

CONSIDERING A CI?

Nancy Hammons
Tom Goulder

NANCY HAMMONS: In my family there are six generations of hearing loss ranging from being born deaf to hard of hearing to late deafened. I grew up hard of hearing, but never knew it until I was 18. So I have experienced a diversity of deafness; first being a CODA, a child of a deaf adult, feeling it was my obligation to interpret and take care of my deaf mother and deaf brother, and then actually becoming deaf myself during my pregnancy, which was a very frightening experience.

I stand in front of you today with nine years of experience with a cochlear implant. Since this time, since 1978, 42 thousand people, mainly adults, have been fitted with cochlear implants. Dr Tom Goulder is here to give you actual facts and numbers of the documentation that he has collected throughout the retreat and the workshops that we have done across the nation.

DR TOM GOULDER: I was skeptical of cochlear implants ten years ago. And probably rightfully so. I was wondering could this technology really help people? I everyone confronting deafness who is considering cochlear has to wrestle with the question of whether it is the right thing to do or not. The answer depends on where you want to be. There are approximately 28 million people with a hearing loss in the United States. Of that group, we are estimating from the medical studies that we have done, that a million and a half people are what we would call late deafened. 26 million are the people we describe as hard of hearing. And then approximately a half a million people who are culturally pre-lingually deaf. But there is another population that I would like to just briefly mention: those with hearing and vision loss. This population is estimated at about 900 thousand people. And it's interesting that many blind people, the leadership at least, are opting for cochlear implants which is very interesting. As Nancy mentioned, there are 42,000 cochlear implants worldwide, as of last year. The interesting fact is that it is true that for a number of years only adults were being implanted. But in the last year, in the year 2000, more children were implanted than adults, which is a turn around.

There are several factors that are accounting for more children being implanted. First of all, a break through has happened in the legislation across America where we now have the early infant screening and identification program. Today there are 32 states that have legislation and/or such a program in place. They are averaging in identifying six children per thousand who have hearing loss.

I have been working in the field of hearing loss since 1958 when I first learned sign language. The average age of identification of hearing loss when I was diagnosed was three years of age. The average age of identifying the children now who are being screened in these 32 state programs, is three days of age. We went in a moment of time from a three year average of identifying the problem and diagnosing it from three years, which is way beyond the beginning of language, to three days.

We need to remember that cochlear implants are not like glasses which can be fitted to precise losses as glasses can. Essentially where we are now is that with cochlear implants one size fits all. Meaning that the amount of sound that you receive, and the clarity of that sound, is determined by the processing instrument.

What are the pre implant issues? Well, there is denial. People are going around and they can't hear anything. The second issue is delay, saying the technology is going to get better, so, I will wait. And the third is the expectations they may have about what they are going to receive. The research that we have been doing indicates that out of the 150 recipients that I have interviewed, all have made sounds and language gains. But the gains varied across the spectrum. Some of them got almost perfect results with almost perfect clarity and almost a hundred percent reception. Others are on the low end of the scale. So, expect expectations have to be realistic. Results are going to vary.

The mean age of the recipients that we have studied is 45 years of age: males at 45 years of age and females at 45 years of age. This study was focused only on adults, not on children. Many more females are receiving cochlear implants than males. Many more women are receiving cochlear implants. And I think that this sort of fits with a lot of other services. Women are much

more apt to go out and seek services that help in general. They are much more active and responsive to their hearing loss and men have a much stronger, macho denial.

In our study, we found that 50 percent of those who received a cochlear implant had a progressive hearing loss. 75 percent were married, and that 52 percent had identified themselves previously as hard of hearing. Now, what's the significance of that? Well, number one, people who are going for cochlear implants, 50 percent of them had been identified as hard of hearing with a progressive hearing loss. Number two, because of the marital situation, families are involved. So, every time you are doing a cochlear implant and consulting with an individual, you are also really talking to a family.

What are the complaints in regard to cochlear implants? One, the lack of pre-implant preparation. Out of 150 people that I interviewed, one of the key complaint factors was that they weren't appropriately prepared. Some of them had never seen the instrument itself and didn't understand how it worked. Number 2, was realistic expectations. What were they expecting from a cochlear implant? It should be real. Then thirdly, a need for a rehabilitation program. By that I mean a language-training program. We need a package from the companies to help us to create rehabilitation for those who have received a cochlear implant; a language listening and improvement program.

There are definite other factors that contribute to success however. First, fear of what might happen leads to denial, delay, in receiving a cochlear implant. The family whether it was supportive or non-supportive was a key factor and then the concern of the implant will affect the ability to function both at home and on the job.

NANCY HAMMONS: Studies are important but the truth also comes from recipients who share their stories with you. So today that is what we are going to do with our discussion, and I want you all to have the opportunity to ask them questions.

PARTICIPANT: I have had my implant for just a little over six years. I have the Nucleus 22. Things were still in research stage at that time.

