

## Transcript

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Compere: **JIM MORA**

Item: **AUCKLAND MOTHER ELENA KEITH EXPLAINS HOW COCHLEAR IMPLANTS WORK AND HOW THEY HAVE DRAMATICALLY IMPROVED HER LIFE AS A HEARING IMPAIRED PERSON.**

JIM MORA: Imagine never hearing anything, never knowing what it was like to live at anything but total silence or to hear things as nothing more than muffled unintelligible noise.

In New Zealand 400,000 people have some form of deafness but many of them don't realise how their lives could be drastically improved by a Cochlear implant.

Unlike a hearing aid, the implant doesn't amplify sound. It works directly by electronically stimulating the auditory nerves inside the Cochlear. To do this, an electronic receiver is placed into the skull bone behind the ear, an external ear piece converts sound into FM radio waves and transmits it to an aerial on the implant.

Messages are then decoded on a microchip and sent into the inner ear to stimulate nerve endings. No surprise that Cochlear implants are dubbed the bionic ear.

Now our guest today is young Auckland mother, Elena Keith, who just over a year ago was so deaf that she couldn't talk on the telephone, couldn't hold down a job, couldn't hear her young children's' first words. Good afternoon, Elena.

ELENA KEITH: Hi Jim, that's for having me on.



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JIM MORA: Nice to have you on. Well, you can hear me loud as a bell now.

ELENA KEITH: [Laughs] I can.

JIM MORA: And that's the result of you receiving a Cochlear implant. So you became profoundly deaf at what - it was a very cruel time in your life really, wasn't it?

ELENA KEITH: Well, yes. I mean, any time is a cruel - not much cruel but, you know, it's a challenge to deal with. I've had a progressive hearing loss since I was born. So it became noticeably bad by the time I was about 26, 27.

Around about the time that, you know, you're having children and joining mothers groups and getting back into the workforce and that and all those opportunities that were open to you before, suddenly they're no longer there.

JIM MORA: You were in HR, you're a very social person, you love networking. That's part of the cruelty of it and you'd just had your first child.

ELENA KEITH: Yes.

JIM MORA: Yeah, okay. But you'd always managed prior to that. How did you manage?

ELENA KEITH: Well, I think it's human nature, you adapt and also lip reading. I mean, everyone lip reads though not realise actually how much you do lip read. And I think it's just as my hearing got worse and worse I'd either get more powerful hearing aids or you just cope better, I think.

It's just part of your nature but it's not until I got the Cochlear implant and actually went to put my old hearing aid back in that I actually realised how bad it really was.

JIM MORA: Yes. You had a good attitude, didn't you, which I think you've credited your mother for and a sense of being able to do anything despite whatever hearing loss you had.

ELENA KEITH: Yes, I mean there were definitely at times I threw my own little pity party, you know, part of the frustration of losing your hearing. But yes, I mean life is as hard as you make it and, and definitely having that attitude helped.

I'm very assertive and I don't like getting beaten by anything, so that definitely helps. But to my mum's credit she never treated me any differently from my brothers.

I was expected to perform as well as them and she never made allowances for it. She gave me every opportunity and I think having that attitude from her really helped.

JIM MORA: She discovered your hearing loss first, didn't she?

ELENA KEITH: It was actually my nanny. They dropped me off at school when I was about five and all my girlfriends were waiting there and she was calling my name and they were all turning around (but I wasn't) and she went back to mum and she said there's definitely something wrong.

JIM MORA: Right. So you couldn't hear your mother calling - or your nanny calling your name?

ELENA KEITH: No. And my brothers, cause I had two older brothers, they also went looking, as children they weren't looking for verbal cues. So if I grunted they'd say oh mum, she wants milk. So mum

was just assuming, you know - I mean, by the time you get to a third one you don't really worry as much.

So I think just having three children in the family and she knew that there was something wrong but the audiologist kept saying no, she's fine, she's fine. I think because my lip reading was so good.

JIM MORA: Are there any theories about what it was caused by?

ELENA KEITH: No. They think she had rubella but they're not really sure.

JIM MORA: Okay. So it just happened really and that's all we need to know now. You weren't institutionalised in any sense? I mean, you didn't get any kind of special education? What was your education like?

