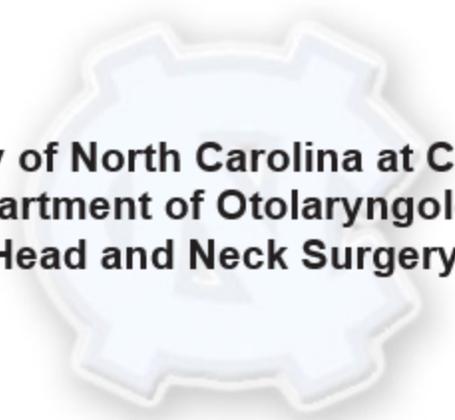


The Children's Cochlear Implant Center at UNC

Patient & Parent Guide



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

the little
place for big
miracles of
sound &
speech

THE
CHILDREN'S COCHLEAR
IMPLANT CENTER AT UNC



UNC
SCHOOL OF MEDICINE

Contents

Welcome	2
Phone Numbers	3
How The Ear Works	5
How A Cochlear Implant Works	6
Familiar Sounds Audiogram	7
Candidacy	8
Before Surgery	9
Risks of CI Surgery	10
Meningitis Vaccination Information	11
What to Expect At Cochlear Implant Activation	12
Success With An Implant	13
Co-Treating	14
Follow-up Information	15
Device Information	16
What Things Cost	17
Language	18
Resources	18
Common Questions	19

Welcome

Welcome to The Children's Cochlear Implant Center at UNC. Our center is part of UNC Chapel Hill School of Medicine in the Department of Otolaryngology. Our team includes Ear, Nose, and Throat surgeons, audiologists and speech-language therapists. Your child was referred to our clinic because they may benefit from a cochlear implant. Our team will test your child's hearing and give you the information you need to decide if a cochlear implant is right for them. If you have questions, please call!

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!](#)



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Please visit our website for at www.ChildrensCICenter.com
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Phone Numbers

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ENT Clinic Numbers

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Surgeons:**Kevin D. Brown, MD, PhD***Associate Professor**Medical Administrative Director*

- **Alison Turner**
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919-966-8961
- **Tracey Stalker, RN**

Lauren Kilpatrick, MD*Assistant Professor*

- **Michelle Handy**
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- **Tracey Stalker, RN**

Brendan O'Connell, MD*Assistant Professor*

- **Phyllis Dixon**
Surgery Schedule & Insurance
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- **Regina Carson, RN**

Surgery Financial Counselor

Paula Brady

984-974-4086

Harold C. Pillsbury III, MD, FACS*Professor, Otolaryngology/Head and Neck Surgery*

