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About This Handbook

This handbook is for families that have a child with hearing loss. We are honored to partner with you on this

journey. Your child will face new situations as they grow. This may require changes to help meet their needs such as:

New hearing aids

Cochlear implants

Environment changes

There is a lot to learn as we work together to provide care for your child. This handbook includes the topics that are

most important. It is not a complete source of information. Your child's audiologist is the best source of information

for their treatment and care.

This handbook can help you:

Understand hearing, hearing loss and devices to treat hearing loss.

Increase your child's involvement in activities.

Address parent and child frustration.

Empower your child.

Build your child's self-esteem.

Audiology services are available at the following locations. Not all types of audiology services are available at each

location.

Children's Healthcare of Atlanta at Arthur M. Blank Hospital: 404-785-3257

Children's at Town Center: 404-785-8178

Children's at Chantilly: 404-785-8181

Children's Medical Office Building: 404-785-2877

This handbook should not replace instructions given to you by your child's doctor and healthcare team. It is not

meant to be medical advice or a complete source of all information about this subject. Your child's doctor is the best

source of information about what is best for your child's treatment and care.

Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

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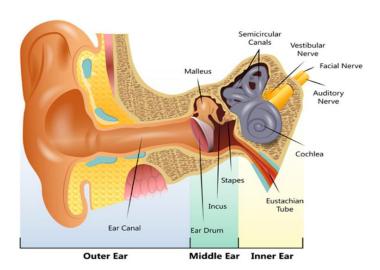
Hearing Loss

Hearing loss is when your child cannot hear some sounds or any sounds at all. Hearing loss:

- May be short term or permanent.
- Can start at any age.
- Can be in 1 or both ears.

How hearing works

- Sound travels down the ear canal to the eardrum (tympanic membrane).
- The movement of the eardrum makes the tiny bones (ossicles) in the middle ear vibrate.
- These vibrations are transferred to the inner ear (cochlea).
- Tiny sensory hair cells in the inner ear send signals to the hearing nerve.
- The brain understands those signals as sound.



Types of hearing loss

Sensorineural

This type of hearing loss happens when the inner ear or hearing nerve is damaged or not working as it should. It is often treated with traditional hearing aids.

Sensorineural hearing loss can happen in 1 or both ears. It is called unilateral hearing loss if it is in 1 ear.

Sometimes there is little to no hearing in 1 ear, but there is normal hearing in the other ear. This is called single-sided deafness.

Sensorineural hearing loss is permanent. It may be genetic or caused by:

- Diseases
- Exposure to noise
- Certain medicines
- The aging process

Conductive

This type of hearing loss happens when sound is not moving through the outer or middle ear to reach the inner ear.

The hearing nerve is healthy and works, but the sound cannot get to the nerve.

Conductive hearing loss may be caused by:

- Blockages or malformations
- Ear infections
- Microtia/atresia
- Down syndrome, Goldenhar syndrome or Treacher Collins syndrome
- Cholesteatomas
- Middle ear surgeries

Mixed

This type of hearing loss is a combination of conductive and sensorineural hearing loss.

Auditory Neuropathy Spectrum Disorder (ANSD)

The ear gathers sounds and changes them into messages the brain can understand. When a child has ANSD these messages get mixed up or the sounds do not reach the brain.

ANSD happens when there is damage along the hearing (auditory) nerve. This nerve is the path between the inner ear's cochlea (which takes sounds and turns them into messages) and the brain.

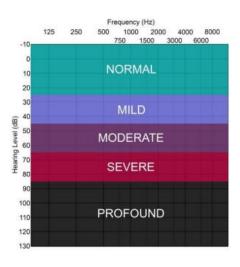
Most children with ANSD are born with it, but symptoms can start at any age. Hearing loss can be mild to profound (very bad). Some children hear sounds, but they have trouble understanding speech.

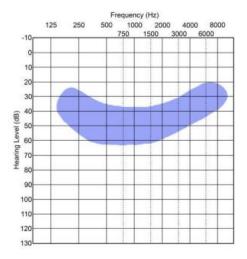
Audiogram

An audiogram is a graph that shows the softest sounds a person can hear at different pitches, or frequencies. The sounds are put on a graph. The softest sound noted on the graph shows the amount of hearing loss.

- The softest sounds are marked at the top of the graph. The loudest sounds are at the bottom of the graph.
- The pitches shown on the audiogram are the most important for hearing and understanding speech. The pitch is noted from right to left across the graph.
- An "O" is often used to mark the right ear.
- An "X" is often used to mark the left ear.
- Each sound we hear has a different pitch and loudness. For example, the "ss" sound is high in pitch and quiet.