ELENA KEITH: It was pretty good in that mum and dad sacrificed a lot to give us the best education money could buy and I think that has made a big difference in my, I guess, my successful outcome of being a human being.

It was - I don't know. You know, as a kid you've got nothing to compare it to. It's not like you're thinking this is good or bad or anything like that but definitely, I remember being the only kid at school that wore hearing aids or who was deaf.

So, you know as a child, you don't really want to be different from anyone else. You don't want to draw that line in the sand. So you tend to want to conform and be like everyone else. So I just remember trying to fly under the radar and try not to draw attention to it.

JIM MORA: You had speech and drama didn't you, which helped?

ELENA KEITH: Yes, which helped enormously.



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JIM MORA: You also assumed, or were you kidding yourself that you weren't that good at subjects like maths because the teacher would face - I've read the teacher would face the blackboard and you couldn't lip read.

ELENA KEITH: No.

JIM MORA: You didn't know what the teacher was saying. So how did you cope with that?

ELENA KEITH: Well, I just assumed I sucked at maths. I just thought oh I'm just really bad at maths. You don't as a kid make that correlation. You just assume that you're not picking up on the subject.

But I've got a, I've got a slightly photographic memory, which really helps. Every time I went into exams I would just remember what I'd seen in the textbooks or anything like that. I always came top of the class for English, which really helped.

So the amount of reading I did got me through school. But yeah, it wasn't that hard.

JIM MORA: Elena Keith is with us. So you managed very well until your late twenties and was it the pregnancy that...

ELENA KEITH: Yes some people do find their hearing goes when they've been pregnant. Maybe it's the extra load, you know, with all that extra fluid running round the body. But definitely, both times I noticed a drop in hearing.

I went to see the audiologist and he said there's actually nothing more I can do for you and that was when he referred me to the Cochlear implant program.

JIM MORA: You think the painkillers may have killed the, the hair cells in your ears, don't you? You've had a...

ELENA KEITH: Yes it could've. There are drugs known to do that. There's a guy down in Nelson who is a violinist, studied at the Manhattan School of Music, amazing guy. He lost his hearing to (radiation) drugs and another guy from Rotorua has just got a Cochlear implant who also lost his hearing to the (antibiotic) drugs that he had.

JIM MORA: Now, we're going to talk about the Cochlear implants and who they're suited to and who they're not. But this must've been very dismaying. This must've been very worrying when you started to lose the rest of it?

ELENA KEITH: Jim, it can be debilitating because your whole situation's so ambiguous. You're thinking am I going to lose my friendships, my marriage? Am I ever going to get another well paying job again?

Every social situation you enter into is a drama. You can't contribute to any discussion. You go into a meeting, you come out thinking I've just missed almost everything what was being said. How the hell am I going to do my job?

So you start to lose yourself. It is a bit like losing yourself because you're not the person you used to be. So you have to kind of reconfigure your whole lifestyle and it's not the lifestyle that you're used to having or that you want to have.

So there's a lot of frustration and there's a lot of anger and even a lot of kind of - I guess it's like the stages of grief that you move through. You know, you've got your shock and then your anger and then your denial and then negotiation and acceptance and all that.

And some people losing their hearing never really get out of the denial stage. So they never take steps to, you know, get a Cochlear implant or go and get a hearing aid and always kind of stuck on that stage



and that's where your family is saying please, could you go and get a hearing test or something like that.

JIM MORA: Did you know about Cochlear implants? Because the first thing you did was try and improve your hearing aid, wasn't it?

ELENA KEITH: Yes. I'd known of them only because my mother was living in Melbourne and she was very familiar with the program over there but it was the darkest day of my life when he said, you know, you need to have a Cochlear implant.

I was like oh my god, it's gotten that bad, you know, I just thought there's no hope for me now. But my ear nose and throat specialist, Dr Robert Gunn, he was bouncing off his chair with excitement about the new technology and just saying well it's just brilliant.

He had a client came in and his phone bill was just pages long. It was really expensive because he spent the whole time on the phone to all his friends.

JIM MORA: Most of us probably can't imagine that, that hell of being completely deaf.

ELENA KEITH: It's isolating.

