

Why not all deaf people want to be cured

For many deaf people, hearing-boosting cochlear implants are a godsend; but for others, they're a threat to their way of life. What are they afraid of?



Photo: ILLUSTRATION BY NEIL WEBB

By Sally Williams

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Laura Mcauley is deaf. Born with a slight auditory defect, her hearing declined significantly at the age of four, and precipitously at 17.

“It was literally an overnight thing,” she says. “I just woke up one morning and my hearing aids didn’t work anymore. It was like turning off a light.”

Fortunately, in 2003, the light was turned on again. Doctors fitted Laura with a cochlear implant; a so-called “bionic ear” that mimics normal hearing.

“I was really excited,” she says. “Because I’d waited so long for it.” But her boyfriend Owen,

who was with her when they switched the device on, wasn't so sure. "What if you don't like the sound of my voice?" he asked. "Are you still going to want to be with me?"

"Don't be stupid," she scoffed. Then the audiologist flicked a switch and voices gradually began to fill her ears. Sitting on a sofa in her home in Huntingdon, Laura becomes emotional as she recalls the moment she heard Owen for the first time.

"He said, 'Hello'. And I went, 'Oh, hello'. It was so strange!" she says. "But he had a nice voice; deep. Then, while I was talking to the audiologist, someone else spoke and I said, 'That's my mum's voice.' And Mum just burst into tears."

First introduced to Britain in the late Eighties, a cochlear implant is an electronic device that's inserted into the inner ear and wired up to the cochlea, the snail-shaped cavity that normally helps to transmit sounds to the brain.

Acting as a receiver, it picks up sounds from a microphone worn on the outer ear, converts the sounds to an electrical signal and then sends the signal to electrodes to stimulate the auditory nerve.

Today, there are around 200,000 users worldwide, but, until recently, the procedure had been reserved either for children or adults who had previously been able to hear.

Adults who had been deaf all their lives were not considered suitable, first because they had learnt to manage their disability, and second because they were able to communicate quite proficiently using sign language and lip reading. What's more, research had shown that the adult brain found it more difficult to adapt to the "hearing world" than that of a child, so didn't benefit as much from an implant.

But, as the technology has improved, and long-term outcomes have become apparent, this attitude has slowly started to change.

In the past few years, implants have become increasingly sophisticated. The long-term evidence has been documented and, in 2009, the National Institute for Health and Clinical Excellence (NICE), the regulator of medicines and medical procedures in England and Wales, recommended cochlear implants for both adults and children, whether born deaf or hearing.

Suddenly, thousands of people who thought they would spend their whole lives deaf are contemplating a very different future.

“It’s important it’s not just children,” says Suzanne Harrigan, a speech therapist for The Ear Foundation, a group for cochlear implant patients. “Implants provide adults with the opportunity to hear speech in a way that hearing aids can’t and that enables them to participate more fully in life. In other words: work, talk to your family and friends and enjoy all that the hearing world has to offer.”

Laura was lucky; her health care trust took an autonomous decision in 2003 to sanction implants for adults who’d been deaf since birth. Within six months Laura could hear the whirr of her computer and conduct a conversation with Owen from opposite ends of the house. She could hear — rather than just feel — the engine of her car and spent time standing in her shower in the morning (even though you’re not meant to get the cochlear microphone wet) listening to the sound of the water. She was also horrified to discover the noises people made in public toilets. “Oh my God!” she said to her mother. “Do people hear this all the time?!”

Having written off her dream of becoming a teacher before receiving her implant, she has now taken a postgraduate certificate in education and, last year, took up a post at a primary school in Cambridge. “My implants have given me so much, not just my hearing but my confidence as well,” she says. “I can do what I’ve always wanted to do — work with children — and make something of myself.”

Throughout our conversation, Laura speaks in a slightly louder voice than the norm. But, apart from this, and a quick dart of her eyes to my lips when I’m speaking, there are no clues to her deafness.

Rebekah Moore, a 29 year-old from Hilton, South Derbyshire, is another success story.

Increasingly deaf from the age of four, she had an implant fitted eight years ago. She sends me an email listing some of the things she’d never heard before her operation: “Birds, footsteps, zips, water running, wind in the trees, paper rustling, kettles boiling, keys jangling. I had an apple and I was astonished at how noisy it was.”