 The "oo" sound is low in pitch and louder.
- The audiogram shown below on the right has a shaded area that shows the range of pitch and loudness for most speech sounds. This is called the speech banana.





Degree of hearing loss

- Normal hearing means there are very few or no hearing related problems.
- Mild hearing loss means your child may have trouble hearing quiet voices. They may have trouble listening to someone talk when it is noisy. They may miss consonant sounds.
- Moderate hearing loss means your child may only be able to understand speech if they can see the speaker's face. They may miss up to half of the speech sounds.
- Severe hearing loss means your child will miss most or all speech sounds.
- Profound hearing loss means your child will not be able to hear most sounds, including loud sounds.

There are websites that can help you understand what your child's hearing is like.

- Hearing Like Me: <u>hearinglikeme.com/hearing-loss-simulator</u>
- Starkey: starkey.com/hearing-loss-simulator/simulator
- Phonak: phonak.com/us/en/hearing-loss/signs-of-hearing-loss-and-what-to-do/hearing-loss-simulation.html

Hearing Solutions

Treatments for hearing loss

Your child's audiologist and ear, nose and throat (ENT) doctor will work with you to choose the right hearing solution for your child's age, lifestyle and hearing needs. Some of these hearing solutions include:

- Medicine or surgery for temporary hearing loss.
- Traditional hearing aids. Hearing aids make sounds louder so that your child can hear speech better. Hearing
 aids are useful for mild to severe hearing loss in 1 or both ears.
- Bone conduction hearing devices. A traditional hearing aid may not be useful if it does not fit correctly or requires a lot of volume increase. A bone conduction hearing device transmits sound through bones.
- Cochlear implants when hearing aids are not a solution.
 - A cochlear implant is an electronic device that is put inside your child's inner ear during surgery.
 - There is a headpiece and speech processor that is worn outside of their body, like a hearing aid.
- Speech therapy is important for your child to learn to listen and speak.

Practice listening and speaking

Your child should practice listening and speaking. There are many resources for speech therapy and rehabilitation.

- Auditory-Verbal Center (AVC) offers in-person and online auditory-verbal therapy: avchears.org.
- Atlanta Speech School offers speech language therapy and preschool classes for children with hearing loss: atlantaspeechschool.org.
- Cochlear America's Communication Corner offers many online rehabilitation resources:
 cochlear.com/us/communication-corner.
- Advanced Bionics has activities for all ages in the Listening Room: <u>thelisteningroom.com</u>.
- Resources are available for school-age children through the public school system. Your child will need to be
 evaluated by the school system to get special services.

Hearing aids

What is a hearing aid?

Hearing aids make sound louder so your child can hear speech better. Hearing aids are useful for mild to severe hearing loss in 1 or both ears. The hearing aid has:

• A microphone that picks up sound.

- An amplifier that makes the sound louder. Sounds are amplified depending on your child's hearing loss.
- A receiver or tubing and earmold that put the amplified sound into the ear canal where it travels through the hearing system to the nerve of hearing.

Parts of the hearing aid



Cleaning the earmold

Sweat and ear wax will dirty your child's earmold.

- Take the earmold off the hearing aid or cochlear implant processor before cleaning.
- Soak the earmold in mild dish soap with warm water. Let the earmold dry all the way. You may need to use an
 air blower to remove water from the earmold tubing.
- Put the earmold back on the hearing aid or cochlear implant processor.

Troubleshooting tips

- Hearing aids are water-resistant, but not waterproof.
- Remove hearing aids from damp spaces like bathroom or shower areas.
- Store hearing aids in their hard case to keep from losing the devices and to help prevent damage.
- Keep hearing aids away from extreme temperatures such as the oven, microwave, and hot or cold car.
- Use dry aid jar any time you think the hearing aid could have gotten wet.
- Remove hearing aids before putting on liquids and lotions near ears. This includes hair gel, hairspray, ear drops, sunblock and bug spray.
- Keep hearing aids out of reach from pets and young children.