JIM MORA: I once spoke to a group of - don't take this as a tasteless remark but I once spoke to a group of the deaf and they said we would sooner be blind than deaf. And I mean that's obviously just, you know, a piece of hyperbole in a sense. But it conveyed to me the, you use the word grief, the absolutely devastating nature of that silent universe you have to inhabit.

ELENA KEITH: Yes. I think it's, I think it was Helen Keller who said, you know, when you lose your sight, you lose your relationship with things.



When you lose your hearing, you lose your relationship with people. And it's true.

I mean, communication is what connects us to everyone which is why the deaf community actually is quite well supported in that they have their own language.

But if I couldn't actually sit down with my husband and even when he was looking directly at me and not being able to understand what he was saying, I mean it's just, it just becomes so frustrating.

There's no easiness. I mean now the world is just such a, you know, a more accessible and more easy and more friendlier place.

JIM MORA: Absolutely. Your husband Gideon never had a problem with it though, did he?

ELENA KEITH: No, no. He's been - he's the most patient man I've ever met and probably apart from my father.

JIM MORA: Had you ever had to learn sign cause...

ELENA KEITH: I did take a course about four years ago when it got particularly bad when I was pregnant with my first son because I thought well, if the Cochlear implant is not an option for me, it may well not have been.

JIM MORA: But you weren't adept enough to, for some say really easy communication?

ELENA KEITH: No, no, definitely not.

JIM MORA: So your audio - your audiologist referred you to the Cochlear program.

ELENA KEITH: Yes.

JIM MORA: Now, you had - you had to undergo six months of assessment, is that right?

ELENA KEITH: Yes.

JIM MORA: Why?

ELENA KEITH: Well, what they want to do is make sure that you're a good candidate before they invest all this money and technology inside your head. So it's a psychological assessment. There's an audiological assessment to make sure that, you know, you actually are deaf enough to receive one.

There's an MRI scan to make sure that the cochlea can receive the electrodes into the cochlea. Some people have ossification or they might have a tumour or there might be lots of different reasons why they can't.

So there's a lot of sort of factors to - success factors, if you like, that they're trying to pre-empt before they actually implant you.

JIM MORA: Age is no barrier though?

ELENA KEITH: Age is no barrier. I think the oldest - I'm not too sure of the oldest but I do keep in contact with a woman who's 83.

JIM MORA: Eighty - oh, that's good.

ELENA KEITH: But the great thing is she is sitting there while everyone else in the rest home is losing their hearing and she's - she can hear everything. So it's quite good.

JIM MORA: So psychologically, I guess they - they assess you - they want you to be mentally sound?

ELENA KEITH: Well, I think it's more that you have a motivation to hear.

JIM MORA: A motivation?

ELENA KEITH: And you have a good - you have a good expectation of what the outcome may be. Some people have, you know, too - not what we would call reasonable expectations.

JIM MORA: All right. And the auditory nerve needs to function first?

ELENA KEITH: It does need to function, yes.

JIM MORA: Okay. So a Cochlear implant doesn't suit everyone but it suits a lot of people. It's just the cost.

ELENA KEITH: The cost, which thankfully there is a public program and it is fully funded by the government. The problem with that it's capped funding so there is a waiting list, I think, at the moment is about 80 adults on the waiting list.

Children do not have to wait for funding. They're implanted if and when they need it. There's a critical and sensitive stage of speech development which is between zero and three. So it's imperative that those children are implanted before the age of three so that the brain can associate with signals that the Cochlear implant gives it and they can actually recognise speech to speak it and to understand it.

JIM MORA: But you weren't diagnosed til five so there must be a lot of children under the age of five who need one but haven't been...

ELENA KEITH: Well, yes, there could be. With the newborn screening program that's being rolled out in the Waikato at the moment, they're hoping to, you know, reduce that risk.

JIM MORA: All right. You would've had this a lot sooner if you'd known, would you?

ELENA KEITH: Oh, absolutely. I think as soon as you can't use the phone, as soon as - as soon as you can't discriminate speech, you know, even with hearing aids, which - without lip reading I think yes, it could be an option.

I'm not too sure what the criteria is but, you know, there is talk of maybe moving it to severe to profound as opposed to just profound.

JIM MORA: Okay. You talk about a waiting list of 80 which doesn't sound too bad but I presume that's 80 out of a huge number of potential people.

