The cochlear implant process from candidacy to surgery, a guidebook for parents and teachers

Jill Nichole Hardesty

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THE COCHLEAR IMPLANT PROCESS FROM CANDIDACY TO SURGERY, A GUIDEBOOK FOR PARENTS AND TEACHERS

by

Jill Nichole Hardesty

An Independent Study
submitted in partial fulfillment of the requirements for the degree of:

Master of Science in Deaf Education

Washington University School of Medicine
Program in Audiology and Communication Sciences

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Approved by:
Lynda Berkowitz, M.S., C.E.D., Independent Study Advisor

Abstract: A guidebook for parents and educators to further understand the cochlear implant process from candidacy to surgery.
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The Cochlear Implant Process from Candidacy to Surgery

Introduction

While working as a student teacher this past year, I observed different families working their way through the process of getting a cochlear implant for their child. Many parents seemed overwhelmed at the amount of information that was given to them. The families expressed confusion about the cochlear implant process as a whole, and what is required. In addition, these families still may have been dealing with the diagnosis of their child’s hearing impairment. Beyond adjusting to and accepting this diagnosis, they are thrown into a whole new world of cochlear implants. The process of getting an implant is daunting and I observed some families struggle with the many decisions that they were facing. I got a sense from these parents that they had little involvement in the cochlear implant process other than showing up to appointments and that they were left at the mercy of the doctors and other professionals to tell them what decisions would be best for their child.

As I watched these parents go through the process, I realized they could benefit from additional knowledge and guidance. I thought a guidebook of information that is easy to understand and that can be followed in a progression might be helpful. My objective was to provide a parent-friendly guide that would include, a history of the cochlear implant, a brief overview of how the cochlear implant works, candidacy, initial consultation, audiological/speech perception evaluations, medical evaluations, psychological consultation, rehabilitation consultation, choosing a cochlear implant, suggestions of questions parents might ask, and scheduling of the surgery.
A Brief Literature Review

Parents of children with a hearing loss are faced with many difficult decisions including, educational placement, decisions regarding assistive technology, and perhaps medical decisions. These issues may cause considerable anxiety and stress among parents. When parents are faced with the decision of cochlear implantation, the choices become even more difficult. Most and Zaidman-Zait (2003, 2005) have studied the needs of parents of children with cochlear implants, cochlear implants in children and maternal expectations, and the impact of the cochlear implants on the family. The amount of information that is available to families going through the process is often difficult to understand, confusing, and sometimes the parents must seek out information from different sources and then try to piece all the information together. Accordingly, Most (2003) suggests that the cochlear implant process involves decision making, surgery, and highly demanding (re)habilitation. Parents often experience considerable anxiety and fear prior to, during, and after the cochlear implant process.

To be considered for a cochlear implant a child must meet the candidacy requirements. There are a few exceptions, but for the most part there are general guidelines that doctors and audiologist follow to determine candidacy as set forth by the Food and Drug Administration. For a child from 12 months to 17 years of age to be considered for a cochlear implant they must have a documented hearing loss in the severe to profound range (http://www.bionicear.com/tour/how_implants_work.asp, 2006). They must also demonstrate a lack of progress in the development of auditory skills with hearing aids. The family must be highly motivated throughout the process and in the future to prepare themselves for the amount of work it takes to help a child make full use of their cochlear implant. They must also have realistic expectations for how the cochlear implant will help their child. The cochlear implant
process requires a commitment from the parents to manage the use of this sophisticated technology and encouragement and support for their child. Additionally, other medical conditions or developmental disabilities, if present, can affect the cochlear implant procedure and outcome. If the child is in poor health or the child has other issues that might make the surgery difficult, the child may not be a candidate for a cochlear implant. “Some centers may not implant children with severe emotional, behavioral, or cognitive delays when it is perceived that these characteristics may prevent participation in the educational/training programs necessary to actualize benefit from the cochlear implant” (Nussbaum, 2003).

