The Children’s Cochlear Implant Center at UNC

Patient & Parent Information

University of North Carolina at Chapel Hill
Department of Otolaryngology
Head and Neck Surgery

UNC
SCHOOL OF MEDICINE
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Welcome

Welcome to The Children’s Cochlear Implant Center at UNC. Our center is part of the University of North Carolina-Chapel Hill, Department of Otolaryngology at the University of North Carolina Hospital and Clinics. Our pediatric cochlear implant program, is served by 3 otolaryngologists (oh-toh-lar-ing-gol-uh-jists), staffed by 4 full time audiologists (aw-dee-ol-uh-jists), and is supported by a team of speech-language pathologists who are certified Listening and Spoken Language Specialist. The Children’s Cochlear Implant Center at UNC embodies a very active clinical program, ongoing clinical research, and an educational facility that includes a model intervention and coaching/training program for therapists and educators.

Your child has been referred to this clinic because he or she may benefit from a cochlear implant. We will assess your child and give you the information you need to decide if a cochlear implant is the right choice for your child. Please bring this document to each appointment and keep it as a record of information we discuss.

If you have questions at any time please feel free to call. Our goal is to provide you with all the information you need to assist you in this important decision.

We look forward to getting to know you and your child.

The Children’s Cochlear Implant Center staff

Find us and other families on social media!

UNC Ear and Hearing Center – UNCPedsCIs UNCCochlearImplants

Please visit our website for additional information at http://www.uncearandhearing.com
5501 Fortune's Ridge Dr., Suite A Durham, NC 27713
Phone: (919) 419-1449  *  Fax: (919) 419-1399
Important Phone Numbers

**Clinic Numbers**
- 919-419-1449 (office)
- 919-419-1428 (office)
- 919-419-1399 (fax)

**ENT Clinic:**
- 984-974-6484
- 984-974-3499 (fax)

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Associate Professor
How The Ear Works

- **Outer ear**: consists of the ear canal and eardrum. Sound travels down the ear canal, striking the eardrum and causing it to move or vibrate.
- **Middle ear**: a space behind the eardrum that has three small bones. This chain of tiny bones is connected to the eardrum at one end and to an opening of the inner ear at the other end.
- Vibrations from the eardrum cause the bones to move which causes fluid in the **inner ear** to move.
- Movement of the fluid in the inner ear, or **cochlea** (koh-klee-uh), causes changes in tiny hair cells. Movement of the hair cells sends electric signals from the inner ear up the hearing nerve to the brain.
A cochlear implant is made up of pieces worn outside the ear and pieces surgically placed inside the ear. During surgery, a cut is made behind the ear and the internal piece is secured under the skin and hair. The electrode array is put into the cochlea, stimulating the hearing nerve.

1. External hardware (includes microphone, speech processor, coil/cable and battery)
   - The microphone captures sound in our environment.
   - The speech processor converts the environmental sound into a digital signal.
   - The signal is sent through the cable to the coil.

2. Internal receiver
   - The signal is sent across the skin to the implant, where it is converted to electrical energy and decoded.

3. Electrode array
   - The electrical energy is sent to the electrode array within the cochlea, where it stimulates the hearing nerve.

4. Hearing nerve
   - The stimulation of the hearing nerve is perceived as sound.
An audiogram is a graph that shows the softest sounds a person can hear across different frequencies or pitches (low to high pitch). The pictures show loudness and pitch of speech sounds and environmental sounds.
Candidacy

Who is a Cochlear Implant candidate?

Cochlear implants are recommended when a person has significant sensorineural hearing loss and has limited benefit from a hearing aid:

FDA Criteria

- Children at least 12 months of age
- Children with severe-to-profound hearing loss
- Children who are not making appropriate progress with speech and language development despite appropriately fit hearing aid
- Children who are healthy enough to have the surgery
- Children whose families are motivated to follow through with therapy and full time device use.