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919-966-9153
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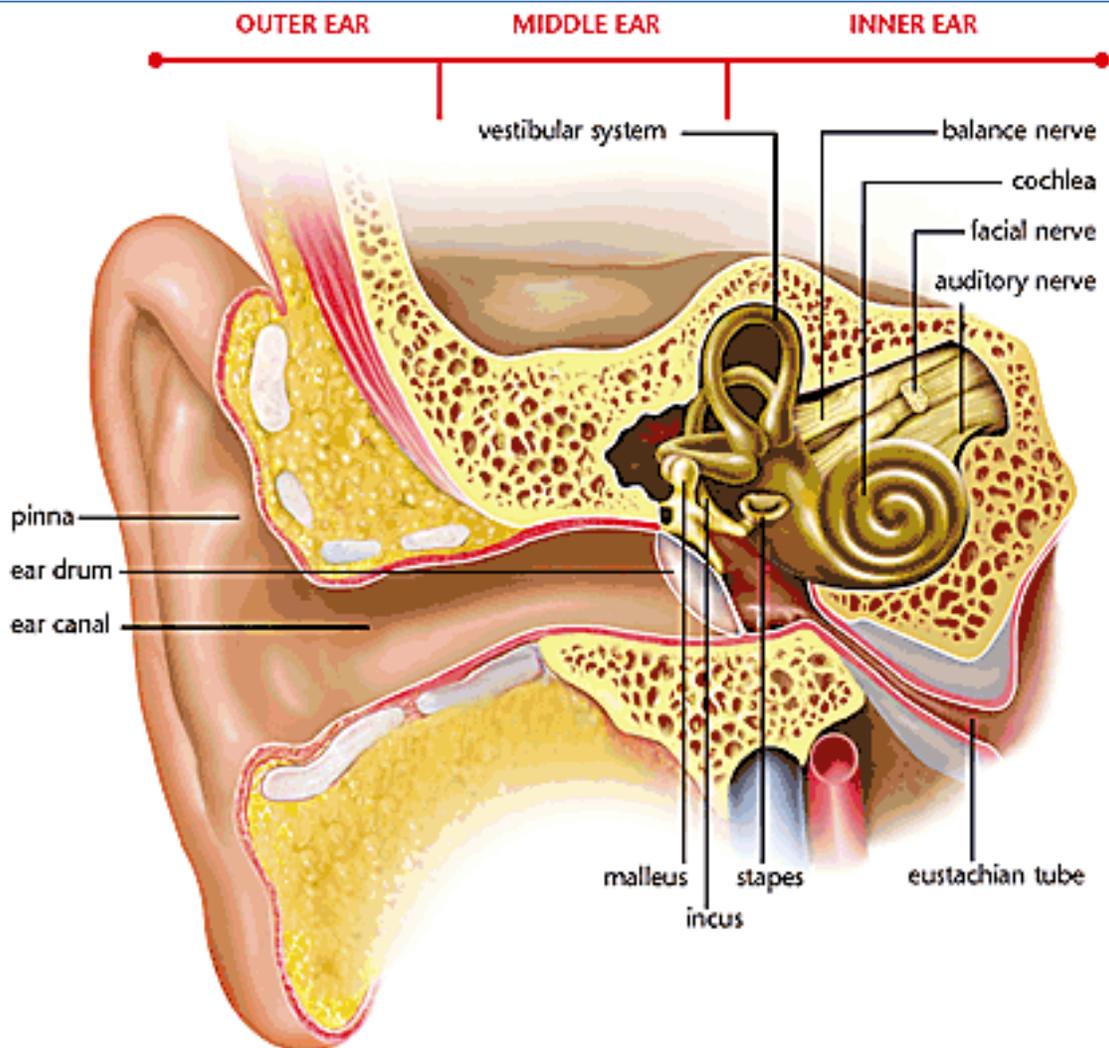
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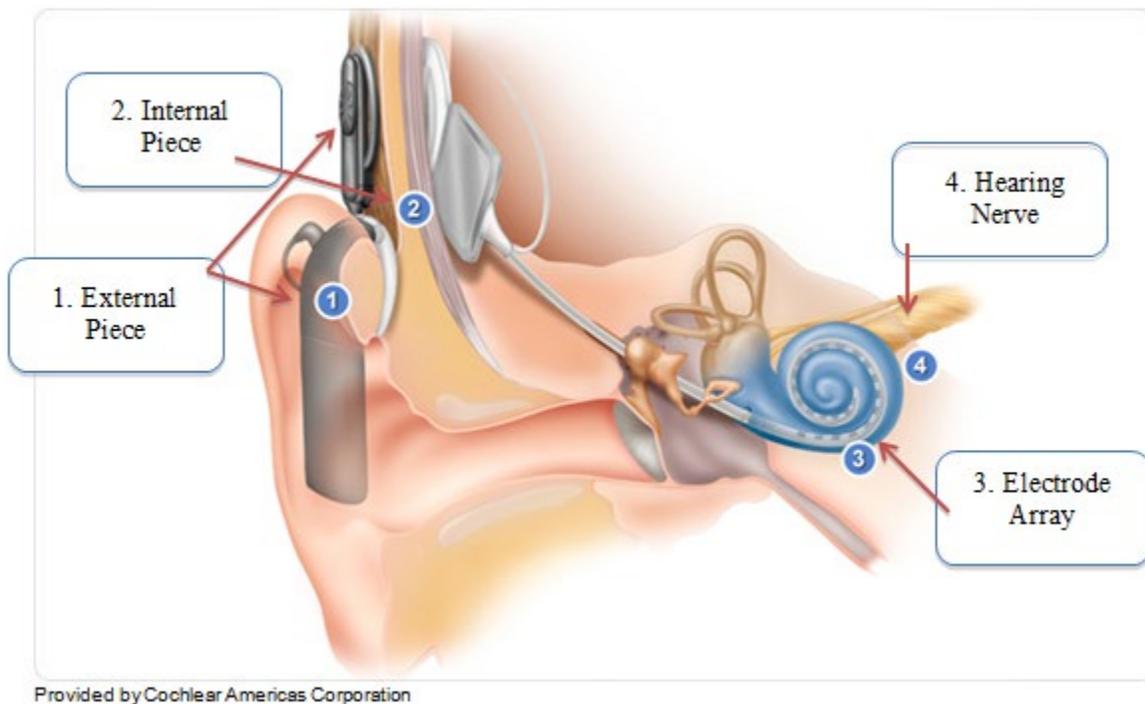