The process for getting a cochlear implant typically involves several appointments with many different professionals such as, an otolaryngologist, audiologists, speech-language pathologists, and/or psychologists. This group of professionals makes up the cochlear implant team. These professionals will inform, guide, support, and collaborate with parents consistently so that parents understand the process and have realistic expectations for the future. Yeagle (2005) states that, “during the cochlear implant process there is a great deal of information given to the parents regarding pre and post implantation appointments, types of devices, the surgery itself, and appropriate expectations for cochlear implantation”. Once they review this information the parents may have many questions that may result in few clear-cut answers. Meeting with professionals to discuss the process can help to alleviate some of the stress these parents feel (Most, Zaidman-Zait 2003). Intervention programs are generally designed by the professionals involved in the cochlear implantation process and they base the program on what they believe it should contain rather than what parents actually wish was covered (Most, Zaidman-Zait 2003). Parents believe that information should be customized to the needs of the
family at various intervals throughout the process. Due to the complexity, intensity, and length of the implant process, parents’ understanding of the cochlear implant and support-needs must be assessed at different stages throughout the implantation process (Nunes, Pretzlik, Ilicak, 2005).

Parents can become overwhelmed when selecting a device for their child. Currently, there are three devices approved by the Federal Food and Drug Administration (FDA) for use in the United States. Parents are often concerned about choosing a device for their child. During the cochlear implant process the parent is given an appointment to meet with an experienced member of the implant team and discuss the choice of a device (Seymour, Stott, Lynch, Aleksy, Graham). Here parents are able to discuss the features of the different implants with the team. The professionals will compare characteristics of the implants, present pros and cons of each device, and provide information to take home and read about each device. Families can use this information to help them make informed decisions when choosing a particular cochlear implant.

When parents are misinformed or have unrealistic expectations of the cochlear implant, their expectations of the device might not be fulfilled immediately following the implant surgery. A study conducted by Sach and Whynes (2004) found that parents place high expectations on communication, social adjustments, academics and future change. When going through the cochlear implant process the cochlear implant team tries to help parents understand the “realistic” expectations that they can expect after the surgery and an understanding of how much time and effort the parents themselves will have to put into the (re)habilitation process (Zaidman-Zait, Most, 2005). It would benefit the parents if professionals, during the cochlear implant candidacy evaluation and (re)habilitation, would acknowledge parents’ high hopes and continue to provide the parents with up-to-date information on cochlear implants and focus on parental expectations concerning the demanding post-implant (re)habilitation process (Zaidman-Zait,
Most, 2005). This might give parents a clearer picture of appropriate expectations. Zaidman-Zait and Most (2005) also point out that the cochlear implant team should identify where parents are in the grieving process that is typical among families dealing with difficult issues. Are the parents still grieving over their child’s deafness? What are the parents’ methods for coping with the deafness? These factors may also influence parents’ reasons for wanting the cochlear implant and expectations concerning the outcomes. Accordingly, Zaidman-Zait and Most (2005) reported that parents experienced disappointment several months after the surgery due to their unrealistic expectations that there would be immediate change in their child’s communication skills. It must be emphasized over and over again that speech intelligibility does not improve overnight or even within the first year. However, parents can be reassured that it will improve overtime even beyond 5 years (Sach and Whynes, 2005). It is also important to note to parents that even when their expectations are not initially met, parents are generally satisfied with the cochlear implantation and reported that the device had a positive effect on their child and their family (Nicholas, Geers 2003).

Parents with children who have already gone through the cochlear implant process provide a great resource for these anxious parents. When making such an important decision, parents feel that it would help them to know more about the views of these parents who already have experience with cochlear implants (Nunes, Pretzlik, Ilicak, 2005). Parents whose children have received implants can offer comments of great value to other parents and implant teams alike. Most and Zaidman-Zait’s (2003) study found that the information gathering and the decision making-process must be considered extensively by parents, but with many meetings with the cochlear implant team and the opportunity to meet parents of children who had received
a cochlear implant, parents become better aware that they are not opting for a miracle cure and that much hard work will be necessary for success.

