## Cochlear Implants:

The Journey To Hearing

Diala Ayaad



Cochlear Implants: The Journey To Hearing
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ISBN 978-9957-67-291-1
2871/6/2019

# Cochlear Implants:

### The Journey To Hearing

This book is dedicated to all those who still suffer from hearing loss,
to my loving parents and brothers,
to my amazing aunt
and to MED-EL.

By Diala Ayyad

"Every child has the right for education, it's a human right. If you can't hear you can't exercise that right.

It's a big challenge for society across the world to provide hearing aids and hearing implants to those who can't hear.

We want to achieve this by providing implantable hearing solutions, not only the devices, but also the support all around it. This includes the preoperative stage, during surgery and afterwards where rehab is really important to get the maximum benefit"

#### **Ingeborg Hochmair, MED-EL CEO and Founder**







#### Introduction

Life is full of contradictions: smiles and tears, pain and cheer. Of all feelings though, hope is what keeps us going; the hope that despite hardships, everything will work out in the end. For those who suffer from hearing loss, they have hope that one day they will hear.

Another important feeling is control; it is integral to our psychological well-being and is in a way related to hope. Many of the most frustrating situations in life are those where we have no say or sway over events that affect us. Again, a little control given to those who have problems with hearing is important to their well- being; this is what cochlear implants are essentially about: hope and control for those who may feel they have been given neither.

This journey started for me when I was at school and my cousin was diagnosed with profound hearing loss in his left ear and severe hearing loss in his right ear. He has always been dear to my heart, not only because he is my cousin, but also because he has a unique personality that distinguishes him from any other child. That is why I made the decision to study hard and specialize in cochlear implants; I was driven to gain all the relevant knowledge I needed to help him. After university, I worked for an exceptional company that opened many doors for me; of course, I became responsible for his medical condition and started the process of arranging for his cochlear implant.

It was not easy, not easy at all. I went through the process with him step by step; all the emotions, setbacks, family reactions and medical procedures. On top of all of that, he had some additional medical issues that we did not foresee, but he fought through them bravely, as did we.

This experience had a huge impact on me and helped me understand my patients from a unique perspective; when I tell a patient that I empathize with what they are going through I really mean it.

My experiences in this field have driven me to write this book so future cochlear implant recipients can get to know the stages, the body acceptance and other steps involved in taking this journey. I wanted something that patients can read with their families, something to support patients with hearing loss who are considering cochlear implant surgery, but are getting cold feet.

Something for those who decide to take the journey but stop half way through with tons of questions on what's happening to their body. This book is for all those people, and I hope it will help make the journey to hearing.

#### **Life Changing Technology**

Every time I meet with the parents of a child with hearing loss, my heart beats a little faster when I'm faced with the question they always ask. I take a second to think about whether there is better way to respond. I take a deep breath; my palms begin to sweat. I know that what I'm about to say will stun them. They don't expect to hear that there is a solution, a guaranteed life changing technology to restore hearing to their child. Their joyous faces afterwards are one of the many reasons I do this.

#### **Hearing loss**

According to the World Health Organization a person who is not able to hear as well as someone with normal hearing – hearing thresholds of 25 decibels (*The decibel is the unit used to measure the intensity of a sound*) or better in both ears – is said to have hearing loss. Hearing loss may be mild, moderate, severe, or profound. It can affect one ear or both ears and leads to difficulty in hearing conversational speech or loud sounds.

Hard of hearing refers to people with hearing loss ranging from mild to severe.



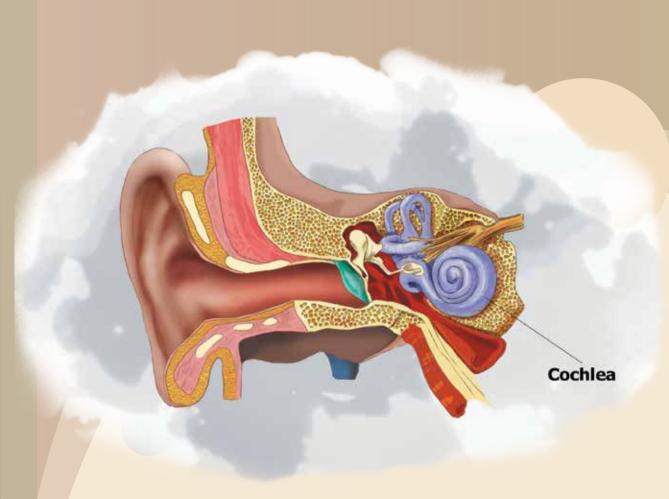
People who are hard of hearing usually communicate through spoken language and can benefit from hearing aids, cochlear implants, and other assistive devices. People with more significant hearing losses may benefit from cochlear implants.