ELENA KEITH: Yes. They reckon there's about 4,000 adults and children who could benefit from it. I think 80 is a significant number when you think that only 15 adults a year are coming through the program.

JIM MORA: Yes, that's the capped funding?

ELENA KEITH: Yes.

JIM MORA: All right.

ELENA KEITH: There is a private option. I think there's been almost 500 people under the public program since 1986 and there's probably about another 250 people have gone on to have it done privately.

JIM MORA: How much would it fully cost full up, do you reckon, private?

ELENA KEITH: About \$50,000.

JIM MORA: Yes. You see, that's a lot of dosh, isn't it?

ELENA KEITH: It is a lot of dosh. But for me, you know, if I'd known how good it'd been, I would've paid that money, you know, four years ago, if I could get back in to the workforce.

JIM MORA: You would mortgage the house to pay the money?

ELENA KEITH: Exactly. What I could give - you know, to go back into the workforce. I mean, not being able to use a phone or contribute at meetings is very hard.

JIM MORA: Oh, God, yes. Well, do you think it would be a sensible idea to look at subsidising? Say you part public, part private, which would increase the number of people who could have it done?

ELENA KEITH: There is talk about that and that is an option, yes. The way that that's to be configured I think it needs to go before the Ministry of Health and get them to look at it. I mean, it makes sense, it really does. It does make sense and insurance companies too should be involved with that.

JIM MORA: Elena Keith is with us talking about Cochlear implants.

So tell us about the fitting process. How long does it take?

ELENA KEITH: Right. Well, after the - after the surgery, which takes about three hours, you have a three week rest period, if you like, for the wound to heal. And then they put the - you go into a what they call a mapping session, switch on mapping session, and they put the external part on and then they turn it on and I'll be honest, it was horrendous. It was awful.

JIM MORA: Why?

ELENA KEITH: Well, you - they say it's not going to sound like anything you've ever heard before but you're not prepared for actually how bad it is. Everything just sounds robotic and very unnatural and it's almost like a [makes squeaking sound] - the kids sound like chipmunks on helium and big burly men sound like little girls.

Cars sound like [makes whooshing noise] but there's all these high frequency noises I've never heard before. And - so the brain's also trying to make sense of what it is. And it was - I think it was about 24 hours and then it all settled down and suddenly my brain caught up with the new data it was basically getting.

It was like, oh, that's hand knocking on wood or, oh, that's the teacup hitting the bench. But before - I mean, the weird thing was I was getting clarity. I could understand speech but it was just so unnatural.

And then it was about a week later and I was sitting at Mission Bay in Auckland and I was with the kids and we were feeding chips to the seagulls, and I could actually pick the difference between the fat one and the thin one, the different squawk.

So that was when I went, you know what, I don't care if it sounds robotic for the rest of my life because if I can pick that out, that's amazing.

But now it sounds completely natural. My auditory memory has been superseded by what I now hear.

JIM MORA: So your brain's done some reprocessing?

ELENA KEITH: Yes, which is a great thing about neural pathways. I mean, it's an elastic product.

JIM MORA: It's incredible though, isn't it?

ELENA KEITH: Yes, it's amazing.

JIM MORA: So things don't sound screechy and metallic in sound now?

ELENA KEITH: No, no. Everything sounds normal.

JIM MORA: Fantastic. Elena Keith is with us talking about Cochlear implants.

So it was horrendous but that first 24 hours must've been vile though?

ELENA KEITH: I was - yes, I was in tears a lot and of course, there was a lot of expectation. People were, you know, what's it like, what's it like? But yes, it - it was amazing actually how long it didn't take for the brain to catch up.

JIM MORA: Do you ever take it off?

ELENA KEITH: At night time when I sleep and when I obviously shower or go for a swim or anything like that. It's not waterproof. It's better than it used to be. It used to see water and die whereas now it's what they call splash proof.

JIM MORA: Splash proof?

ELENA KEITH: Splash proof.

JIM MORA: I see. You wouldn't want it to die, would you, because that would be expensive?

ELENA KEITH: Well, under the public program, the upgrades and the replacement parts and all that sort of thing are covered but you have to be - you have to have insurance.

