

Cochlear Implant Myths Dispelled

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The author had a progressive hearing loss from the age of seven as a possible result of Scarlet Fever. He wore hearing aids until he experiences a sudden, total collapse of his residual hearing when he was 30. He was totally deaf, depended on lip reading for 35 years. He received bilateral cochlear implant surgery before his 65th birthday. His speech comprehension went from zero to 85% with rehabilitation.

In December 2015 bilateral cochlear implant surgery was performed by Dr. Loren Bartels of Tampa Hearing and Balance. Four weeks later, activation with two Cochlear Nucleus 6 processors (later upgraded to Nucleus 7) was done by Dr. Victoria Moore of The Hearing Spa in Sarasota Florida.

Activation was typical of most cochlear implant recipients. There were sounds without comprehension. Surgery and activation are just the beginning of the process to regain natural sound. Cochlear implant candidates need to understand that rehabilitation is a critical component for success.

Although the amount of time it takes for rehabilitation varies for each recipient, it took four weeks of rehabilitation, with a program I designed, for speech to normalize. Independent of needing a second person to help with rehabilitation, it utilized a combination of audio books and lectures from the Great Courses series. I dedicated four to six hours every day for listening practice. With time and practice the brain adapted and everything sounded normal. Sounds I had been missing for decades came back. Conversations without the need to lip read and the ability to use a telephone, something I missed for 35 years, returned.

Music took longer to normalize. Music takes more rehabilitation practice than speech due to the complexity of sound. I created

a music rehabilitation program incorporating listening practice via internet radio and YouTube musical videos with lyrics. Eventually everything sounded as I remembered. Many candidates feel that music is more important than speech. Losing the ability to enjoy music is devastating. I later produced a music rehabilitation program which is incorporated in the Cochlear Implant Basics website (see RESOURCES). Enlisting musicians, each of who donated a two minute audio clip of their specialty, using the program, cochlear implant recipients can train their brain to relearn the sounds of the guitar, drums, harps, and more than two dozen other instruments. By repeated listening, the brain recognizes the sound associated with each instrument.

When I mentor or assist cochlear implant candidates, the most obvious question that I am asked is: Why did you wait 35 years to get cochlear implants?

The answer is that I was discouraged by misinformation or lack of any reliable information.

In 1980 when I lost my residual hearing, cochlear implants were in their infancy. I wanted the fidelity of music and was fearful of the sounds of speech being mechanical. At the time, these issues were realistic. I delayed hoping for science to find a "cure" for my deafness.

There was little information about cochlear implants that encouraged me to move forward. In those decades of deafness I can only recall articles that were discouraging and reinforced my negative notions about cochlear implants.

Rush Limbaugh, the most publically recognized cochlear implant recipient in the USA, mentioned that he was unable to distin-

guish between male or female voices, among several issues that he had. He had opted for a cochlear implant (later he went bilateral) because of the necessity to keep his hearing to perform his career as a radio show host. It was many years later, I learned that his results were less than optimal because of issues in the cochlea and few electrodes were operating. Nonetheless, for years it discouraged me from moving forward.

This is the power of misinformation.

Case Study; Chris G

This transcript is taken from a podcast interview found on the Cochlear Implant Basics website. Chris G. tells of the misinformation she received and resulted in her delay getting a cochlear implant for many years. I asked her why she had waited:

Chris: I almost got one back in 2011 and then waited six years. Probably, I should have done it sooner, but on the other hand, when I moved to Sarasota, I had found the quality of the healthcare and the whole community of people, surgeons, audiologist who specialize in cochlear implant rehab, other people, the Hearing Loss Association. It has been such a strong support group.

Richard: Tell me a little bit why you hesitated because it is not an uncommon thing for people to hesitate. How about your experience?

Chris: Well, first of all, one of my ear doctors said to me, "Oh, you don't want a cochlear implant. It is very artificial and robotic hearing. That would only be your last resort". I believed this guy. He's an authority figure. Like "Oh, okay. Okay. Well, I'm losing my hearing every year, but that doesn't sound like an option". Then another in North Carolina, ear doctor, says, "I don't think a cochlear implant is something you need". I really dug my heels in. Meanwhile, I had gone to National HLAA conference and gathered all the material from the manufacturers. I was scared. I was scared of the surgery.

Chris: These two doctors saying, "No, no". That gave me the reason to procrastinate and convince myself, "Well, they must be right". Even though I've met all these people who said, "Oh, I wish I had never delayed". Then my big procrastination along with the fear was the misconception that, "Get it done and technology moves on and there you are. You're stuck with the 2011".