According to the American Speech-language-Hearing Association hearing aids do not help everyone with hearing loss. A cochlear implant may be an option.

#### **Cochlear Implant**

A cochlear (koe-klee-er) implant is a device that can help if you have a severe hearing loss. It allows you to take in information through your auditory nerve. It does not, however, lead to normal hearing.

Cochlear implants are used in cases of sensorineural hearing loss; This means is that the hearing loss, or deafness, is due to a problem in the inner ear that includes the cochlea. The cochlea is made up of hair cells; they allow us to hear, when those hair cells are damaged, they cannot send sounds to the auditory nerve anymore. A cochlear implant skips around the damaged hair cells and sends sounds right to the nerve.



Cochlear implants are not new. The FDA first approved cochlear implant devices for adults in 1985 and children in 1990.

The number of people who use cochlear implants keeps growing. More than 324,200 people across the world have cochlear implants.

(Source: National Institutes on Deafness and Other Communication Disorders, 2017)

I will never forget the first cochlear implant surgery I attended, I was amazed by the whole process and since then I never stopped beliving in this life changing technology.

#### **Cochlear Implant Components**

The cochlear implant system consists of two major parts; an external part called the audio processor. The audio processor selects and arranges sounds picked up by its microphone, passing them on to the second part: the implant itself. The audio processor has different designs; you can choose the best match for you and parents can choose the best match for their child. Each design has its features and you can always go for the discreet hidden under the hair design.



The implant is internal part, receiving signals from the audio processor and converting them into electric impulses. This implant has an electrode array, a group of electrodes, that sends those impulses to different regions of the auditory nerve.



#### **Cochlear Implants VS. Hearing Aids**

While most people with hearing loss are quite successful with hearing aids, there are some individuals with severe to profound hearing loss for whom hearing aids do not provide enough benefit. For these people with severe damage to the sensory cells in the inner ear, a cochlear implant is often the best option for better hearing. Both children and adults can make exceptional candidates for cochlear implants depending on the hearing loss. Candidacy requirements have expanded exponentially thanks to ongoing research. As a result, cochlear implant candidacy is usually determined on a case-by-case basis.

Children who receive cochlear implants when they are very young make greater gains in acquiring age-appropriate language skills than children implanted when they are older. Cochlear implants differ from hearing aids as they bypass the damaged hair cells in the cochlea and directly stimulate the auditory nerve. Some speech sounds, such as "s" are never heard by children with severe-to-profound hearing losses because hearing aids cannot make the sound loud enough, or because there are no longer cochlear hair cells left to transmit the sound. Often when kids get a cochlear implant, the first change you'll see is the ability to pick up "s". They hear these soft speech sounds and it's so evident.



#### **First Steps... Hearing Tests**



The process of getting a cochlear implant begins by performing audiological tests to make sure that the implant is the right solution for the patient.



Several types of hearing tests are required before hearing loss is diagnosed and children can be tested for hearing loss at any age.



Comprehensive assessment is necessary to evaluate both children and adults for their suitability to receive a cochlear implant.

#### **Cochlear Implants Candidate**

Luckily for all involved, the general candidacy guidelines for implants have expanded significantly since they were first approved by the FDA to include the following, from the American Speech - Language - Hearing Association:

Children with hearing loss as young as 8 months old can be eligible for a cochlear implant. Experts recommend implantation as early as possible to expose children to sounds during the critical period of language acquisition.

Children are considered viable candidates when they:

- Have profound hearing loss in both ears
- Get little or no benefit from hearing aids
- Are healthy and any medical conditions would not compromise surgery
- Understand (when able), along with their parents, their role in the sucessful use of cochlear implants
- Have support from an educational program that will emphasize the development of auditory skills.

Adults may qualify for cochlear implantation regardless of whether they lost their hearing before or after learning language. Those adults who developed language before losing their hearing (postlingually deafened) typically have greater success with cochlear implants than those who had not developed language before losing their hearing (prelingually deafened).