JIM MORA: Right. So you'd want to be very careful with it?

ELENA KEITH: Yes.

JIM MORA: You can't see it. I'm looking at you and I can't see it.

ELENA KEITH: No. I mean, the external part, for those of you listening out there, is like  
- it's a little like a hearing aid very much and it just sort of  
sits on the outside of the ear.

JIM MORA: So it's tucked behind your ear?

ELENA KEITH: Yes.

JIM MORA: Is it smaller than a hearing aid?

ELENA KEITH: No, it's about the same because of the amount of batteries that have to be  
put into the back of it.

JIM MORA: Right, okay. So people, if they could see it, would just think you're  
wearing a hearing aid?

ELENA KEITH: Yes.

JIM MORA: Yes, okay. So you take it off for sleeping but you wouldn't - did you say  
you'd shower with it or not?

ELENA KEITH: No, no, definitely not.

JIM MORA: No, it's not that splash - right, right. So you have to upgrade the external  
technology at all? Has that happened?

ELENA KEITH: Yes, about very five years. The internal part is basically in for life but the external part gets upgraded and the technology is getting better and better all the time. There's an outfit in Melbourne called the Bionic Ear Institute and they do a lot of research.

They've just actually released this new technology which will make music that much more enjoyable and be able to enhance your speech discrimination in noisy places, which is a big thing.

So I think what they need to do now is licence back to the Cochlear and then Cochlear will then upgrade all their processors.

JIM MORA: Okay. So there is still a problem with a crowded room?

ELENA KEITH: Yes, not so bad. It's quite sophisticated in that I've got what you call a program that I can switch to and it suppresses all the background noise and I'll hear just the people who are in front of me or maybe to the side of me.

JIM MORA: How do you do that?

ELENA KEITH: You just - there's a button on the back of it and you just press. It's a bit like a hearing aid that you can switch to your T Coil switch for the telephone and that sort of thing.

JIM MORA: Wow, so you've got a crowd mode?

ELENA KEITH: I've got a crowd mode. I've got a party mode. [laughs] So when I'm on the plane, I can suppress all that background noise. I don't hear anything on the plane. All I can hear is the people around me. I don't hear any of that background drone going on, which is fantastic. It's almost like a noise cancelling set of headphones.

JIM MORA: That's fantastic. But you can't turn it off as such, can you? I mean, you wouldn't want to, I suppose?

ELENA KEITH: No, you can - I mean, you have volume switches and that sort of thing so you can take it right down.

JIM MORA: So you've got a mute mode too?

ELENA KEITH: Yes. You know, if you've got a hangover and you just want to sort of dampen things down a little, it's quite handy for that.

JIM MORA: It's an amazing thing. Do you feel it inside? I mean, the inner component, do you feel it in any sort of sense?

ELENA KEITH: No, no. I mean, even after surgery, it's a little tender. I mean, they do take a bit of bone out to put that magnet in and to drill the electrodes down into the cochlea.

But considering it's head surgery it's not invasive, not like the good old days, need to shave half your head and open you right up. It's actually pretty tidy these days, you could say that.

JIM MORA: Your experience is a great advertisement for it. So now you're focused on getting more implants into more people and you're involved with the Pindrop Foundation?

ELENA KEITH: Yes.

JIM MORA: And what does it do precisely?

ELENA KEITH: The Pindrop Foundation was set up to raise awareness of them, which is what we're doing now, and to try and get more privately funded implants.

The problem is because of the cost of them and because the public generally perceive it to be a government responsibility, it is quite difficult getting that funding for adults, because children are funded out of right.

I'm finding when we're campaigning for funding, and there's your fluffy dog or sick kids, it's not quite as easy but when people meet me or other people who have a Cochlear implant, they can see the direct benefit.

Really it's one of those things you actually have to see in action to really appreciate how good they are.

JIM MORA: Of course. So that's the Pindrop Foundation and you've got your father-in-law, Hamish Keith, involved in fundraising?

ELENA KEITH: Yes.

JIM MORA: And can you tell us, he's commissioned ten artists?

ELENA KEITH: Well, nine because Dick Frizzell has done it twice. But what it was is I got him over for a bottle of wine and a chat and I said, now, stop me if you've heard this one before. How about a charity art auction?