Just to give you a quick background, I lost my hearing the first time at the age of 3 and a half. I was then hard of hearing but pretty stable until I got out into the work force and that's when it started going down. Six years ago, it bottomed out completely. They could not measure anything. Living and working in a hearing environment I had to make a decision on what I was going to do. I had been told about two years before about the technology, and so, I got the implant in May of '95. And it has been wonderful. I could participate in almost everything at work. The only problem is I have is on the phone. I don't have any trouble at home, it's quiet, but at work it is so noisy. I train all the people I work with to answer the phone.

PARTICIPANT: I have only had my cochlear implant for about five months. I started to lose my hearing almost three years ago from an autoimmune disorder. It went up and down, up and down for about two years and then right around new years of this year, I reached a point where hearing aids were not helping me, not even the most powerful ones. At that point I got an evaluation for an implant and then actually got it in April. It was really an easy decision for me as it was something I had been thinking about this whole time. So, when I finally reached that point when hearing aids were not helping, I said okay, I want to do this. So, I was just a very easy decision for me.

I have the clarion, using the behind the ear model and it's been great. I have been able to talk on the phone, sometimes it's a little hard, and I don't pick up the phone without thinking about it first, but it's manageable and it really has been an amazing change for me.

PARTICIPANT: I received my cochlear implant about six months ago. I was born with my hearing loss. I think that what motivated me most to get a cochlear implant was that once I finished college and entered the work force, I found it difficult to communicate with people. I saw people I graduated with getting ahead, getting promoted, and I was still at the same level. It was difficult for me to attend meetings. A cochlear implant was something I never thought I wanted. I was part of the deaf community. I signed. My husband is also deaf. I just figured I had nothing to lose and I didn't have a lot of expectations for my implant. I had it hooked up, didn't think too much about it. After the first couple of days, I start being able to connect to sounds that -- I was hearing people's

voices, with environmental noises around me. I could identify things after awhile, and then I realized that I could understand people who are speaking to me without looking at them.

Having my cochlear implant has really changed my life; made it a whole lot easier and I'm very happy to have it. Before my implant, my life was about guessing what people were saying, guessing what was going on.

PARTICIPANT: I lost my hearing overnight. Mine was not a progressive loss. I was implanted six months ago in Dallas and -- I have been happy and thrilled with it. And I think I chose to have the implant because the high power hearing aids didn't really help me. I had a really hard time deciding. So, if you are having a hard time, I can sympathize with you. I had a hard time choosing which implant company to go with and eventually went with Med-El, but it really has added so much more depth to my life. One of my favorite sounds to hear, is when you open coke and you pour the coke, the ice in the glass, it makes a fizzing sounds. It just blows me away that I can hear that. It's exciting and I'm still learning and making progress.

PARTICIPANT: I first found out I had a profound hearing loss at the age of two. I first found out about the cochlear implant ten years ago. And I have a nephew who has a hearing loss. And my brother found out about the cochlear implants on the internet. I saw the results of my nephew with the cochlear implant who was implanted at five and is now nine. It amazed me how well he did. He is even talking on the phone, and made me realize that maybe I should consider getting one. I have now had my implant 7 and a half months, a nucleus 24, because I like the design and the behind the ear option. The day I got hooked up, I was very overwhelmed with all the noise that I was hearing. I could not believe how much I could get with the cochlear implants. I loved music, and now, I listen to music, I hear the words and I can understand the words. And it's been a great experience for me.

I just bought my first cell phone two days ago, as a matter of fact. I called my mom and she was really amazed. I think this is the best thing that ever happened to me. I'm learning every day. And it gets better every day. And I would encourage everyone to get a cochlear implant.

PARTICIPANT: I have a Nucleus 24 implant. I have had it for ten years. I had a progressive hearing loss, but I functioned, hard of hearing, lip reading, struggling, for many years. Eventually I went to Gallaudet University, I learned sign language, but I was considering an implant.

After one year of college in the graduate program, social work, at Gallaudet, I decided that I wanted to also work with hard of hearing people. But at that point I could not communicate with hard of hearing people. So, I decided to get the cochlear implant. This was at a time when there was a lot of negative reaction, negativity about people having cochlear implants. I was very interested to see the responses of the other students. I felt they accepted me because I was an adult, but also because I really wouldn't listen to what they had to say about it. I was still going to have the implant, regardless. I finished Gallaudet, started a job, and actually, in the first year of the implant, I was using the phone. I talk to my sons for the first time in their lives, at that point. And it was a very moving experience. I have three sons, and they could even call me and I could identify which voice I was talking to. I was enjoying music. The implant continues to get better and better. And in my work, I was talking to anyone, everywhere. I didn't even know these people. I was able to understand them.