Many parents don’t know what to expect as they begin the cochlear implant process. Yeagle (2005) states in her article that the cochlear implant process consists of several appointments such as, audiological consultation, speech perception testing, CT scans, medical evaluation, device discussion and others. However, this process is not the same for everyone and can be very different for children than adults.
Method

In order to compile this guidebook, I researched many different articles, journals and websites. I also interviewed parents who have gone through the cochlear implant process with their child. I talked with audiologists to gather information on the tests given by audiologists. I gathered information from the St. Louis Children’s Hospital cochlear implant team and learned through guest lectures on such topics as counseling the parents through the cochlear implant process, parents of children with cochlear implants, and habilitation after implantation.

In order to determine what types of questions parents might want to ask while going through the cochlear implant process, 20 parents were asked to participate in an interview about their experience in getting a cochlear implant for their child, what questions they found important to ask, and which questions they wished they would have asked while going through the process. Ten parents consented to being interviewed. The parents selected to participate had a child with a cochlear implant currently enrolled in an oral school or in a mainstream classroom. All of the children had been implanted for at least 3 months at the time of the interview. Of the families interviewed four of the children were from oral schools located in the St. Louis, Missouri region. Three of the children were from an oral school in Jacksonville, Florida and three of the children were from a mainstream school in St. Louis, Missouri.

Questions asked during the interview included:

- What questions did you ask the cochlear implant team as you were going through the process of getting your child a cochlear implant?

- What questions do you wish you would have thought to ask at any particular appointment?
• What are some questions that you feel that if you were going through it again you wish you would have known to ask?

• What are some questions that you feel would have given you more of a sense of control or power during the process?

• Can you remember a good question that you asked that was not addressed by the professionals until you asked it?

• Do you think if you had a guidebook at the time you found out your child might benefit from a cochlear implant, you would have appreciated the information presented in an easy-to-read, step-by-step format?
Results

Ten people were interviewed for the guidebook on the cochlear implant process. During the interview process the parents that I interviewed were very willing to share their experience going through the cochlear implant process with their child. From those interviews I was able to determine the type of information to include in a guidebook for future parents going through the cochlear implantation process.

Results of the interview questions are as follows:

- **What questions did you ask the cochlear implant team as you were going through the process of getting your child a cochlear implant?**
  - What is the surgery like? How long will it take? What risks and complications are associated with the surgery?
    - How long will my child be sedated?
    - What will my child be like when they are waking up?
    - How many implant surgeries has the surgeon performed?
    - What should we consider when choosing an implant?
    - Where could I get an unbiased opinion about device information?
    - What can we expect from the cochlear implant with our child?
    - What is considered a success?
    - How does the cochlear implant work?
    - Will my child hear what I hear?

- **What questions do you wish you would have thought to ask at any particular appointment?**
- Explain to me what the hearing loss means? What can my child hear? What can’t my child hear? (At initial audiology appointment)

- Is my child deaf, hard of hearing, hearing impaired, can you explain each of these terms to me? (audiology appointment)

- What are some realistic outcomes we can expect from the cochlear implant after the surgery?

- What are some questions that you feel that if you were going through it again you wish you would have known to ask?
  - What will it be like when my child wakes up from the surgery?
  - Is there a parent I can contact who has been through the cochlear implant process with their child?
  - What will the incision look like? Will there be a visible scar?

- What are some questions that you feel would have given you more of a sense of control or power during the process?
  - If my child decides later that he or she doesn’t want the implant can it be removed?
  - Will my child have identity issues? Does the implant make him or her part of the hearing world or the deaf world?
  - What are the pros and cons of the implant that I am considering?

- Can you remember a good question that you asked that was not addressed by the professionals until you asked it?
- Is there ever a time when it is too late for an implant?
- Would you ever not recommend an implant because of age?
- What if technology changes, will my child need a new implant?
- Can my child play sports with the implant?
- Tell me about static electricity and the cochlear implant? How will that affect my child?