It takes time for patients to get used to an implant and Rebekah had regular appointments to

retune her device and gradually increase the parameters of her hearing.

“Each session would be followed by a period of readjustment as I got used to more sounds and more clarity,” she writes. “Each time I couldn’t quite believe it could get any better but it did.”

But not everybody who’s deaf is so keen to join the “hearing world”. Sara Kendall, profoundly deaf from birth, lives with her deaf mother and deaf boyfriend in Nottingham, and feels she has nothing to gain from an implant.

“I was offered cochlear implants when I was younger but my parents refused and I’m very happy with that because I’ve seen some cochlear users admit that they feel they don’t belong.”

What many hearing people might not realise is the strong community that exists in the silent world. In fact, it’s more than a community. Deaf people (with a capital D) see themselves more as an ethnic minority, with their own (sign) language, schools and proud history.

The National Association of the Deaf was created by deaf people to advocate for deaf rights in 1880. The Deaf don’t see deafness as a disability but a cultural identity (motto: different but not deficient). It’s a world so warm and welcoming, many wouldn’t want to become hearing, even given the choice.

“I don’t feel upset that I can’t be in the hearing world completely, because I’m content where I am,” says Sara. Moreover, cochlear implants are not always an unambiguous success.

Paul and Sally Taylor are 73 and from Rochester, New York. Born deaf, they met as children at the Central Institute for the Deaf, and built up a successful life together. He went on to become a professor at a college for deaf students; she became a teacher. (She was also so skilled at long-distance lip-reading she was occasionally hired by the police for surveillance purposes.)

Lovable and charming, they headed up a close family of three hearing children. Then in 2004, after 65 years of silence, they decided to have implants. “A big part of it was curiosity, combined with living in a time in history when it was possible,” says Irene Taylor Brodsky, their daughter and a film-maker who chronicled her parents’ first year living with implants in an award-winning documentary, *Hear and Now*.

The dominant emotion portrayed in the film isn’t joy but bafflement. “When you haven’t heard

anything your whole life, you don't have the neurological ability to render meaning from all these sounds," says Irene. "Mum had daydreams about hearing music for the first time. She'd always listened to heavy metal and rock 'n' roll because it is very vibration intensive, so she was looking forward to hearing different kinds of music."

In fact, Sally can now pick out the high notes on a violin, but that's about it. "I have not yet become a music fan," Sally confirms in an email.

Many of Paul's hopes were also dashed. "He wanted to be able to have good conversations with people and not have to repeat things three or four times, which slows everything down," says his daughter. "He wanted to be able to talk on the phone. None of these things has he been able to do." Paul also discovered that, far from being adorable, the voices of his grandchildren were rather shrill and often best experienced with the implant turned off.

And yet the couple are not dispirited. "We're more aware of the environment around us," they say. Sally now understands why people look at her when she gets her sandwiches out of a plastic bag on a train. Before she had just assumed that, because the bag was soft, it didn't make a noise.

But the truth is that cochlear implants can provide only limited benefits to those patients who receive them so late in life. Austin Chapman, a 23-year-old from Orange County, California, has had a far more positive experience, but due to a new, powerful set of hearing aids, not an implant. (He says the thought of the surgery scared him.) His blog, where he has been describing his first experiences of hearing music, has attracted thousands of readers.

"When Mozart's *Lacrimosa* came on, I was blown away by the beauty of it; it sounded like angels singing and I suddenly realised this was the first time I was able to appreciate music," he writes. "Tears rolled down my face..."

He's now on a musical binge, fast-tracking through history, listening to everything from Guillaume de Machaut's *Agnus Dei* from the 14th century to Led Zeppelin. When he went to a club during the summer, he couldn't stop himself from dancing. "I will be going to as many live shows as I can in the next couple years," he says. But, despite his elation, Austin admits there have also been some disappointments. The sounds of traffic and dogs barking are "ugly", he says.

And his favourite sound is still silence. It's something he's long been familiar with and he has found that, when he turns his hearing aids off, his other senses become sharper. Food tastes better. His golf game improves and wakeboarding and rock climbing are more enjoyable. He only turns his hearing aids on for music and conversation.

"I actually feel bad for hearing people," he says. "I wish that more people could experience the power and peace of utter silence."

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