Issue	Possible Cause	Solution		
Hearing aid is not making	Battery is low or dead	Replace battery with fresh one (make		
sound		sure the tab is removed) or place aid in		
		charger		
	Battery is put in the wrong way	Replace battery correctly (flip over)		
	Battery door is not fully closed	Close door all the way		
	Wax or moisture is in the earmold or tubing	Remove earmold and clean it		
	Blocked receiver filter	Change wax filter at the end of the		
		receiver		
	Hearing aid is not working or broken	Call your child's audiologist		
Hearing aid is whistling	Earmold is not in the ear in the correct	Try to put the earmold in again to make		
	way	it more secure		
	Loose or poorly fitting earmold	Call your child's audiologist		
	Split in tubing	Call your child's audiologist		
	Earwax in ear canal	Use at-home earwax management or		
		call your child's ENT		
Hearing aid is too quiet	Low or dead battery	Replace battery		
	Wax or moisture in the earmold	Remove the earmold and clean it		
	Change in hearing	Call your child's audiologist		
Intermittent, noisy or unclear sound	Low or dead battery	Replace battery		
	Moisture in hearing aid or damage	Call your child's audiologist		
Hearing aid gets wet	Place in dry aid kit or dry in a warm place	away from direct sunlight and heat. Call		
	your child's audiologist if needed			

Bone conduction hearing devices

What is a bone conduction hearing device?

Sometimes a traditional hearing aid may not be the best way to treat a hearing loss. This can be due to the fit of the device or the amount of volume needed to treat the hearing loss. A bone conduction hearing device could be a solution. Bone conduction hearing devices skip over the damaged middle or outer ear and send a clearer and more crisp sound directly to the inner ear using vibration or bone conduction.

A bone conduction device can be worn on the outside of the ear using an adjustable headband or it can be placed, or implanted, in surgery.

Could a bone conduction device help my child?

A bone conduction device could help your child if they have:

- Microtia or atresia in 1 or both ears.
 - Microtia is when a person has a small or abnormally shaped external ear.
 - Atresia is when a person has no ear canal.
- Chronic ear infections or draining ears.
- Conductive or mixed hearing loss in 1 or both ears.
- Trouble getting enough loudness using hearing aids, especially for soft speech or listening in noise.
- Narrowed or small ear canals that create discomfort or pain with hearing aid fit and feedback.
- Single sided deafness.

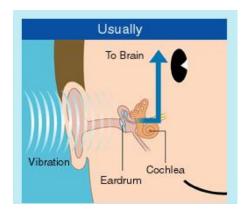
How does a bone conduction device work?

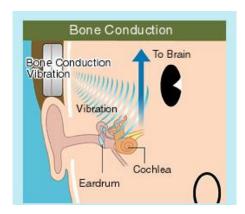
Bone conduction devices use the body's ability to transfer sound through bones. The sound processor changes sounds into vibrations. The vibrations are sent through the skull bone to the inner ear.

A bone conduction hearing device has 2 parts:

- Sound processor
- Sound transmission device. This could include headbands, stickers and surgical implants.

The sound processor picks up sound waves like a traditional hearing aid. Instead of sending the sound waves through the ear canal, it changes them into sound vibrations. The vibrations bypass the outer and middle ear and are sent through the skull bone.





What are the types of bone conduction devices?

There are different types of bone conduction devices. Your child's audiologist will work with you to choose the type that is best for your child. This is based on your child's age and health history.

- Non-surgical devices are used for children under the age of 5. They include headbands or stickers.
- Surgically implanted devices may be used for children 5 years and older. These devices include an implant that is magnetic or an external post to hold the sound processor.

Does my child need follow-up care?

- You and your child will see your child's audiologist for a sound processor fitting 1 to 3 months after the surgery.
- Your child will wear their implanted bone conduction device home from that visit.
- Your child should return to clinic every 6 months to check their progress.

Troubleshooting tips

Issue	Possible cause	Solution
Device is not making	Battery is low or dead	Replace battery. Make sure the tab is
sound		removed
	Battery is put in the wrong way	Replace battery correctly (flip over)
	Battery door is not fully closed	Close battery door all the way
	Device is not working or broken	Call your child's audiologist
Device is whistling	Device is touching the ear or surrounding	Try to move the device so it is no longer
	area	touching the ear or surrounding area

Issue	Possible cause	Solution		
Device is whistling	The softband is too loose or does not fit	Tighten the softband until whistling		
	correctly	stops		
	Debris or hair on the brace	Gently clean the brace area and reattach		
		the device		
Hearing aid is too quiet	Low or dead battery	Replace battery		
	Softband too loose	Tighten the softband		
	Change in hearing	Call your child's audiologist		
Intermittent, noisy or unclear sound	Low or dead battery	Replace battery		
4.10.04.	Broken or wet	Call your child's audiologist		
Hearing aid gets wet	Place in dry aid kit or dry in a warm place away from direct sunlight and heat. Call your			
	child's audiologist if needed			

Cochlear implants

Hearing loss can be so severe that a traditional hearing aid is not enough to be effective. A cochlear implant may be the best option for children with this level of hearing loss.