How The Ear Works



- **Outer ear:** The part of the ear that people can see along with ear canal and ear drum. The outer ear collects sound. Sound then travels down the ear canal, hitting the eardrum and making it to move or vibrate.
- **Middle ear:** a space behind the ear drum that has three small bones. This chain of tiny bones is linked to the eardrum at one end and to the inner ear at the other end. Sound hitting the ear drum moves these bones.
- **Inner ear:** The cochlea is a shell shaped organ that is filled with fluid and tiny hair cells. Movement from the middle ear bones vibrates the fluid in the inner ear bending the tiny hair cells. Movement of these hair cells sends electric signals from the inner ear up the hearing nerve to the brain.

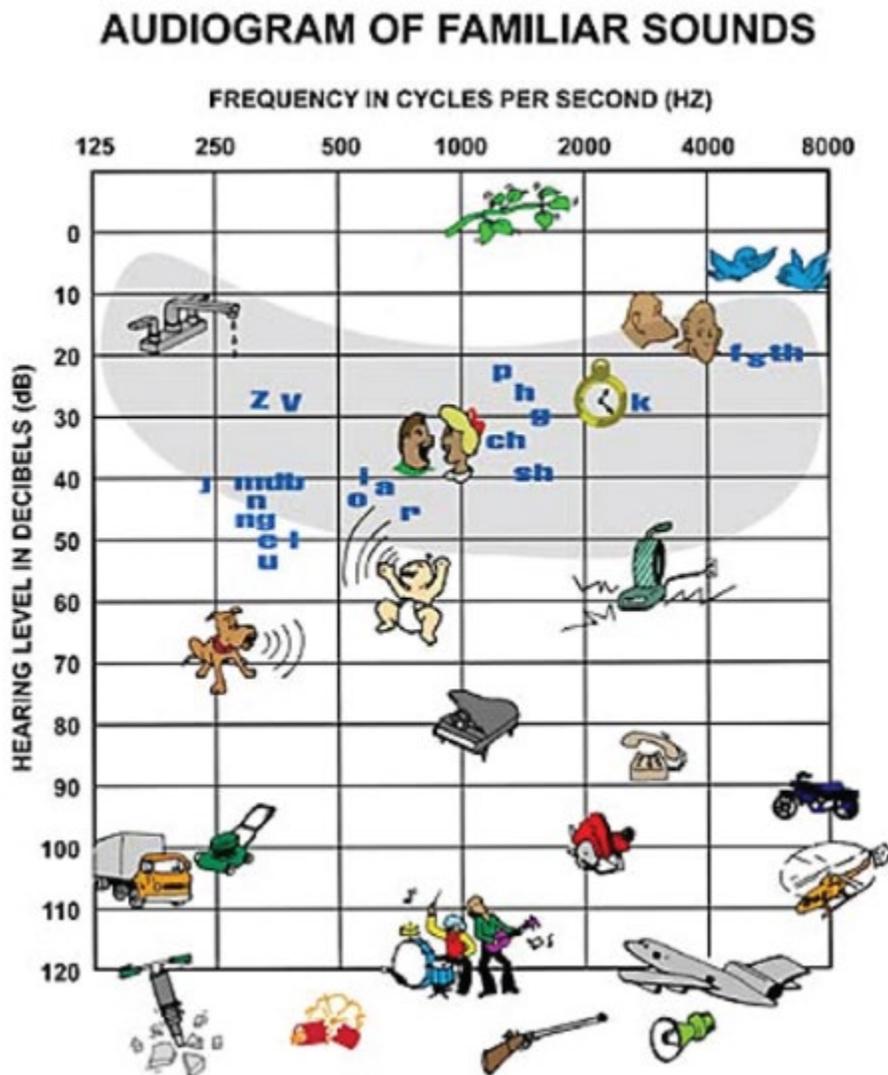
How A Cochlear Implant Works



A CI is made up of two parts. One part is worn outside the ear and a second is placed inside the ear during surgery. At the end of the internal device is the electrode array. This is put in the cochlea to send sound to the hearing nerve.