And he just rolled his eyes and said, no, not another one. And he's quite right, you know, most art sold at charity art auctions is devalued. The people are there to support the foundation not necessarily the artist.

So it was very much like the Barry Lett multiple series is that he very kindly approached his contacts and his artists or people that he knows within the art world and asked that they would do a screen print.

And we produced sixty the first year or a set of four - 60 of the limited edition run and that was Jacqueline Fahey, Denys Watkins, Kate Small, a young emerging artist and Dick Frizzell and we repeated it again for this year and it's Shane Cotton, John Pule, Judy Miller, Sara Hughes, Dick Frizzell again and Robert Ellis and it's called The Art of Hearing.

JIM MORA: The Art of Hearing. And it'll raise a bit of dosh?

ELENA KEITH: It's going fantastically well. People are getting really behind it.

JIM MORA: Good on them for doing that, the artists.

Do you have to be completely deaf? I mean, at what stage of hearing loss can you be before you get a Cochlear?

ELENA KEITH: Well I'm not sure because I'm not a clinician so I can't answer that with certainty but I think it's pretty much, again, if your hearing aids don't really give you any benefit. I mean for me, I could hear environmental noise but I couldn't understand what was being said, and I think that's the crux of the matter, is can you actually understand what's being said around you?

And there's a safety issue. You need to be able to hear environmental noise and make sure it's not a car coming up behind you or a car horn or a barking dog and all that sort of thing. But really for me it was about being connected to people around me.

JIM MORA: You get emails from people asking if they're eligible, don't you?

ELENA KEITH: Yes, we do, yes, through the Pindrop Foundation. Normally what we would do is refer them on to their GP or their audiologist and then from there they will refer them on to the program.

JIM MORA: You also tell other mothers who are freaking out about their own children that it's not irredeemable any more?

ELENA KEITH: No. I mean, the thing is it's a mind set and I believe that if you give your child every opportunity, that you treat them like a normal child, they will have normal outcomes as long as you don't sort of protect them too much or, you know, try and do everything for them. They need to be independent, they need to find their own resources in themselves.

So yes, it's a physiological concern. It's a - what would you call it - it's a communication issue you need to resolve and be that with signing or be that with hearing aids or be that with Cochlear implants, just find the best option for your child.

JIM MORA: Yes. Do you have heightened concerns about your own children?

ELENA KEITH: No. No, my children are bullet-proof. I certainly think that.

[Laughter]

JIM MORA: And if you aren't available - I mean, if you aren't eligible for a Cochlear implant, you'd recommend sign - do you think - would you have liked to have learned sign more comprehensively earlier?

ELENA KEITH: Absolutely because I think it would've given me - I mean access to the deaf community but again the deaf community is about a culture. So it's very much about shared language and shared history and humour and experiences and all those sorts of things.

So unless you sort of grow up with that culture, you're always kind of an outsider. So although I could learn to sign, it was more about so I could

sign with my interpreter as opposed to joining the deaf culture.

JIM MORA: Right. So the essential advice is to talk to your GP or talk to Plunket in the case of your little ones?

ELENA KEITH: Yes.

JIM MORA: And you are also part of a working party which makes up a Ministry of Health panel setting up a hearing conservation program for schools, Elena?

ELENA KEITH: Yes, we are looking at that at the moment. We're trying to work with multiple government agencies to bring that online next year. We're finding that noise induced hearing loss in this country is starting to - well, for ACC it's in the top five claims.

They were spending, I think it was \$55 million a year on noise induced hearing loss claims. That's a huge amount of money and it's growing by 20 per cent a year so it's going to cost them \$66 million next year. It's a major concern for them.

So what we've found is that looking at overseas models, one of the most effective ways to sort of address that is to start with children so that when they go into the workforce, they're taken responsibility for their own hearing.

It's not about legislation or policy changes or anything; it's purely about the individual.



JIM MORA: That's great to hear of your experience and such an optimistic thing to be talking about. I mean, the tech will only get better and better and better, won't it?

ELENA KEITH: Yes.

JIM MORA: Elena Keith. So she's been our guest. Pindrop.org.nz?

ELENA KEITH: That's the one.

JIM MORA: Thank you, Elena.

ELENA KEITH: Thank you.

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