- The cochlea is a snail-shaped part of the inner ear. It turns sound vibrations into electrical signals that travel along the auditory (hearing) nerve.
- The brain translates these signals into familiar sounds.
- The cochlear implant skips over the damaged parts of the cochlea to stimulate the auditory nerve directly. They may be able to help with hearing when a hearing aid cannot.
- Children may be able to get a cochlear implant if their cochlea does not send sounds to the brain.

How do cochlear implants work?

A cochlear implant has 2 main parts:

- Speech processor that attaches outside the body
 - A microphone picks up sound and sends it to the processor.
 - The processor is a tiny computer that changes the sound into digital information.
 - The transmitter sends the digital signal to the receiver, also called the stimulator.

- Receiver or stimulator that is placed under skin and muscle behind the ear
 - It gets information from the processor.
 - It sends electrical signals through a wire to electrodes placed in the cochlea.
 - The electrodes stimulate the auditory nerve that sends a signal to the brain.
 - The brain uses the information to recognize sounds and understand speech.

Sound from a cochlear implant is different from normal hearing.

- A normal cochlea has many hair cells that send signals to the brain.
- A cochlear implant has a smaller number of electrodes that send signals. The sounds that a child hears are not natural.

A cochlear implant lets someone sense sounds that they could not hear without the implant. Babies who have never heard sound can build new brain pathways to start making sense of the sounds. Children can learn how to interpret sounds to understand speech with therapy and practice.

Who can get a cochlear implant?

A health care team assesses and advises for an implant surgery for children when needed. A child must come to all visits.

Implantation may not be advised for some children. The care team will explain why and will talk with you about other treatments.

A cochlear implant team will help your family decide if cochlear implants are a good option. This team includes an:

- Audiologist
- Ear, nose and throat doctor (ENT)
- Speech therapist
- Psychologist
- Social worker

The cochlear implant team assesses many things to determine if an implant could be helpful. An implant requires a large commitment from the family. Also keep in mind that no one can know if developmental issues will be present such as:

- A learning disability
- Attention Deficit Disorder (ADD)
- Autism Spectrum Disorder

What happens during cochlear implant surgery?

Cochlear implant surgery is done under general anesthesia. This means your child will be put to sleep and will not feel pain. The surgeon (doctor who does surgery):

- Makes an incision (cut) and places the implant under the skin against the skull.
- Threads the wire with the electrodes into the spirals of the cochlea.
- Secures the implant and closes the incision with stitches.

The doctor may advise for 2 cochlear implants, 1 for each ear. This may be done at the same time or at different times. People with 2 implants:

- Are better able to tell where sound is coming from.
- Hear better in noisy settings.
- Hear sound from both sides without having to turn their head.

What are the risks?

All surgeries come with some risks. The most common problems after cochlear implant surgery include:

- Infection at the surgery site.
- Ringing in the ears (tinnitus).
- Dizziness or balance problems (vertigo).
- Numbness around the ears.

Rare problems include:

- Weakness in the muscles of the face.
- Leakage of cerebrospinal fluid (CSF) from around the brain.
- Malfunction of the implant. The implant does not work correctly.
- Infection of the brain (meningitis).

Children with cochlear implants have a higher risk for some types of meningitis. It is important that they get their vaccines on time. Children over 2 years old with cochlear implants should get a pneumococcal polysaccharide vaccine to help protect against meningitis. Talk with your child's doctor to learn more.

What can I expect?

Talk with your child's Audiology and ENT teams about what to expect after the cochlear implant is placed. This includes:

• Your child's progress with a cochlear implant depends on many things including:

- Age of your child.
- Structure of the outer, middle and inner ear.
- Potential for your child's development.
- Your child must wear the processor during waking hours of the day. Your child cannot hear any sounds without wearing a speech processor.
- Family involvement is important. Family must support a good listening and speaking setting at home and during activities.
- Your child must get speech therapy and auditory verbal therapy. Practice should continue at home with your family.
- Your child's visits to program and adjust the external processor. These are called mapping sessions. This checks the internal device.

Troubleshooting tips

Check batteries

- Use the disposable battery pack with a fresh set of 675 **implant plus** batteries.
- Do not use regular 675 hearing aid batteries.
- Check that your charger is working and that the rechargeable battery can be charged.
- Try a few batteries and see if you keep having problems.

Change microphone protectors

- Over time these can get clogged. This will cause distorted sound.
- You can find extra protectors and instructions on how to change them in your care kit. There are videos online for instruction.

Switch out each part

There is an extra cable, coil and battery pack in your care kit. If you switch out one part and the implant starts working, then you know that the other side needs to be replaced.