**Do you think if you had a guidebook at the time you found out your child might benefit from a cochlear implant, you would have appreciated the information presented in an easy-to-read, step-by-step format?**
- All ten of the parents felt this would have been a beneficial piece of material to have in hand as they went through the process.
**Purpose of the Guide**

A guidebook for parents and educators to further understand the cochlear implant process from candidacy to surgery has been developed based on the information obtained through research and parent interviews. This guide should be helpful through all stages of the cochlear implant process including; a history of the cochlear implant, a brief overview of how the cochlear implant works, candidacy, initial consultation, audiological/speech perception evaluations, medical evaluations, psychological consultation, rehabilitation consultation, choosing a cochlear implant, and scheduling of the surgery.

A list of most frequently asked questions and questions parents felt were most helpful to ask were compiled to help parents know what questions to ask and what questions other parents have asked in the past. In addition, there is a notes section in hopes that in the future parents can take this guidebook along with them to appointments, ask questions, take notes, and keep records. The final page of this guide lists resources that might be helpful as families go through the cochlear implant process.

It is hoped that this guidebook will be a resource for both parents and educators.
Guide to the Cochlear Implant Process for Parents and Teachers

compiled by

Jill Hardesty
Please note that many different sources were used to compile this guidebook. All sources are listed on the reference page at the end of this guide.
Outline of Guide

I. Guidebook for Cochlear Implant Process

   A. History of Cochlear Implants

   B. Overview of how the cochlear implant works
       1. External vs. Internal
           a) What does the external device do?
           b) What does the internal device do?

   C. Candidacy

   D. Cochlear Implant Process
       1. Initial consultation
       2. Audiological/Speech Perception Evaluation
           a) Auditory Brainstem Response
           b) Behavioral Testing
           c) Hearing aid trial
       3. Medical Evaluation
           a) Evaluation by the ear, nose, and throat doctor (otolaryngologist)
           b) CT scan or MRI
           c) Psychological consultation
           d) Rehabilitative consultation
           e) Device discussion
E. Frequently Asked Questions

F. Scheduling of Surgery

G. Resource Guide
Guide to the Cochlear Implant Process

History of Cochlear Implants

The history and development of the cochlear implant as we know them now has been a subject of intensive research over the past four decades. In the late 18th century, sometime around 1790, a man by the name of Alessandro Volta became interested in the electrical methods of stimulating hearing. Using himself as his own study participant Volta connected a battery to two metal rods and then inserted them into his ear. “In his findings he reported that he received the sensation of a boom within the head followed by a sound similar to that of boiling thick soup” (Niparko, Wilson, 2000). This is the first known attempt at using electricity to hear. In 1855 another attempt was made by a man named Duchenne of Boulogne. He stimulated the ear with an alternating current and succeeded in producing a sound which was an improvement, but still not satisfactory.

It wasn’t until the 1930’s that researchers found that putting an electrical current near the ear can create auditory sensation. Because of this, researchers also discovered that electrical energy can be transformed into sound before reaching the inner ear. The year 1957 brought a big breakthrough. Two scientists by the name of Djourno and Eyries provided the first detailed description of the first stimulation of an acoustic nerve with an electrode (Niparko, J. & Wilson, B., 2000). During this experiment it was reported that the person could hear background noise.

People were becoming very interested in the research by the 1960’s. In 1961 a doctor by the name of William House implanted 3 patients with the first cochlear implants. All three patients found they could get some benefit from the implant. From 1964 to 1966 researchers
learned more about electrodes in the cochlea and the importance of the positioning of those electrodes (Niparko, J. & Wilson, B., 2000).