Then after seven years I started experiencing problems with the implant. It finally stopped working. I went for about four months of testing, trying to figure out what was going on--whether it was internal or external. And it was internal. I learned later that only one percent of the implants fail, and I just happened to be one of the one percent. But believe me, the decision to be deaf or to have an implant was never a question in my mind. I said as soon as you can, I want to be re-implanted. That was two years ago. I was re-implanted. I just had my first conversation with my sons again on the phone. So, I'm getting there. It's taking me a little longer this time. And possibly that's because of age. I'm absolutely thrilled.

Don't let this story deter you from getting an implant. It can happen, but it's wonderful what you get from the implant. Thank you.

AUDIENCE MEMBER: Do any of you know other implant users who are really not happy?

NANCY HAMMONS: In the nine years of my experience, I have never, I can honestly say this, I have never met somebody who was disappointed in having an implant. Five days ago, I visited my son, one of his roommates has a cochlear implant, and he was not wearing it and said that it was because none of his friends understand. So, this was really the only person that I have met who was not happy. But he didn't say he wasn't happy with the implant itself, it was more of an identify acceptance for him. And in some of my research, I found regarding children who have been implanted in their teens, there is some rejection of the implant due to peer pressure, but they go on to adapt to their implants later.

PARTICIPANT: I don't know of anyone unhappy either but I think it's Important to remember that you don't know going in how well it's going to work, I was cautioned again and again by the audiologist, and other people who have implants, you have to keep in mind you don't know how well it's going to work. It sounds like we have all been lucky. But there is no way to predict how well it's going to work.

TOM GOULDER: In our research of 165 people, there's only been one person who said he wouldn't do it again. But, again, there are conditions to that, that he went, when he was hooked up, got his first mapping and never went back. His expectation was that he would hear normally right away.

NANCY HAMMONS: If you are interested in getting an implant, do your research. There are resources on the net, go on line to chat rooms and talk to people who have implants. Check with your insurance. But you do not get an implant without doing research. I can't say this enough, it's a personal choice. It's your personal choice and you shouldn't care about what somebody else thinks.

AUDINECE MEMBER: With the implant what was your biggest disappointment?

NANCY HAMMONS: Taking it off.

PARTICIPANT: I have never been disappointed. I love it. I can't wait to put it on, first thing in the morning. It's not an overnight miracle. I think the first year it's critical for everybody, because

everybody learns differently. It's amazing, I hear things that I don't even know what it is, and I have to ask people, what is that sound? And it really works. And like I said before, I did research for ten years, I didn't think it would work. But now I'm living proof, I can tell you that it works. That's why I'm here. I'm volunteering for CI, I didn't want anybody to wait ten years. I think the sooner you get it, the better it is.

DOCTOR TOM GOULDER: Those who get the greatest gain are those that have had a progressive loss and who had a language base in prior to losing their hearing. So, how we process language is a critical factor in recipients. And as a result the most frequent ones being implanted and the ones having the most success are those who have experienced progressive loss. Those who are born profoundly deaf and have heard very little of sound or of language, over a period of years, are going to have more difficulty because they have no language base within the brain structure, so, they have to start off somewhat as a child would start off in learning what these sounds would mean. The main complaint of those who are struggling with interpreting sound is that we do not have a legitimate language development program for cochlear implant adults. We do have it for children.

AUDIENCE MEMBER: Can you sleep with the processor on?

PARTICIPANT: You can if you want to. There is no reason why not other than comfort.

AUDIENCE MEMBER: Are the speaking voices of deaf people improved by the implant?

NANCY AHMMONS: I grew up hard of hearing. Even with my implant, I still don't say the s's appropriately. But it is like reprogramming. Somebody who is deaf that has the implant will never perfect their speech, but they will be able to speak more clearly.

PARTICIPANT: When I got my implant, my goal was not to speak like a hearing person. That didn't cross my mind. I know that I do speak better with the implant than I ever spoke with my hearing aids. I know that because people tend to understand me better. I'm asked to repeat myself

less often. To me I sound normal, but to other people, I think they can still detect that I have a hearing loss.

AUDIENCE MEMBER: What about nerve damage to the face as a result of the surgery?

NANCY HAMMONS: My surgery was nine years ago and my surgeon explained the process that they were using and technology and science improves every year. They have instruments that are attached to the facial nerve so that when the doctor's instrument comes close a light blinks. So, they are very, very careful in these days today. Honestly today that's a thing of the past.

Nancy Hammons has a rich diversity of deafness and hearing loss in her family for the past six generations. Raised in a bi-cultural family (deaf and hearing) she experienced the transition of progressive hearing loss from her early teens to become fully deafened as an adult. She currently serves as ALDA Regional 4 Director, Cochlear Implant support Co-ordinator for Northern California. She presents workshops and training nationally on cochlear implant and diversity of deafness. She is a certified trainer "Living with Hearing Loss" Gaulladet University, 1993; Para professional Geriatric Training Santa Clara County Department of Mental health and Aging, 1994. HammonsN@aol.com