Adult candidates are generally eligible for an implant if they:

- Have severe or profound hearing loss in both ears.
- Get little or no benefit from hearing aids.
- Have no medical problems that could put them at risk during surgery.
- Have a strong desire to be part of the hearing world and communicate through listening, speaking, and speechreading.

#### **Getting Prepared**



If the candidate meets the guidelines, tests needed for the surgery are performed; if the results are positive, then talking to a professional about what will happen after the implant is a very crucial factor. It is important that the patient and his family understand what the implant can and can't do. They also need to understand what they will have to do to make the implant work. This applies to both children and adults, but since most of my implanted patients are children, this step is usually for parents at my office.

What do they need to know? The surgeon will make an incision (a small cut) behind the child's ear. The surgeon will place the implant in the inner ear. The incision will leave a scar that will fade with time. The implant may make a small bump under the skin behind the ear. Most children go home the day after the surgery.

Your child's hearing will not change as soon as he or she has the surgery. The change won't happen until the implant is turned on around 4 weeks later. This gives the ear time to heal.

A cochlear implant can improve how well your child understands speech and speaks. It will not give your child normal hearing. How well your child's implant works depends on many things. These include how long your child has been unable to hear and how well his or her auditory nerves work. You and your child will work with a speech therapist after programming the processor to learn how to make the most of the implant.

I want to tell each and every parent, teenager, adult or eldery that you have the right to know all the information and details you need before your surgery, so please ask as much as you need, visit the audiologist, the surgeon and the speech therapist before the surgery and try to answer all your questions and concerns, so you would enter the surgery with peace of mind, and always remember to stay in close contact with your cochlear implant team throughout this journey, as they will be able to offer you detailed information and medical advice, specific to your case.

#### **The Surgery**

Surgery is next.
The surgeon will implant the receiver and electrodes. Time will be needed to heal from that before you can turn on the implant.



Cochlear implant surgery is typically performed under general anesthesia.

The surgeon will make a small incision behind the ear and sometimes a small area of hair may be shaved away from the incision site. The surgical team will perform tests during the surgery to measure the response to the implant.

#### **Flipping The Hearing Switch**

Around four weeks after surgery, the external parts are added. Audiologists call this day the "Switch-on Day"; I like to call it the "Beeps Day" because the first thing the patient hears are beeps from the computer.

An audiologist will program the implant, which may take a few visits to complete. During these visits, the audiologist gives instructions on how to use the processor and take care of it. I usually tell parents to welcome this new family member, the processor, into their home as this device will have an impact on the life of the whole family and not only the child's. After that, visiting the audiologist at least once a year for checkups is important.

#### **Programming The Processor**

The journey from silence to sound begins when the implant processor is activated two to four weeks after surgery. Hearing sound through a cochlear implant during those first months is often unstable as thresholds change, and unpredictable as the quality of sounds change. The first sounds have been described like speaking through a microphone, like ducks quacking or just plain "weird".

How is it programmed exactly, you may ask? Each electrode along the array is stimulated one at a time. The first step the audiologist takes is to find the upper level of stimulation by stimulating each electrode individually and raising the current to find a level that is the most comfortably loud.

The second step is to find the lowest level of current needed to barely hear a sound to establish a threshold, and then finally balancing the level of current across all electrodes.

There are different strategies an audiologist can use that determines the way that the electrodes are stimulated.

For small babies with limited language skills, the process of programming the processor can be challenging and time consuming. Programming of the processor takes a month at least through weekly sessions, allowing us to find out what works best.

"Mapping" is a new term you will hear, it is used by audiologists to describe how we have set the audio processor of a cochlear implant to provide sound to your child; imagine the internal part of the cochlear implant as an electric organ keyboard. I have to set each electrode to play a particular note loud enough for your child to hear and to make sure it is never too loud. The softest level for your child to hear is called the T level (*threshold level*) and the upper level is the C level (*comfort level*). The T and C levels are different for each child. The audiologist sets these levels over several sessions. So, the way that a particular audio processor is set for a particular child is called his/her "MAP". The first day of Mapping is sometimes not as exciting as anticipated.