Around the 1970’s implant technology began to improve. During this time, more people were getting implanted, the research was continuing, and the first multi-channel implant was designed. “In cochlear implant systems, the term channel refers to the number of stimulation sites within the inner ear, or cochlea, and is defined by a range of frequencies, or pitch” (Gross, 2002). In a single channel system, all the sound information is delivered to only one channel. This means that all the information is transmitted to a single area of stimulation within the cochlea. “In a multi-channel cochlear implant, systems divide the incoming signal into various frequency bands that are then transmitted to various sites of stimulation spanning the inner ear” (Gross, 2002). The general belief is that multiple channels provide a more detailed representation of sound and, therefore, better speech understanding than just one channel is capable of transmitting (Gross, 2002). In 1984 the cochlear implant was approved by the Federal Drug Administration and was no longer considered experimental.

Over the years, the number of implant patients has grown and the risks have been minimized. Cochlear Implants are becoming more widely accepted and increasing in popularity. According to the Food and Drug Administration 2002 data, in the United States, approximately 13,000 adults and nearly 10,000 children have received a cochlear implant (http://www.nidcd.nih.gov/health/hearing/coch.asp, 2002).
What is a Cochlear Implant and How Does it Work?

For sounds to be heard, the ear needs to send a message to the brain. With normal hearing, the message comes in through the outer ear and passes through a series of parts within the middle and inner ear. In a normal hearing ear, thousands of little nerve pathways transmit sound information from the hair cells up to the hearing center of the brain. With a sensorineural hearing loss there is damage that occurs to the hair cells within the cochlea. When these hair cells are damaged a hearing loss occurs and the ear can no longer function as a normal hearing ear. A cochlear implant, however, is able to bypass the damaged hair cells in the cochlea delivering electrical signals through tiny contacts, or electrodes, to the hearing nerve inside the cochlea, and then the hearing nerve carries the signal information to the brain, where it is interpreted as sound (http://www.bionicear.com/tour/how_implants_work.asp, 2006).

Advanced Bionics, a company that makes cochlear implants, helps to explain the process of how the cochlear implant works. They explain that with each cochlear implant there is a microphone on the external part of the cochlear implant. Sounds in the environment are picked up by that microphone. The sound is processed into digital information through the speech processor. The digital information is then sent up the coil and is transmitted through the skin to the implant. The implant converts the digital information into electrical signals that will cause electrical pulses to stimulate the electrodes that have been placed inside the cochlea. The auditory nerve then picks up these signals sending them to the brain which in turn recognizes them as sound (http://www.bionicear.com/tour/how_implants_work.asp, 2006).

Cochlear implants are made up of two separate parts, an external (outside) device and an internal (inside) device. The external device consists of a microphone, a speech processor, and a transmitting coil. All of these parts are worn outside the body and can be removed. The internal
device consists of a receiver-stimulator and electrodes which are surgically implanted in the head. These parts can not be removed without surgery.
Who is a Candidate for a Cochlear Implant?

According to FDA guidelines, for a child from 12 months to 17 years of age to be considered for a cochlear implant they must have a documented hearing loss in the severe to profound range. They must receive limited benefit from hearing aids and have poor speech perception abilities. “When such measures cannot be obtained on young children, hospital centers make individual decisions regarding whether or not a child would be able to do well on such tests given documented hearing levels and traditional hearing aids” (Nussbaum, 2003). A severe to profound hearing loss means that only sounds louder than 70-90 dB can be detected. Some examples of sounds produced in this range of loudness include: a lawnmower, an airplane, a chainsaw etc. The child must also try to make use of hearing aids first, before being considered for a cochlear implant. A child who is failing to progress in speech, language, and listening development with traditional hearing aids based on parent report and educational information may be considered as a candidate (Nussbaum, 2003). Hearing aids have limitations on the amount of amplification they can provide. If a child with a hearing loss in this range is using hearing aids, it is likely that the child is not receiving significant benefit from them. It is also important to note that for a child to be a candidate, the family must understand and accept the lifelong commitment it takes to keep the implant working and help the child receive benefit from it throughout their life. Family willingness to follow recommendations; enroll in speech, language, and listening therapy; and return for follow-up appointments is a factor in candidacy. Some cochlear implant centers strongly suggest participation in an oral educational setting (Nussbaum, 2003). The doctors must also determine if it is physically possible to implant the device, making sure the child does not have medical issues that might cause problems with electrode insertion in the cochlea or placement of the receiver inside their head. The patient’s
medical status is also a factor that is considered. If the child is in poor health or has other issues that might make the surgery difficult, the child might not be a candidate for surgery. “Some centers may not implant children with severe emotional, behavioral, or cognitive delays when it is perceived that these characteristics may prevent participation in the educational/training programs necessary to actualize benefit from the cochlear implant” (Nussbaum, 2003).
What is the Cochlear Implant Process?

