

This seemed scant consolation — until Hope's situation was put into context on our first visit to Great Ormond Street Hospital. There, we saw many children attending the audiology unit for whom deafness is only one of the many challenges they face.

The next step was to determine exactly what Hope's future might hold. In the simplest terms, we were faced with an enormous choice: accept that Hope was unable to hear and raise her as a deaf child, or pursue a radical alternative — cochlear implants. The former guaranteed Hope some tried- and-trusted means for communication: signing and lip-reading. It also offered her a place in the deaf community, a network of incredibly kind, welcoming, sympathetic and vastly experienced people.

Whereas the latter would involve permitting someone to drill into both sides of Hope's skull, perform major surgery just millimetres away from her facial nerve, and implant a series of electrodes: an operation that would leave her ever-dependent on technology, always reliant on a battery, and for ever "part man, part machine".

It seemed like a no-brainer. But we went with the cyborg option. Why? Because we wanted Hope to be part of the hearing world. If modern science meant there was a chance that she might access sound and speech, who were we to deny her? So, in 2011, on July 4 — "Independence from Silence Day" as it came to be known — nine-month-old Hope became one of the youngest babies to undergo bilateral cochlear implant surgery. The operation was a success. She was now the proud owner of a pair of Nucleus 5s.

We waited the long and agonizing fortnight for her processors to be activated. The specialists are obliged to manage people's expectations — and rightly so — but I had already met some of the

cochlear implant success stories: a four-year-old girl who responded to sound and communicated like any other four-year-old; an eight-year-old boy who was top of his class and clearly destined for great things; and a 20-year-old university graduate, whose boyfriend confided that he'd only realised she was deaf three months into the relationship, when intimacy had finally led him to notice the discreet device nestling behind her ear. So yes, I dared to dream, once again, that we might get our happy ending. And yes, finally, we did. Hope's results have been nothing short of spectacular. Within days of her switch-on, she was responding to a door slamming, our dogs barking and — most thrilling of all — her parents talking. It seemed like things couldn't get any better. Then they did. We had been advised that some implantees find it difficult to enjoy music. Yet it wasn't long before Hope was dancing and singing along to her favourite sounds: Maggie May by Rod Stewart, Rolling in the Deep by Adele, and ping! by our microwave.

And the good news just kept on coming. By the time she was 14 months old, her communication skills were judged "age appropriate". In other words, her hearing and speech were comparable with those of a normal hearing child. There is now no reason why her upbringing, schooling and life choices should be any different to those of her peers. And here's the icing on the cake: while most children's hearing will deteriorate with age, Hope's will only improve as further software updates and hardware upgrades become available. While her dad's ears get furrier and fuzzier, hers will only get sleeker and clearer. Mine are scrapheap-bound, while Hope's are future-proof.

There must be some downsides, you're thinking. But the recharging and maintenance of an implant are no more demanding than having an iPod or iPad. It means that she can't hear when she swims, but that's only likely to be a concern if daddy is yelling "Shark!" And she sleeps without the processors; again, only problematic if daddy has cause to shout "Fire!"

And what of the stigma attached to the wearing of such devices? I see precious little. Maybe because wherever one looks nowadays, one sees people sporting Bluetooth headsets and headphones that are far more cumbersome and crude than Hope's equipment. Maybe it's because people with implants aren't ashamed of them. They don't hide them. Hell, no, they pimp them. (The processors wouldn't be available in zebra print or Pucci-style patterns unless there was a demand, one reasons.) Perhaps it's also down to the fact that we live in an age where dependence on technology is accepted as the norm. This would explain why kids wearing implants are greeted with wonder in the playground, rather than bullying. To the younger generation, the fact that wearers are able to plug themselves into a USB port isn't grounds for ridicule, but "really cool".

All I have to say is how much I am indebted: to so many health professionals (I will never say a bad word about the NHS again); to the endless courage of my wife Becky; and to the fantastic support of our families. Collectively it was these people's efforts that allowed a miracle to take place.

If I were able to go back to the days after Hope's hearing loss was diagnosed, I would cradle that blubbering, red-faced, helpless child lying curled up in the foetal position, and say: "Everything is going to be okay, Oliver." Then I'd give myself a good slap and a pressing reality check. Feelings of anger, despair and guilt aren't going to help; time spent obsessing about the injustice of it all is time wasted. "Why me?" is not only a selfish inquiry but also a redundant one. After all, parenthood demands a seismic shift in priorities: it's no longer about what you deserve, but what your child deserves. And happily, thanks to cochlear implants, Hope is now getting exactly what she deserves: the opportunity to live life to its fullest.

Oliver Dennis has donated the fee for this article to Great Ormond Street Hospital

High-tech hearing and how it works

A cochlear implant provides sound for a person who is profoundly deaf or severely hard of hearing. This degree of hearing loss, known as sensorineural, is caused by an absence of, or damage to, the tiny hair cells that line the cochlea. With a cochlear implant, the faulty hair cells are bypassed and the auditory nerve is stimulated directly using electrical impulses.

The implant has both external and internal parts. The external device includes a microphone, which looks like a behind-the-ear hearing aid: it picks up sound and sends it to the speech processor. Also housed behind the ear, the speech processor is a computer that analyses and digitises sound signals and sends them to a transmitter coil worn just above the ear. This coil sends the sound, via a magnet, to a receiver implanted just beneath the skin. The receiver takes the coded electrical signals from the transmitter and delivers them to the array of electrodes that have been surgically inserted in the cochlea. The electrodes then stimulate the fibres of the auditory nerve and the brain deciphers the sound frequencies as it would if the information were coming from working cochlear hair cells.