**Each case is evaluated on an individual basis, pending the case; recommendations might be outside FDA criteria**
Evaluation

The Process:

1. At least two audiology appointments to:
   - Talk about your child’s health and school history
   - Understand your child’s hearing status with and without hearing aids
   - Provide information to you about hearing, hearing loss and cochlear implants
   - Talk about your hopes and goals for the child and answer any questions

2. A speech and language evaluation to:
   - Assess your child’s communication abilities
   - Provide information on speech and language development
   - Collect information about your child’s current educational plan and offer support
   - Inform you about therapy options through our program

3. At least two doctor visits to:
   - Decide if your child is medically a candidate for a cochlear implant
   - Look for the cause of hearing loss (genetic testing, MRI or CT scan)
   - Talk about the surgery and risks involved
Evaluation Checklist

Audiology
- Case history
- Consent form
- Grant application
- Unaided audiogram
- Aided audiogram
- Appropriately fit hearing aids for at least 3 months
- Basics of hearing, hearing loss, hearing aids and cochlear implantation
- ABR/OAE
- Speech perception assessment
- CI devices
- Follow-up schedule

Speech Pathology
- Speech and Language Evaluation
- Therapy/school services optimized
- Completion of therapy trial if needed
- Completion of other evaluations if necessary

ENT Physician
- ENT appointment
- MRI/CT
- EKG
- Healthy ears
- Meningitis vaccine recommendations
- Surgery procedure and risks

Once the evaluation is completed and the decision to move forward with a CI is made, one final appointment before surgery will be scheduled at The Children’s Cochlear Implant Center. We will talk about what families can expect with the implant and review the device of choice.

Once you decide to go ahead with surgery, the ear to implant and the device brand and style are chosen. Surgery will be scheduled and plans for follow up appointments can be made.
The Profile

At your final visit before surgery, we will review the Candidacy Profile with you. This is a summary of the factors that affect outcome with a cochlear implant. It includes the information collected during the evaluation. The Profile helps identify areas that can be affected by change, and helps families develop realistic expectations for their child's use of an implant. The items we review include those shown on this figure:

- **Hearing History**
  - Onset of hearing loss
  - Degree & type of loss
  - Age at diagnosis

- **Aspects of the Child**
  - Anatomical
  - Physiological
  - Cognitive
  - Developmental
  - Behavioral

- **Use of Technology**
  - Age at fit
  - Consistency of use
  - Maintenance

- **Family and Environment**
  - Social
  - Economic
  - Cultural
  - Commitment
  - Resources

- **Educational & Therapeutic Methods**
  - Consistency of therapy
  - Expertise & experience
  - Family support for carryover & expansion
  - Emphasis on auditory learning
  - Integration of audition for communication

Before Surgery

- A surgery scheduler will call you with your pre-op date and time; **PLEASE make sure we have the right contact information.**

- At least 2 weeks before the surgery date call the ENT Department Financial Counselor at (984) 974-4206 to confirm that surgery is APPROVED/COVERED.

- The day before surgery a scheduler will call you to confirm your surgery time.

- Let us know about any signs of illness or temperature that occur within 3 days before surgery to the ENT office (984) 974-6484.

- Do not give your child aspirin or aspirin containing products within 2 weeks before surgery as it acts as a blood thinner.

- Your child should have nothing to eat after midnight the day before surgery and only small amounts of clear liquids the day of surgery.

- Cochlear implant surgery lasts about 3-4 hours. Children are usually sent home the day of surgery but parents should come prepared to stay overnight.

- Your child will wear hospital clothes for the surgery but bring his or her own clothes to wear home. A shirt that buttons or zips up the front is best as the bandage will be too big for a pullover type shirt.

- A nurse will teach you how to care for the stitches and bandages at home. Keep the area clean and dry until your child returns to the doctor to have the stitches and bandage taken off about 7 days after surgery.

- Your child will see the surgeon one week after surgery. However, if you have any concerns about the stitches, call the ENT office right away at (984) 974-6484.