- **Initial Consultation**

  Before you begin the cochlear implantation process, your child typically will have a trial with hearing aids before being considered for a cochlear implant. In general, the audiologist that is providing the hearing aid services to your child will refer you to a cochlear implant center for cochlear implantation evaluations due to limited benefits from the hearing aids. Should you have to contact a site yourself, you can receive help through early intervention professionals. Once you have contacted the implant center you will want to schedule an initial consultation with the professionals there. Most implant centers have a cochlear implant team to provide a comprehensive assessment of your child. The cochlear implant team members differ from place to place, but the following is a general list of who is usually on the team; otolaryngologist (ear, nose, and throat doctor), an audiologist, a speech-language pathologist, psychologist, and a surgeon.

  During the initial consultation, professionals from the implant team inform the families of the cochlear implant process. They may talk about such topics as pre-implantation testing, types of devices, the surgery, counseling, programming, insurance coverage or funding, and the training process after surgery.
• **Audiological/Speech-Perception Evaluation**

During this time tests are administered to determine if your child is likely to receive benefit from a cochlear implant. These tests are performed by an audiologist. Some of the tests that might be administered depending on age and situation are:

1. **Otoacoustic Emissions (OAE) Test**: A measure of how your cochlea responds to environmental sounds. This test helps to determine hair cell function within your child’s cochlea.

OAEs are measured by presenting a series of very brief clicks, to the ear through a probe that is inserted in the outer third of the ear canal. The probe contains a loudspeaker that generates clicks and a microphone that measures the resulting OAEs that are produced in the cochlea and are then reflected back through the middle ear into the outer ear canal.

OAEs only occur in a normal cochlea with normal hearing. If there is damage to the outer hair cells then OAEs will not be present.

2. **Auditory Brainstem Response (ABR) Test**: Measures how the cochlea and nerves respond to sounds up to the level of the brainstem.

With the auditory brainstem response (ABR) test, soft clicking sounds are presented to the ear through small earphones. Sensors placed on the head are connected to a computer that measures brain wave activity in response to sound. Children are generally sedated for this test since movement affects the results.
3. **Pure Tone Test (air conduction):** This test is administered in a sound-proof booth. Headphones or ear inserts are fit on the child. Tones and sounds are played to determine the softest sounds the child can hear (at what level) at each frequency (pitch) between 250 Hertz (very low) and 8,000 Hertz (very high).

Your ability to hear tones at different volumes and pitches is measured when the sound is transmitted through bone and through air. A comparison between these two types of conduction can help determine which part of the ear (outer, middle, or inner) is responsible for the hearing loss. (see bone conduction below)

4. **Bone Conduction Test:** An oscillator (tiny box) is placed behind the ear or on the forehead. Sound is transmitted through the bones of the skull directly to the inner ear, bypassing the outer and middle ear. This testing helps determine if the loss is sensorineural or not.

Bone conduction is tested when air conduction testing shows a hearing loss. Bone conduction in conjunction with air conduction testing can determine if there is a conductive component to the loss. If pure tone testing and bone conduction testing are the same, the hearing loss is sensorineural.

5. **Tympanogram:** This test detects disorders (problems) of the middle ear, tests mobility of the ear drum as well as the bones in the middle ear.