This first MAP may be conservative so that a child can get used to the new sounds. New sounds usually have no meaning to a child at first, and he or she will require many experiences with sounds before they start to have meaning. There may not be many observable differences in your child after the first day of Mapping; that is fine though, as it's going to improve gradually. All parents need to understand that programming is not clicking a button, it takes time. But if you listen to the audiologists' instructions and pay attention to your child you will be able to accelerate the process of reaching the perfect program for your child; be patient and trust the system.

#### Step By Step...Rehabilitation



A cochlear implant recipient will not hear right away. Treatment is needed to help figure out what the sounds are and what they mean; this is called rehabilitation. During this rehabilitation period seeing an audiologist and a speech language pathologist (*SLP*) is crucial. Rehabilitation is very important to help the patient learn to listen and speak clearly.

Most recipients successfully learn to use their cochlear implants, but it takes time and hard work.

Technological advances have brought dramatic changes in candidacy criteria, opening the door for more people with severe and profound hearing loss to choose this option; despite this, they need to know that practice and patience are the two factors they'll need to hear and understand spoken language.

Cochlear implants are not a miracle cure for deafness. There is a lot of variability in cochlear implant outcomes: acquiring

language development skills equivalent to peers and improving language development skills but not reaching the language levels of peers just to mention a few. This variability depends on the date of deafness onset, age at implantation, the presence of other medical issue and more.

Programming the cochlear implant processor is just the first step. Getting an implant is like being given the keys to a car but not knowing how to drive it. Rehabilitation is the key to helping children interpret sound in their environment and use it in a meaningful way to acquire spoken language. The rehabilitation process begins even before the programming of the child's processor is complete; this is to establish a readiness to listen. Through structured play, the child is taught to react to loud, low-frequency sounds from various locations within the room, and to understand that speech has a purpose and makes things happen. After programming, rehabilitation serves a dual role in promoting the development of speaking and listening skills and assessing those abilities to provide feedback to the audiologist about the cochlear implant speech processor settings.



Parents play an important role in rehabilitation and they are their child's primary teacher. Whenever possible, parents should be active participants in therapy sessions, and try to weave listening and speech learning into activities throughout the day. Coordination between school teachers and parents is also very helpful as school personnel often have little experience with children who use a cochlear implant, making it very important that parents provide information about how an implant works, the auditory cues an implant provides, and the development of auditory skills with an implant. Schools, in turn, can assist the parents, speech language pathologists and audiologists by providing information about the child's development and language use in the classroom.



Children derive the greatest benefit when they are implanted early and receive appropriate family-centered therapy and support.

Rehabilitation targets are set step by step after evaluation and reviewed with the parents in a plan that includes long term and short-term goals. Speech therapists will work on these goals in sessions and parents will have to generalize these goals in life. A child's weaker areas can be specifically addressed and worked on. Collaboration with parents is crucial in this process, because they are the most important therapists in their child's life and must continue with the intensive rehabilitation process at home.

At the beginning the child will learn to hear. This period is not long and is the part of the process which focuses on auditory through detecting a sound, localizing a sound and then discriminating the speaker. After that, the process of verbal rehabilitation starts in two parts: working on receptive language and working on expressive language.

Rehabilitation for children begins shortly after the implant is activated. Speech rehabilitation centers require that families commit to a rehabilitation plan for the child in order to maximize outcomes. Each rehabilitation session tends to be an hour long. Goals and objectives in the plan are tailored to meet the individualized needs of the pediatric and adult patients. In the rehabilitation sessions, therapists empower patients (children and parents, adults and their support network) to understand and advocate for their personal communication needs.

Parents nowadays can easily find materials online that are specifically developed for the needs of implanted children of different age groups. They can also find tips, tricks, exercises and many other approaches that they can use at home to maximize the benefit from the rehabilitation sessions. Speech therapists and audiologists give significant counseling to parents, as they are a key element in successful implanting stories. No matter what age a child is or what their parents' financial capabilities are, those around them can help to make a difference.

#### **Adult Recipients**

For adults, getting a cochlear implant brings changes in their communication abilities and their relationships; most people have been dependent on a family member for a considerable part of their life and the cochlear implant changes these relationships. Adults also need practice in listening without visual cues; rehabilitation provides a more focused approach in building on the auditory information they already have achieved through hearing aids, and it will help them learn to listen with the implant much faster.