- We will turn on the device about 3 weeks after surgery. Your child may continue to wear his or her hearing aid in the other ear. Talk about this with your audiologist.
Risks of CI Surgery

Your surgeon will talk with you about these in as much detail as you need

- Risks of cochlear implant surgery
  - Loss of remaining hearing in the implanted ear
  - Higher risk for meningitis (men-in-gi-tis)
  - Facial nerve stimulation/involuntary facial movement
  - Inflammation/extrusion/swelling
    - Soreness, redness or breakdown of skin in area around the implant, which may need more medical treatment, surgery and/or removal of device
  - Failure of surgery, possibly requiring removal of the implant
  - Failure of implanted pieces, which may need replacing
    - The CI may not work correctly or it may cause your child to feel or hear odd or uncomfortably loud sounds

- Risks associated with any ear surgery
  - Numbness/tenderness around implant site
  - Neck pain
  - Loss of feeling in face
  - Change in taste
  - Fluid leak
  - Dizziness (vertigo)
  - Tinnitus or “ringing in the ears”
  - Blood, fluid or infection at the site or close to the site of surgery
  - Skin reactions (rashes)

- General risks
  - Pain, scarring, bleeding and infection
  - Anesthetic risks (medicines used to put the child to sleep) associated with the heart, lungs, kidneys, liver and brain
Meningitis Vaccination Information

Bacterial meningitis (bak-\textit{teer-ee-}a/ men-in-\textit{gi}-tis) is a serious infection of the brain and the fluid around the brain. It is a life-threatening infection. People who have a cochlear implant are at higher risk for bacterial meningitis. Although this risk is small, it is important for children and adults with a cochlear implant to be vaccinated.

Cochlear implant users and their families should know that vaccines against the bacteria that cause meningitis are available. These vaccines strengthen the body’s ability to protect against the common causes of bacterial meningitis.

More information is available from this CDC website


**Schedule of Pneumo (noo-\textit{muh-}) Vaccines:**

<table>
<thead>
<tr>
<th>Age (years):</th>
<th>0</th>
<th>2</th>
<th>4</th>
<th>6</th>
<th>8</th>
<th>10</th>
<th>20</th>
<th>30</th>
<th>65</th>
</tr>
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<tbody>
<tr>
<td><strong>Prevnar</strong></td>
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<tr>
<td><strong>At least one Pneumovax vaccination should be given</strong></td>
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Ask about second Pneumovax 5 years or more after first Pneumovax & at age 65

**Follow-up Care**

Vaccinations do not eliminate the risk of meningitis. Children and adults with cochlear implants who develop a middle ear infection (otitis media) or a fever of uncertain cause should see their doctor. **Infections in a child or an adult with a cochlear implant should be taken seriously.** Untreated middle ear and other infections may spread to produce meningitis.

In addition, if an ear with a cochlear implant develops fluid that leaks from the ear canal, or has unusual ear symptoms or a watery fluid from the nose, it is important to have that ear checked by a cochlear implant surgeon.
What to Expect at First Fit

After surgery
- 3-4 weeks after surgery, after the stitches have healed, the child returns to the implant center to be fitted with the outside parts of the device and to have the speech processor “mapped” or programmed.
- The first few months of implant use, as hearing improves, reprogramming happens often; later on fewer visits are required.

The first visit is about two hours long and has the following goals:
- Fit the sound processor, microphone, headpiece
- Create a “first-pass” map or program that is comfortable for the child. More maps will also be created for the child to try before the next clinic visit
- Counsel family about the use of the device, troubleshooting, equipment care and maintenance
- Complete Product Registration and Warranty information