To perform the test, a soft probe is placed into the ear canal and a small amount of pressure is applied. The instrument then measures movement of the tympanic membrane (eardrum) in responses to the pressure changes. A "flat" line on a tympanogram may indicate that the eardrum
is not mobile, while a "peaked" pattern often indicates normal function. One common reason children may demonstrate a “flat” tympanogram is due to the presence of fluid in the middle ear.

- **Medical Evaluation**

  1. **Otolaryngologist (Ear, Nose, and Throat Doctor):** This is the doctor who will usually perform the surgery. This doctor will assess your child’s medical history, evaluate the ears, including a physical examination of the ears as well as making sure that the ear purposed for implantation is free of infection, and the doctor will make sure there are no other medical reasons why the child should not be a candidate.

  2. **Computerized Tomography (CT) Scan:** This is a test to determine if the structure of the internal ear is normal. The doctors will look at the cochlea and auditory nerve to determine whether the cochlea has a normal shape and whether there is bony growth that can potentially compromise insertion of the cochlear implant electrode array. They will also check to make sure the auditory nerve is present. Sometimes during this procedure doctors will seek to determine which ear stimulates best with an electrical signal, thus often times becoming a deciding factor into which ear to implant.

  3. **Magnetic Resonance Imaging (MRI):** During this test a special imaging technique is used to see “soft tissue” within the ear, such as parts of the middle and inner ear.
At the time of the CT scan or MRI your child will be sedated. The doctors must use sedation because the child can not move during this process. The doctors generally give an oral sedative and your child will fall asleep. This procedure is painless and takes about 30 minutes.

4. **Psychological Consultation**: This part of the evaluation involves questions and informal discussion to determine if parents of children considering an implant truly understand how much time, work, and commitment is needed for a child to obtain the greatest benefit from the implant. The professionals will also try to promote “realistic” expectations for the cochlear implant process and outcomes.

5. **Rehabilitative Consultation**: Before implantation, family members will meet with specialists that are trained in speech and language development that may provide services following the surgery. Parents are informed about the habilitation process and the importance of auditory training following initial stimulation of the implant. Professionals will explain activities and strategies that might be used after implantation to promote and develop auditory skills.

6. **Device Discussion**: Professionals will inform you of the three devices available for implantation. They will explain each implant, compare characteristics of the implants, present pros and cons of each device, and provide information to take home and read about each device. Parents can use this information to help them make informed decisions when choosing a particular cochlear implant.
These are a list of evaluations most generally administered. Other evaluations may be given or your child may not go through all evaluations listed above. It is also important to note that depending on your child’s team, these evaluations may take place in a different order than listed above.
Cochlear Implant Process Check List

○ Have you had your initial consultation with the cochlear implant team at your hospital implant center or implant department?

○ Have you had your Audiological/Speech Perception Evaluations?

○ Have you had an evaluation with your Ear, Nose, and Throat specialist?

○ Have you had your CT scan/MRI?

○ Have you had your psychological consultation?

○ Have you had your rehabilitation consultation?

○ Have you discussed and chosen a cochlear implant device?
Throughout the process that parents go through in order to provide their child with a cochlear implant, they will likely have many questions. They may in fact not even know what questions to ask. The following list of questions was compiled from interviews with several parents who had previously experienced the cochlear implant process. Each of the parents had a child with a cochlear implant currently enrolled in an oral school or in a mainstream classroom. While this list is certainly not exhaustive, its intent is to provide parents with a way to obtain important information. Some of the questions may inspire additional questions or concerns that you will want to discuss with the professionals on the cochlear implant team.
Frequently Asked Questions

1. Explain to me what the hearing loss means? What can my child hear? What can’t my child hear?

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2. Is my child deaf, hard of hearing, or hearing impaired? Can you explain each of these terms to me?

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3. What is the surgery like? How long will it take? What risks and complications are associated with the surgery?

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4. What are some realistic outcomes we can expect from the cochlear implant after the surgery? Is there ever a time when it is too late for an implant?

