



REIMPLANTATION

All of us are aware that our implanted electrode device can fail and this may be of concern to some users and to potential candidates. Failure rates overall of modern devices is but

0.5% or less which means possibly a handful of cases each year across the UK. But despite the difficult experience of implant failure, reimplantation is usually very successful and this gives us users confidence in the huge benefits of cochlear implantation which so outweigh the minor risks that can be experienced by some. Here are 2 people's real, encouraging stories. Do readers have others?

Lesley Pinchbeck

Quite unexpectedly, after a really amazing start, my Nucleus Freedom cochlear implant turned out to be faulty, and the quality of sound deteriorated so rapidly that I was left without any hearing at all, exactly five months to the day after it was switched on. It wasn't much consolation to be told that there have only been four failures in 10,000 implants of this particular type if you are the unlucky 4th. Even less so when they say that it's a fault they've never seen before.

The first inkling I had that all was not well was in July, at the end of the tuning in period after they had first switched me on in April 2006. I had been returning every week to see the audiologist but after 3 months I was still struggling. When retuned, everything was great, and I was even beginning to have conversations with people without looking at them. There was no longer anyone whose speech I couldn't follow, but it didn't last. As the week drew on, sounds would become progressively sharper, noisier and increasingly intolerable. I began to have frequent migraines, due to what I can only describe as "earstrain"; the equivalent perhaps in visual terms to being in a constant piercing white light. Everything would be extremely clear and visible, but to stay in it for too long would give you eyestrain and a headache. At the hospital, I was told that some people took longer to get used to hearing sounds for the first time, and that I seemed to have very sensitive hearing. I would just have to persevere and keep trying and eventually it would settle down. I began to get quite depressed. I particularly remember a family party at the three month mark, two days after a retune, where the laughter of the children cut through my head like a jagged edge of tin and reduced me to tears.

On what proved to be my last tuning trip, the Nucleus technical advisor was visiting the hospital and was asked to run my implant through his box of tricks and see if

everything was OK. One moment I was in for yet another retune, the next minute I found myself sitting plugged into a computer with a technician who had gone very, very quiet. I knew it wasn't good news. In fact I was completely shocked, so much so that five minutes later, when I was told to go home and wait for a phone call, while the technical experts decided what to do, I was speechless-not something that happens very often! It was twenty minutes later and halfway to the station before I found my voice-"It's not good, is it?" My husband agreed-he was as shocked as I was. We had been through so much this year, to get this far-and now this?

It was a week before they told me what I knew already that my implant was faulty and would have to be removed and replaced. The following week I returned to the hospital, and was told that it would be treated as a priority and replaced as soon as possible. The next six weeks before I finally had the replacement operation went by in a kind of numb, disbelieving, stressed-out haze. I couldn't bear to be in a social situation, I could hear nothing and not only that, due to having had such success with the implant at first, I now knew just how much I was missing. I couldn't bear it, and I felt mentally exhausted. In October I returned to the hospital, and had the faulty implant removed and replaced. The operation was quite straightforward; I'm told there was no visible damage to the implant. I didn't have much pain and I recovered much more quickly this time, with no balance problems or other side effects.

Three weeks later I returned for switch-on number two. I hadn't dared let my hopes get too high, but I was relieved and delighted to find that speech was easily intelligible straight away, with only a small amount of background chittery squeaky noises. I also heard a new bass note in the tuning process, which I was told was due to the implant being in a slightly different-and better-position this time round. By the second week I was starting to understand some speech without lipreading, and by the third week I suddenly realised I was listening to the news on the radio-and following the story, which is something I've never been able to do before in my life. I've also started tentatively to use the phone. Mind you, there are drawbacks, I was in Woolworths the first week and had to leave because I couldn't stand the horrible jangly background noise, whatever it was. The next week I went in there and suddenly realised I could hear every word and note of a rock version of Jingle Bells crystal clear, and I wasn't a bit grateful!! I think it is probable that having been without any high frequency hearing for over 50 years, it has taken my brain longer than most to learn how to handle all these extra noises, and also to learn which ones need to be disregarded to a certain extent. Things continue to get better, and I am so glad I have reached this point, however long and difficult the journey has been. I have to say I would do it all again if I had to, and I would reassure everyone that even though it is a tiny percentage of implants that do fail, it's not the end of the world, and they can be replaced.