Programming (mapping)
- The speech processor is connected to a computer
- The appointment will begin with a check of the internal device (impedances)
- Some or all of the electrodes may be stimulated. Each electrode carries a slightly different frequency or pitch.
- If old enough, the child may report when sound is heard. Younger children play a game to indicate when a sound is detected. For very young children, parents and audiologists observe the child’s behavior for any evidence that sound is heard.
- Responses vary and can range from crying, to smiling, to no response at all.
- You are welcome to invite a few family members or educators/therapists to the visits and you may videotape at the appointments. Please keep the size of our clinic rooms in mind when you are inviting guests.
Success with Implant

Wear Time
- For the best outcomes with a cochlear implant, the device should be worn during **ALL** waking hours, with the exception of bathing.
- To ensure your child is hearing, the cochlear implant headpiece/coil must be connected to the internal device via the magnet. **If the magnet is not attached, your child is not hearing.**
  - If you are struggling with CI retention or wear time please contact your audiologist for support.

Retention Options
- The following is list of resources for cochlear implant retention devices
  - **Double-Sided Tape**
    - [http://www.sallybeauty.com/topstick-hairpiece-tape/VAPON2.default.pd.html#q=topstick&start=1](http://www.sallybeauty.com/topstick-hairpiece-tape/VAPON2.default.pd.html#q=topstick&start=1)
    - [http://www.amazon.com/gp/product/B000F3DXLU?keywords=topstick&qid=1445001382&ref_=sr_1_1&s=beauty&sr=1-1](http://www.amazon.com/gp/product/B000F3DXLU?keywords=topstick&qid=1445001382&ref_=sr_1_1&s=beauty&sr=1-1)
  - **Hearing aid/Cochlear Implant Cords**
    - [https://www.etsy.com/shop/thebebopshop](https://www.etsy.com/shop/thebebopshop)
  - **Pilot Caps**
    - [http://www.hannaandersson.com](http://www.hannaandersson.com) (pilot cap)
    - [http://anchoryourhearing.com](http://anchoryourhearing.com)
  - **Cochlear Implant Headbands**
    - [http://hearinghenry.com](http://hearinghenry.com)
    - [http://joybandsllc.com](http://joybandsllc.com)
  - **Water Retention**
Co-Treating

A speech language pathologist certified in Listening and Spoken Language (LSLS) may be present in audiologist appointments. This team approach allows for better device programming by the audiologist and parental support for therapy. Our LSLS therapist can provide early listening goals, therapy techniques and additional support in building spoken language. Please take advantage of having them participate in audiology appointments and ask any questions you may have regarding early language development.
Follow-up Information

Follow Up Appointments
- Because of the quick adaptation of the hearing system, many mapping changes are needed in the first year of cochlear implant use. For this reason, we have made the following schedule after surgery:
  - First fit (3-4 weeks after surgery)
  - Following first fit:
    - 2 weeks
    - 5 weeks
    - 9 weeks
    - 3 months
    - 6 months
    - 9 months
    - 1 year
- Children are then seen at six month intervals while they are school aged and then they are seen once per year
- Parents may schedule more appointments as needed.

Expectations
- Before children with normal hearing learn to speak, they spend over a year listening to sounds around them.
- Speech and language develops with time and experience.
- Expose your child to a lot of spoken language by reading aloud every day and by talking about things that happen in your home and during the school day.
- The guidance of an experienced speech and hearing professional is important to help parents learn the best ways to help a child make progress.
- With full time use and appropriate therapy in place, expect the cochlear implant to provide useful sound and improved hearing with practice and patience.
- Therapy with a professional with experience in Listening and Spoken Language is critical to your child’s success with a cochlear implant.
- Every child is unique!
Device Information

Cochlear implants are made up of inside and outside pieces that work together. The design of the inside device and outside pieces may look different, but they function very similarly. There is no clear-cut evidence that one implant system provides better results than another.

We will review each cochlear implant system during your appointments. Please consult the websites or the booklets provided for more detailed information.