Notes

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5. What do we do after the surgery? How will my child react after the surgery when he or she wakes up? What will the incision look like? Will there be a scar?

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6. How do I know which implant to pick? All of them seem right for my child.

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7. What if technology changes, will my child need a new implant?

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8. What are the pros and cons of the implant that I am considering?

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9. Tell me about static electricity and the cochlear implant? How will that affect my child? Can my child play sports with the implant?

Notes

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10. Where can I get more information about particular devices? Where can I get a completely unbiased opinion?

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11. Is there a parent I can contact who has been through the cochlear implant process with their child?

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Scheduling of Surgery

When meeting with the doctors to schedule the surgery, they will explain the steps of the surgery and then select a time and date for the surgery to take place.

The morning of the surgery your child will not be allowed to eat or drink. Implant surgery is performed under general anesthesia and lasts from two to three hours. An incision is made behind the ear to open the mastoid bone leading to the middle ear. The procedure may be done as an outpatient, or may require a stay in the hospital, overnight or for several days. Today's cochlear implant surgery is a relatively minor operation of just a few hours. Depending on the length of the surgery and other factors, the patient may either be sent home shortly after surgery or have to stay in the hospital for a short while. Children who have had the surgery have been known to go home immediately afterwards, with minimal post-surgical effects. The surgery has the same normal risks associated with any surgery, and serious complications are rare. The implant candidate is anesthetized with a general anesthesia. A small amount of hair is shaved in the area where the surgery will be done, behind the ear. Following insertion of the electrode array and some preliminary testing, the surgical area is closed up with stitches (a small permanent scar may result) and the head is bandaged. In some cases, the stitches will dissolve without being removed or you may have to go back to the doctor in about a week to have the stitches removed. Immediately after waking, your child may feel pressure or discomfort over his or her implanted ear. Other common symptoms can include dizziness, nausea, disorientation or confusion, and/or a sore throat from the breathing tube used during general anesthesia.

During the recuperation from the surgery, after you have gone home, there may be minimal side effects such as temporary swelling.
Resources

Organizations

Alexander Graham Bell Association
for the Deaf and Hard of Hearing
3417 Volta Place, N.W.
Washington, D.C. 20007
(202) 337-5220
http://www.agbell.org

National Institute on Deafness and Other Communication Disorders
1 Communication Avenue
Bethesda, MD 20892-3456
1-800-241-1044 (voice) Monday - Friday 8:30 a.m. to 5 p.m. EST
1-800-241-1055 (TTY)

Cochlear Implant Association
5335 Wisconsin Avenue, NW, Suite 440
Washington, D.C. 20015
(202) 895-2781 Voice/TTY

Beginnings for Deaf Children
P.O.Box 17646
Raleigh, N.C. 27619
(919) 850-2746

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852
800-638-8255 (V/TTY)

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
(301) 587-1788

Network of Educators of Children of Children with Cochlear Implants
Dr. Mary Ellen Nevins, Cochlear Implant Center
Lenox Hill Hospital
186 East 76th Street
New York, New York 10021
212-434-6650 (V)
Educational Audiology Association
13153 N Dale Mabry Hwy, Suite 105
Tampa, Florida 33618
800-460-7322

John Tracy Clinic
806 West Adams Boulevard
Los Angeles, CA 90007
800-522-4582

Cochlear Implant Device Information

Advanced Bionics Clarion System
Mann Biomedical Park
25129 Rye Canyon Loop
Valencia, CA
800-678-2575 (V)
800-678-3575 (TTY)

Cochlear Americas/Nucleus System
400 Inveness Parkway, Suite 400
Englewood, CO 80112
800-523-5798 (V/TTY)

MED-EL Corporation
2222 East Highway 54
Beta Building, Suite 180
Durham, NC 27713
919-572-2222 (V/TTY)
Reference Page


Sach, T.H., & Whynes, D.K. (2005). Paediatric cochlear implantation: the views of parents. *School of Community Health Sciences, b41 Medical School, Queens Medical Centre, University of Nottingham.*


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