Richard: That didn't turn out to be true.

Chris: No. I had to go to a seminar where a Cochlear rep stood up there and brought home the point that, "The great thing here is, you have this little gadget and we can reprogram that and we can reprogram the device inside your inner ear and you then get the benefit of the ongoing technology". That point had never reached me before.

Chris G's experience happens frequently.

The doctor as authority figure

Numbers vary but approximately 700,000 cochlear implant devices are in use worldwide. This number does not differentiate for those who are bilateral. The number of recipients is obviously far smaller. With the current estimated worldwide population of 7 billion, the odds of a medical practitioner meeting a cochlear implant recipient are extremely rare. In the United States, the number of cochlear implant recipients is less than .06 of 1% of the population. Without this personal interaction with cochlear implant recipients, it is hardly surprising that misconceptions abound.

As Chris G. noted the doctors and audiologists, unfamiliar with cochlear implants are still authority figures we trust. "Well, they must be right" was a mindset that prevented her from getting help for years.

Candidates need to know that technology is available to give them superb hearing now. This can be especially critical to those who face loss of employment because of hearing loss. These candidates are facing a hearing emergency. It can result in panic and depression.

In my outreach one universal truth I have discovered is that all hearing losses are as individual as fingerprints. This individuality stems from the candidate's personality and organic factors. Length of deafness, sudden hearing loss, single sided, combined with other medical issues such as Meniere's, cultural issues, insurance issues, offerings from the various cochlear implant manufactures (which vary world-wide), mental capabilities and emotional issues, willingness to partake in rehabilitation, fear (often brought on by misinformation) and vanity (one of the primary reason those who need hearing help wait years to do something about it).

In addition, candidates have various levels of expectation.

Some want guarantees the cochlear implant will work to give them normal hearing. To those who want assurances, I remind them that nothing in life is guaranteed but if a surgeon is willing to operate, they will hear again. The degree of hearing is what cannot be guaranteed but the vast majority of cochlear implant recipients get optimal results with rehabilitation and a positive attitude. Cochlear implants are not a magic bullets but require dedication to listening practice to get the best results.

Common misconceptions and solutions

Less than 5% of those who could benefit from a cochlear implant bother to investigate. These four major misconceptions have prevented thousands of potential candidates from finding their way out of the isolation of deafness, the social withdrawal it causes, the lack of advancement in their career, and mental decline associated with hearing loss. While some of these factors may be true to some degree for some candidates, they are not true for all:

- Sounds will be mechanical. They will never sound natural.
- Candidates who have been deaf for more than five years have little chance of success.
- Music will never sound like the candidate remembered it.
- Cochlear Implant surgery is brain surgery.

With a growing population of hearing-impaired persons, public perception that hearing loss is a disability to hide is beginning to collapse. In the United States, the coming tsunami of over-the-counter hearing aids and the ensuing advertising and promotion will find new candidates seeking help for severe hearing loss when these OTC devices prove ineffective for them.

The best hope to moving candidates off the fence to investigate cochlear implants is education. Education of the candidate and medical professionals who they come in contact with. It is important for a medical professional have enough basic and accurate information about cochlear implants to encourage a severely hard of hearing patient to do research.

During a Cochlear volunteer training seminar I attended, the leader asked the question: How many people here regret getting a cochlear implant? Not one hand went up. The next question was: Who wishes they had not waited so long to get one? Every single person was enthusiastically waving their hand.

Educational tools

Cochlear Implant Basics (cochlearimplantbasics.com) contains a FAQ section and a series of podcast interviews with recipients, surgeons and an audiologist who share their experiences. The podcasts have transcriptions. There is no sponsor for the site and it is non-brand specific. There is also a music rehabilitation link.

In addition, there is link, VIDEOS, on the site to a four minute clip on YouTube that I produced: Cochlear Implant Basics: An Introduction Guide for Medical Professionals.

Bilateral CI Warrior is a Facebook group with members who have bilateral cochlear implants or are seeking information and support.

Hearing well is well being. Good hearing is linked to emotional, social and cognitive functions. Medical professional and audiologist are on the front line as authority figures. They need to be informed about the basics of cochlear implants [1-3].

Bibliography

1. Cochlearimplantbasics.com
2. Facebook site: Bilateral CI Warrior.
3. Cochlear Implant Basics: An Introduction Guide for Medical Professionals - YouTube.

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