There are 3 cochlear implant companies on the market today:

<table>
<thead>
<tr>
<th>Implant Company</th>
<th>Device Warranty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced Bionics</td>
<td>5-year external</td>
</tr>
<tr>
<td>Cochlear</td>
<td>5-year external</td>
</tr>
<tr>
<td>Med-El</td>
<td>5-year external</td>
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</tbody>
</table>

*All manufacturers offer a 10-year warranty for the inside portion of the cochlear implant system.

Warranty on external device

- Warranty policies go into effect on the day of first fit. A one-time replacement for loss or accidental damage (beyond repair) is available during the user's first 3 or 5-year warranty period. Warrantied items are replaced due to “normal wear and tear” only.

Coverage after warranty expires

- Service contracts can be purchased from the manufacturer before the warranty expires for loss, damage, and wear and tear.
- Some families choose to cover the cochlear implant through homeowner’s insurance policies or through insurance providers, but coverage varies. This covers loss or damage only and not normal wear and tear.
- Proper care and storage will affect the durability of the external hardware.

Facts

- Cochlear implants are man-made medical electronics.
- The internal devices are designed to withstand long-term use, but we do not know if they will last a lifetime.
- Inside devices may fail due to electronic malfunction or due to a direct blow to the head. For this reason, we recommend parents carefully consider allowing their child to participate in “high risk” activities, such as contact sports or bicycling or rollerblading without a helmet.
Repairs and Troubleshooting

At some point in time the CI will break due to accidents and normal wear and tear. It’s easy to get overwhelmed when you learn your child is “off the air.” The first thing to do is to pull out the user guide you got at the first fitting and check the troubleshooting section.

If the device breaks or if it is not working properly, check to see if the device is still under warranty (based on time of first fitting). Call the cochlear implant manufacturer directly to receive help on troubleshooting the problem.

Anytime you are making a phone call about your child’s device be sure to have the serial number of the processor and know the names of the parts that need repaired.

Manufacturer Contact Info

<table>
<thead>
<tr>
<th></th>
<th>Cochlear</th>
<th>Med El</th>
<th>Advanced Bionics</th>
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</thead>
<tbody>
<tr>
<td><strong>Phone</strong></td>
<td>1-800-483-3123</td>
<td>919-572-2222</td>
<td>1-877-829-0026</td>
</tr>
<tr>
<td><strong>Email</strong></td>
<td><a href="mailto:hear.always@cochlear.com">hear.always@cochlear.com</a></td>
<td><a href="mailto:implants@medelus.com">implants@medelus.com</a></td>
<td><a href="mailto:hear@advancedbionics.com">hear@advancedbionics.com</a></td>
</tr>
</tbody>
</table>
What Things Cost

The surgery, inside the ear device, and outside equipment costs about $70,000. Most of this cost will be paid by insurance.

All outside parts are covered under manufacturer's warranty for normal wear and tear. If you lose a piece of equipment, the manufacturer will replace it one time within those three years. If you lose equipment again, it will be your responsibility to replace it.

After the warranty is over, you will pay for replacement parts. Medicaid and insurance plans sometimes cover these charges, as does the CCCDP grant program. It is your responsibility to be sure of what will be covered. You should consider buying an extended warranty (called a service contract) when the warranty expires through the implant manufacturer. It is important that the device be covered for loss and damage after the warranty has expired.

You will get two complete sets of equipment, so that your child will always have backup equipment and should never be “off the air.” Please be sure that both speech processors always contain the most current programs and are working well. Bring both to all appointments.

<table>
<thead>
<tr>
<th>Description</th>
<th>Cost</th>
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<tbody>
<tr>
<td>Surgery</td>
<td>$70,000</td>
</tr>
<tr>
<td>External Speech Processor</td>
<td>$8,500</td>
</tr>
<tr>
<td>Accessories</td>
<td>$5 - $1500</td>
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Communication Mode Considerations

As cochlear implant candidacy criteria have changed over time, so have the populations that may benefit from its use. Today, children with cochlear malformations and other developmental delays in addition to hearing loss are being considered for implantation; their communication goals may be very different from a typically developing child who has the diagnosis of hearing loss. This is an important consideration and expectations for outcome with a cochlear implant should be discussed with the family and CI team and educational team.