1. Outside parts (includes microphone, speech processor, coil/cable and battery)
 - The **microphone** takes in sound from the environment.
 - The **speech processor** changes the sound into a digital signal.
 - The signal is sent through the **cable** to the **coil**.
2. Inside parts (receiver)
 - The signal goes across the skin to the **implant**, where it is changed to electric signal.
3. Electrode array
 - The electric energy is sent to the **electrode array** inside the cochlea. It sends sound up the hearing nerve.
4. Hearing nerve
 - The stimulation of the **hearing nerve** is sound.

Familiar Sounds Audiogram



- An audiogram is a graph that shows the softest sounds a person can hear from low to high pitch.
The pictures show where sounds are on the audiogram.
- X = left ear response, no hearing aid
- O = right ear response, no hearing aid

Candidacy

Who can have a cochlear implant?

Cochlear implants are suggested when a person has severe hearing loss and does not understand speech with a well fit hearing aid:

FDA Criteria

Children at least 12-months old

Children with severe-to-profound hearing loss

Children who are not making progress with speech and language, even with a properly fit hearing aid

Children who are healthy enough to have surgery

Children whose families will use the device full time and receive speech therapy

***Current research is showing children benefit from CIs outside this criteria. Each child is treated as an individual. Pending the case, recommendations might be outside FDA criteria. As needed, we will work with your insurance company for coverage.*

Steps to Getting a Cochlear Implant:

A few visits will be scheduled with our audiology team. We will test your child's hearing with and without their hearing aid. You will see the doctor to talk about CI surgery, cause of hearing loss and to have imaging of your child's ear (MRI or CT scan). A speech and language evaluation will be done to learn your child's skills. We will talk about therapy options.



Before Surgery

- A surgery staff person will call you with your pre-op (before surgery) date and time. **PLEASE make sure we have the right phone numbers to reach you.**
- At least 2 weeks before the surgery date call the ENT Financial Person at (984) 974-4086 to confirm that surgery is APPROVED/COVERED.
- Our staff will call you the day before surgery with your surgery time.
- Let us know about any signs of illness (cold, stomach virus, flu like symptoms) or fever 3 days before surgery. Call the ENT office (984) 974-6484.
- Do not give your child aspirin or aspirin products 2 weeks before surgery. Aspirin is a blood thinner.
- Your child should have nothing to eat after midnight the day before surgery. They can only have small amounts of clear liquids the day of surgery.
- CI surgery lasts about 3-4 hours. Children are often sent home the day of surgery. Parents should be ready to stay overnight.
- Your child will wear hospital clothes for the surgery. Bring his or her own clothes to wear home. A shirt that buttons or zips up the front is best. The bandage will be too big for a pullover type shirt.
- A nurse will teach you how to care for the bandages at home. Keep the area clean and dry until your child returns to the doctor to have the bandage taken off. Post-op (after surgery) visits are 3 weeks after surgery.
- If you are worried about the stitches, call the ENT office right away at (984) 974-6484.
- We will turn on the CI about 3 weeks after surgery. This is the same day as your check-up with the ENT. Your child can wear his or her hearing aid in the other ear.

Risks of CI Surgery

Your surgeon will talk to you about risks of CI surgery.