While the cochlear implant provides access to sound, understanding takes more than just hearing. Intensive individualized habilitation (intervention for patients who have never heard before) and rehabilitation (intervention for patients who are learning to hear again) allows for optimal gains for all recipients. Once the cochlear implant is activated, sound can be heard but the brain does not automatically make connections with meaning. Time and practice is needed to adapt and assign meaning to the new incoming sound provided by the cochlear implant, as understanding occurs in the brain.

#### **Getting A Cochlear Implant**

I know that every patient's decision to get a cochlear implant carries weighty medical and social implications, and even stigma in our culture, but the wonderful results of cochlear implants for all ages are increasing our faith in this solution more and more every single day.



I have seen parents hesitate to get a cochlear implant for their child, even though early implantation results in the development of speech perception and the acquisition of oral language; basically, the earlier the implantation, the better the chances of success. Early implantation enables hearing to be put within a behavioral framework by allowing the hearing modality to interact with the environment which provides constant feedback. This is a prerequisite for appropriate learning.

I know that the idea of going to the surgery can be frightening for a few people, and the time leading up to surgery can be nerve-racking and full of anticipation for many. I advice to reach out for cochlear implant recipients, as they may be able to share their experiences with you and offer some further support and advice.

#### **Cochlear Implant Invention**

Cochlear implants and hearing restoration were thought of as science fiction just decades ago; thanks to great men and women of science who never gave up, the dream is now a reality.

#### **How It All Began**

The first cochlear implant was invented by William House in 1961. In 1964, Blair Simmons and Robert J. White implanted a single-channel electrode in a patient's cochlea at Stanford University.

The modern multichannel cochlear implant was independently developed and commercialized by Graeme Clark from Australia and Dr. Ingeborg Hochmair and her husband Prof. Erwin Hochmair.

Ingeborg Hochmair, holding a PhD in electrical engineering, is being recognized for her early contributions to the field of cochlear implants starting with the development of the word's first multi-channel microelectronic cochlear implant that was implanted in Vienna in 1977. This implant included a long, flexible electrode, which could, for the first time, deliver electric signals to the auditory nerve along a large part of the cochlea, the snail-shaped inner ear.

With a modified version of this device, the next milestone in cochlear implant development was reached in 1979: the understanding of words and sentences without lip-reading in a quiet environment via a small, body-worn sound processor. The young recipient, a pioneer herself because she devoted much of her time to cochlear implant research, has enjoyed open speech understanding via a small processor for the past decades.



Intense and continuous innovation followed, including the development of the world's first behind-the-ear (*BTE*) cochlear implant audio processor in 1991.

The next major advancement was the development of a high stimulation rate cochlear implant designed to implement a new speech coding strategy developed by Blake Wilson.

From 1994 forward, this device took its users to the next level of performance. It became the first device with which the majority of post lingually deaf adults achieved more than 50% monosyllabic word understanding within 6 months after implantation. This meant that the majority of those implanted could now have conversations over the phone about unknown topics with an unfamiliar speaker.

Respect for the cochlea and its delicate structures have guided Dr. Hochmair's research and development activities towards a highly flexible electrode array preserving the delicate structures of the cochlea despite deep insertion into the cochlea.

During recent years, Dr. Hochmair and Wilson have collaborated on current topics such as the benefit of bilateral implantation, combined electric and acoustic stimulation, and cochlear implants for single-sided deafness.

The cochlear implant was, and remains, the first replacement of a human sense, the sense of hearing. Dr. Hochmair's intellectual rigor, pioneering spirit, and life-long drive toward excellence have transformed many lives around the world.

Dr. Hochmair said in 2013: "Technological advances have accelerated our research at an unbelievable rate. We are on the threshold of breakthroughs that would have been considered dreams not long ago. After so many years, hearing restoration continues to be a miraculous field, and I still feel a sense of urgency to help improve the quality of life of deaf people. I am honored to have been a part of the development of this life-changing innovation, and look forward to continuing our strong tradition of advancing our technological and scientific foundation in the field of hearing implants for many years to come".

#### **Developing The Technology**

Imagine you have bought yourself a new computer; the computer hardware is the part of the cochlear implant in your head; the computer processor is the external audio processor and the software is the program which is adjusted through a series of mappings with the audiologist. Developers bring out upgrades in the form of software to improve hearing functionality; for example, they try to reduce background noise to provide greater speech clarity and ease of listening in noisy environments.