Alison Patuck

I was first implanted in Sept 2001 (at Bristol), at the age of 19, with Med-El Combi C40+, and used the Tempo+ BTE speech processor. Initially I had problems but after about 2 yrs, I really got going with it, and now I just couldn't live without it until I was unfortunate to experience an implant failure.

Weds 13th Sept 2006 started like any other normal day, implant working well, but there were 2 occasions that morning when it cut out on me – I assumed it was the batteries dying – nothing unusual. Then at lunchtime my CI cut out again – this time giving me painful electrical/static shocks around the eye and down left (implanted) side of face; weird but couldn't get the processor to work again. My Dad arranged an appointment for the next day to get a replacement processor. But it wasn't meant to be, the internal implant had failed and more tests were needed. I was shocked, numb, worried, scared and upset – why me? Ironically on the way home – I realised its 5 yrs to the day (13th Sept) that I was originally implanted – is this fate??

Over the next 7 days I was in limbo – having to manage with total deafness. I continued to work and carry on as best as I could – with lip-reading, visual clues, occasional notes to get by. Found it very tiring, frustrating and depressing. During that week I realised how much I relied on my CI – and the things I now took for granted – like listening to music, radio in the car, the ease of communication with 1 to 1, being aware of environmental sounds around me – like TV, birds singing, traffic. I felt so lost without my CI – as if part of me was missing. Also another issue really got to me was the fact my Tinnitus had returned and was on full blast.

After further tests on the following Thurs (21st Sept), it was confirmed that the internal implant had failed and only way forward was to have it re-implanted – meant further surgery. After that things moved pretty fast. 5 days later, on 26th Sept I was back at the hospital for an appointment to see my consultant who said he would operate the next week, that's dead quick! The feelings I was experiencing were a massive rollercoaster ride – fear, apprehension, dread, worry, upset etc – but I much rather get all this over and done with now rather than later.

I was re-implanted on 5th Oct with the new generation Pulsar CI 100 implant which was tested and working well before I was closed up. Amazingly I felt better post-op than I expected and I didn't feel as bad as the first time when I woke up. I was just so relieved I got through it as I had really worried, wound up, petrified of the whole thing and been dreading the surgery for past few weeks. Looking back now how pathetic I must have been before I went to Theatre – still cringe at the thought of it!

Whilst I was in hospital I begged my audiologist to be switched on as early as possible – as I had no hearing and she gave me an appointment for 2 wks post op! That gave me motivation and I was both excited and apprehensive

as I had been warned that nothing will sound like as it was with my first implant, due to new implant and different positions in the cochlear. I tried really hard to keep my expectations really low, easier said than done though. I gave my hair a good wash



before I went back to be switched on – and it made such a huge difference to how I felt. By then I'd been without sound for 5 weeks (apart from the constant tinnitus) – the longest period in my life.

At switch-on on 19 th Oct I was shocked and taken aback by how surreal and awful it sounded. Due to new implant (which is different) and different positions in the cochlear, it was a new a learning curve and I had to re-learn everything again. Only this time it didn't take quite so long, as I already done this before. I just had to be patient again, which is hard! However I have noticed this time round I was able to pick up more sounds more easily as I knew which sounds were which.

After about a month later I was able to do exercises with my audiologist which required me to listen without lip-reading and did so well – I was shocked at how much I had picked up, so soon after switch on! I think she was surprised as well. I was nowhere at this rate after my first switch-on. This gave me a much needed boost of confidence. I couldn't stop myself smiling for the rest of that day! I've started using the new Phenomena CD which was suggested by another CI user, and found it very helpful and wished I had known about this before. It gets your brain to really work on those 'difficult sounds'. And listening to music on my MP3 player which I now can't live without. It really helps me to switch off and relax. Listening to the radio in the car, conversations are much easier – even with strangers. I can't believe I am saying this; but I am really enjoying listening. I hope from reading this that should you experience a CI failure, which thankfully are rare, don't ever think it's the end of the world – there is life after a CI failure after all.

(We also know of another courageous lady whose Advanced Bionics device failed last year who will be reimplanted this summer. She would have been treated straightaway but that had to be delayed for medical reasons unconnected with her deafness.

So it can happen to us all but there is great encouragement from the above experiences. Ed)