- Risks of CI surgery
 - Lose hearing
 - Higher risk for infection in the lining of the brain (meningitis)
 - Unwanted facial movement (facial nerve stimulation)
 - Swelling
 - Soreness, redness or breakdown of skin in area around the implant. This may need more medical treatment, surgery and/or removal of device.
 - Extrusion – electrode array backs out of cochlea
 - Failure of surgery
 - 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 with any ear surgery
 - Feeling sore around implant site
 - Neck pain
 - Loss of feeling in face
 - Change in taste
 - Fluid leak
 - Dizziness
 - “ringing in the ears”
 - Blood, fluid or infection at the site of surgery
 - Rash

- General risks
 - Pain, scarring, bleeding and infection
 - Anesthetic risks.(medicines used to put the child to sleep)
 - Can affect the heart, lungs, kidneys, liver and brain

What to Expect At Cochlear Implant Activation

After surgery:

- The stitches heal in 2-3 weeks. The child returns to our office to turn on the cochlear implant and program it. This is called mapping.
- The first map will not be the last. Your child will need many maps to hear their best. We will create these maps over your first few visits.

The first visit is about two hours long. During this time our goal is to:

- Fit the outside parts of the sound processor
- Create a map that works for the child. More maps will be made for your child to use at home.
- Talk about how the device works and care
- Complete paperwork

During Mapping:

- The CI is connected to the computer
- Internal device is tested
- Older children raise their hand when they hear sound. Younger children play a game when a sound is heard. Parents of young children work with audiologists to see any signs that the child is hearing sound.
- Each child is different. Reaction to sound can be crying, smiling, or nothing at all.
- You can invite a few family members or others to the visits. Video is allowed. Please keep the size of our clinic rooms in mind if you bring guests.



Success With An Implant

Wear Time

- For the best results with a CI, the device should be worn when they are awake. Eyes open, ears on. Do not wear when sleeping or bathing.
- To hear with the CI, the inside and outside magnets must touch. ***If the magnet is not attached to your child's head, your child is not hearing.***
 - It will be hard to keep the CI on for the first few weeks. Ask your audiologist for tips.

Helpful Wearing Options:

- **Double-Sided Tape**
 - Topstick found at Sally Beauty Supply or www.amazon.com
 - Look for the 1"x3" strips of Topstick to cut into smaller strips
- **Hearing aid/Cochlear Implant Cords**
 - <https://www.etsy.com/shop/thebebopshop?ref=12-shopheader-name>
- **Pilot Caps**
 - <http://www.hannaandersson.com> (pilot cap)
 - <http://anchoryourhearing.com>
- **Cochlear Implant Headbands**
 - <http://hearinghenry.com>
 - <http://joybandsllc.com>
- **Water Wear**
 - <http://www.nammuhats.com/special-needs/cochlear-implants-hats/>



Co-Treating

A speech-language therapist will join all audiology visits for children aged birth to three. This team approach helps us program the CI and support parents. Our speech-language therapists teach listening skills that will help your child learn to listen and talk. We will also work with your other teachers and local therapists to all have the same goals. Feel free to ask questions during these visits.

Keep in Mind:

- Children with normal hearing need more than a year to listen to sounds and learn to speak.
- Speech and language develop with time and practice.
- The more speech your child hears the more they learn. Talk and read to your child every day.
- Speech therapists or other specialists help parents teach their children language.
- To learn speech your child must hear it. Keep the device on all waking hours.
- Be patient, learning language will take time.
- Every child is different!



Follow-up Information

Follow-Up Visits

- Your child will need many visits in the first year. Over time louder maps are needed to hear their best. At each visit your child will go into the sound booth to see how they are hearing. Louder maps will be made until your child is able to hear soft sounds from low to high pitch. This could take many visits. Below is our schedule of visits for the first year.
 - Activation of Cochlear Implant (3-4 weeks after surgery)
 - Following activation
 - 2 weeks- make louder programs
 - 5 weeks- booth testing and mapping
 - 9 weeks- booth testing and mapping
 - 3 months- booth testing and mapping
 - 6 months- booth testing and mapping
 - 9 months- booth testing and mapping
 - 1 year – booth testing and mapping
- Young children return every six months to make sure they are hearing well.
- Older children return every year to update programs as needed.
- Parents may schedule more check ups as needed.



Device Information

Cochlear implants have inside and outside parts that work together. These pieces may look different between companies. There is no data that shows one implant system is better than the other.

We will talk about each cochlear implant system. Each company has a website with more information. We will give you a booklet with information on each system. The ENT might suggest a device based on your child's cochlea.