The advancements developed over the last 30 years were made by evolving technology and by close collaboration between engineers, surgeons and audiologists. The technology evolved from a ceramic to a titanium and silicone casing, from 8 to 16 or 24 active electrodes, from big, body-worn sound processors to single-unit processors or behind the ear processors.

Cochlear implants have come a long way in their 40-year history, and many advances remain to be made. Researchers are already looking into making the technology more accessible and the outcomes more consistent.

#### **Small Audiologist, Big Dreams**

From a young audiologist's perspective, the most important thing I wish cochlear implant recipients to know is that every one's brain is different. That means you cannot predict how well you will do but you can know one thing for sure: implanting is part of the solution and most of the work depends on you and your mental attitude coupled with a lot of practice; the more you practice the better the discrimination of speech becomes. For some clarity happens straight away and for others it takes time, so just believe in yourself, be optimistic, and stay positive.

#### **Epilogue**

Illusion is half of the illness, Peace of mind is half of the medicine And patience is the first step of healing.

Cochlear implantation is becoming a more common medical intervention in treating deafness, particularly in individuals who lost their hearing after acquired speech and language; postlingually deaf.

Despite all the unquestionable benefits of a cochlear implant for adults, not all cochlear implant users deal completely with the psychological trauma of hearing loss.

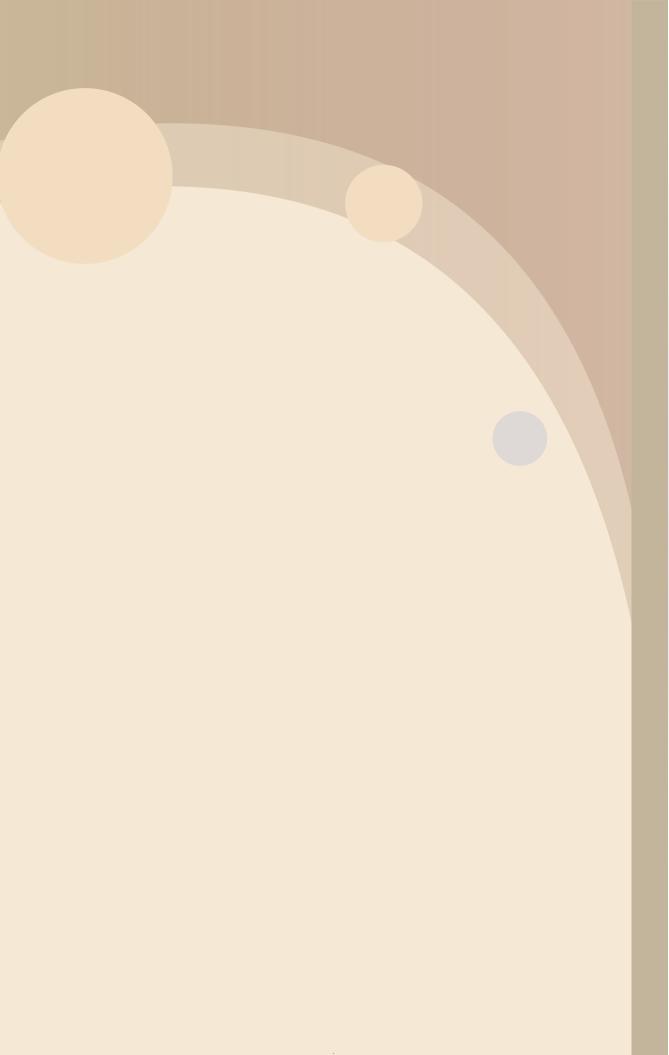
There are some non-audiological factors that should be taken into consideration when caring for recipients: psychological distress, social pressures, and self-esteem. We should strive to support patients and give them the advice and understanding necessary to deal with these issues. Despite the hardships, the results observed and documented from adults and children with cochlear implants indicate that most are successful users.

We need to guide cochlear implant recipients from all ages through the process of improving their ability to enjoy communication with their family, friends and co-workers.

To parents, a cochlear implanted child is going to remember who was there; kids outgrow toys and outfits, but they never outgrow time, love and support.

Diala

Sincerely yours,





The days when hearing loss actually meant that are over; a technology 40 years in development has made it possible for many to hear... The Cochlear Implant. In this book, audiologist Diala Ayaad talks about the technology, who can benefit from it and how it helps millions around the world to hear again.