Recommendations may include:
- Cued Speech
- Sign language
- Augmentative Communication
- Other visual support to aid in independent communication.

Working on listening skills is important and should be a strong part of habilitation. The goal is for each child to achieve his or her communicative potential. This may mean including some form of visual communication to aid sound through the implant.

Resources

BEGINNINGS of NC: a non-profit agency providing an impartial approach to meeting the diverse needs of families with children who are deaf or hard of hearing and the professionals who serve them. BEGINNINGS’ staff members provide valuable technical information, emotional support, resources and referrals to parents and professionals. Services are free to parents in the state of North Carolina.
http://www.ncbegin.org

HITCH-UP: a family-based support group for parents and guardians of children who are Deaf or Hard of Hearing.
http://www.nchitchup.org

Alexander Graham Bell Association For the Deaf and Hard of Hearing, NC Chapter: an advocacy group providing information and support for individuals and families who choose an oral mode of communication. AGBell hosts statewide and national conferences and advocates for individuals with hearing loss.
www.ncagbell.org
Frequently Asked Questions

What is a cochlear implant?

A cochlear implant is a surgically implanted electronic device that provides a sense of sound to a person who is severely hard of hearing or profoundly deaf.

How long have cochlear implants been available?

The U.S. Food and Drug Administration (FDA) first approved cochlear implant devices for adults in 1985 and for children in 1990.

Who is eligible to receive an implant?

Adults and children who meet the criteria approved by the FDA, and are medically healthy for surgery, are candidates for a cochlear implant.

What is the surgery like?

Cochlear implant surgery takes 2 to 3 hours under general anesthesia [an-uh s-thee-zhuh]. Most patients are discharged the same day as operation. An incision is made behind the ear and a section is made in the bone to secure the implant package and to protect it. Once the mastoid bone is opened, the electrode array is placed into the cochlea. Please refer to the pre-surgery & post-surgery section of this handbook for further information.

Does a cochlear implant provide normal hearing?

No. A cochlear implant provides the sense of sound to the hearing system by electrically stimulating the remaining neural elements in the cochlea. A patient will need to learn to listen to these new sounds. Working with an audiologist, speech-language pathologist, early interventionist, or teacher of the deaf will help the child identify sounds and improve auditory skills. Therapy and training that focuses on listening can help the child speak more clearly. Speech and language develops with time and experience.

What outcomes can be expected from a cochlear implant?

The vast majority of patients at our center who receive cochlear implants use them successfully. However, there is a wide range of outcomes. These outcomes will be discussed with you during the evaluation process.
Should my child receive one implant or two?

Hearing with two ears is best. We will work on a case by case basis to ensure your child has the appropriate technology for both ears.

How is the external transmitter held in place correctly?

Usually, the transmitter and receiver contain magnets, which attract each other to stay aligned.

Is re-implantation possible if my implant breaks?

Yes, re-implantation is almost always possible. It may take time for the child to return to his or her previous level of hearing. With time, hearing outcomes after re-implantation have been reported to be as good as or better than the previous device. An older implant is never removed/replaced if it is still working unless there is a decline in performance. The CI manufacturers release new outside equipment every 5 years or so. If it is not immediately compatible with your implant, the manufacturer will work to make it compatible within a few years.

Can the sound processor be removed at night?

Yes. The processor should be removed at night to let the scalp rest and to charge the processor's batteries. The processor should be stored in a Dry-N-Store to remove moisture.

Can I use the implant while playing sports?

Probably. Most implants are durable enough to wear while playing sports. Please use helmets when necessary and avoid full-contact sports. Some devices are waterproof so you may use them in the water. Ask your audiologist if the device chosen may be used in water. Deep water diving may harm the internal implant due to the high water pressure.
Visit our website for more information:

www.uncearandhearing.com

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Last updated 11/23/15