	Cochlear	Med El	Advanced Bionics
Phone	1-800-483-3123	919-572-2222	1-877-829-0026
Email	hear.always@cochlear.com	implants@medelus.com	hear@advancedbionics.com
Website	www.cochlearamericas.com	www.medel.com	http://www.advancedbionics.com

***All companies offer a 10-year warranty for the inside part of the cochlear implant system. They offer a 5-year warranty for the outside speech processor.**

Warranty on CI:

- The warranty starts when the device is turned on. One time during the 5 year warranty a lost device can be replaced. Parts under warranty can be traded as many times as needed. Warrantied items are traded due to "normal wear and tear" only.

When the Warranty Ends:

- Check with the CI company to see if you can buy a longer warrant period. This can cover a lost device or also wear and tear trade-ins.
- You can also cover the CI on your home-owners insurance. This covers loss or damage only.
- Good care and storage helps avoid damage to the cochlear implant.

Facts:

- Cochlear implants are man-made medical electronics.
- The internal devices are designed for long-term use. We do not know if they will last a lifetime.
- Inside pieces may fail due to electronic break down or from a direct blow to the head. Children should wear a helmet when they could fall and hit their head. Please be careful about contact sports. A hit to the head can break the internal device.

What Things Cost

The surgery, inside the ear device, and outside parts costs about \$70,000. Most of this is paid by insurance.

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

You will pay for new parts at the end of the warranty. Medicaid and insurance plans sometimes cover charges. The CCCDP grant program can also help with new parts. It is your job to check warranty status. You should think about buying an extended warranty (called a service contract) when the warranty ends.

Your child gets two full sets of equipment. This means your child always has backup equipment and should never be without sound. Please bring both processors to all visits. This means the newest program is on both devices.

Surgery:	\$50,000
CI Activation Kit:	\$13,000



Language

Cochlear Implant criteria has changed over time. Children with cochlear defects and other developmental delays can receive a CI. Their language and communication goals may be different from an average child. Goals will be made based on your child and their abilities.

Options may include:

- Spoken Language
- Cued Speech
- Sign language
- Augmentative Communication
- Other support

Working on listening skills is important and should be a part of your routine. Our goal is for each child to reach his or her full potential. This could include some form of visual communication along with the cochlear implant.

Resources

BEGINNINGS of NC: a non-profit group to help parents. They give information without bias to parents to meet the different needs of children with hearing loss. BEGINNINGS' staff give information, support, resources and referrals to parents and health care staff. 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 family 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: a group providing information and support for people and families who choose spoken language. AGBell holds state and national meetings. They help those with hearing loss.

www.ncagbell.org



Common Questions

What is a cochlear implant?

A CI is a surgically implanted electronic device that gives a sense of sound to a person who is deaf.

How old are cochlear implants?

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

Who can 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. Most children can leave the same day as the operation. A cut is made behind the ear and the internal device is placed under the skin. The electrode array is placed into the cochlea. Please refer to the pre-surgery & post-surgery section of this handbook for further information.

Is a CI normal hearing?

No, a CI is not the same as normal hearing. A CI is electric hearing. The brain will need time to learn to listen a new way. A patient needs to learn to listen to these new sounds. Working with a team of specialists will help the child learn sounds and improve listening skills. Therapy and training that focuses on listening can help the child speak more clearly. Speech and language comes with time and experience.

What should we expect with a CI?

Most patients at our center with cochlear implants use them successfully. However, there is a wide range of results. This will be discussed during the CI evaluation.

Should my child get one implant or two?

Hearing with two ears is best. We will work with you and your child to make sure they have the technology they need.

Can a CI be replaced?

Yes, re-placement is almost always possible. It will take time for a child to hear well again with a new device. Children are often able to hear like they could before the device was replaced. An older implant is never removed/replaced if it is still working unless they are not understanding well. The CI companies release new processors about every 5 years. It could take time for this to work with your child's internal device. Companies work hard to make new equipment that works for every CI user.

Can the CI be taken off at night?

Yes, the processor should be taken off at night to let the scalp rest. You will also need to charge the processor's batteries. The processor should be stored in a Dry-N-Store to remove moisture.

Can I use the CI while playing sports?

Probably, most implants are strong enough to wear while playing sports. Please use helmets when needed and avoid full-contact sports. Some CIs are waterproof and can be used in the water. Ask your audiologist if the device 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:

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