- When you know which part is broken, you can order the parts from the manufacturer. Call their customer service team.
- You can use backup equipment until you can get your primary implant fixed. Let your child's audiologist know if the backup processor does not have their current programs in it.

Call the company

• The cochlear implant companies have customer service teams who are happy to help. They can help you figure out what is broken and order new parts. Call them whenever you need them.

Their numbers are:

Cochlear Americas: 1-877-883-3101
 Med El Corporation: 1-888-633-3524
 Advanced Bionics: 1-877-829-0026

The company websites have troubleshooting help and videos:

• Cochlear Americas: cochlear.com

• Med El Corporation: <u>medel.com</u>

Advanced Bionics: advancedbionics.com

Schedule a visit with your child's audiologist if you cannot figure out what part it broken. They will find what is not working and order parts from the company.

Static electricity

Static electricity can damage cochlear implants.

- Touch your child before touching the cochlear implant processor. This will get rid of any static.
- Take off the processor if your child is going on a plastic slide or in a plastic ball pit.
- Dress your child before putting on the cochlear implant equipment. This will reduce the static around the processor.

Surgical device care

Head scans

Magnetic resonance imaging (MRI) can damage skin and other tissue or permanently damage your child's implant. It is important to check with your implant team or the implant company before your child gets:

- An MRI.
- Radiation treatments.
- Electrical current treatments.
- Electrical stimulation.

Phone numbers for frequently used implant companies include:

• Cochlear Americas: 1-877-883-3101

Med El Corporation: 1-888-633-3524

Advanced Bionics: 1-877-829-0026

Children with cochlear implants can have regular X-rays, dental X-rays and CT scans without a problem.

Funding

Hearing devices cost a lot of money but are needed for children with hearing loss.

- Georgia Medicaid insurance often pays for the full cost of a hearing device.
- Most private insurance companies pay for part of the cost. There are organizations that help families pay for their child's hearing aids if they need help.

Over the counter hearing aids are not made for children. Children who need hearing aids should only get them from a certified audiologist that works with children. Children have special needs that are different from adults.

Let Georgia Hear has information about insurance coverage: <u>letgeorgiahear.org/amicovered</u>.

These are just some of the organizations that may be able to help with the cost of hearing aids. Talk with your child's audiologist about other options.

- Georgia Charitable Care Network: gacharitycare.org/ga-hearing-aid-dispatch.html
- United Healthcare Children's Foundation: <u>uhccf.org</u>
- Jason Cunningham Foundation: <u>cunninghamcharity.org</u>
- Ear Community: https://earcommunity.org/helpful-resources/financial/hearing-aid-financial-assistance. This site is designed for children with microtia/atresia.

Caring for Your Hearing Device

Maintenance and listening checks

Daily care

- Wipe the outside with a soft, dry cloth. A microfiber cloth is often provided in the care kit at the fitting visit.
- Do not use water or liquids to clean it.
- Some devices have a wind protector over the microphone to reduce wind noise. Brush off the microphone with a soft, dry toothbrush and change it as instructed.
- Do a listening check:
 - Each morning before therapy and school.
 - When you have a concern about the device.

How to do a listening check

- Check the device for damage. Make sure:
 - The case is not cracked or broken.
 - There are no signs of water damage.
 - The earmold is not plugged with wax.
- Check the earmold and earmold tubing for moisture or cracks.
- Check the battery if your device uses disposable batteries. Use a battery tester:
 - Place the battery plus (+) side up.
 - Slide it in the direction the arrow points.
 - An indicator will tell you if the battery is good or needs to be replaced.
- Use a listening scope or earphone to listen to the hearing aids. The sounds should be clear and the same each day.
 - Turn on the hearing aid by closing the battery door with an active battery.
 - Place your earmold into the bell end.
 - Put the other end in your ear.
 - Listen to sounds around you; then listen to your own voice.
 - Say the Ling 6 Sounds (ah, ee, oo, mm, sh, ss).

Batteries and chargers

Hearing aid batteries can be toxic if swallowed or used wrong. Call Poison Control <u>right away</u> at 1-800-222-1222 if anyone swallows a battery.

Hearing aids, cochlear implants and bone conduction devices may use disposable batteries. Some are rechargeable.

- Chargers are often provided by manufacturer warranty. Call your child's audiologist for questions about replacement chargers.
- You can buy disposable batteries at a pharmacy or online.

Disposable batteries come in different sizes. The sizes are color-coded.

- Size 10 batteries are yellow.
- Size 13 batteries are orange.
- Size 312 batteries are brown.
- Size 675 batteries are blue.
- High-powered zinc air 675 batteries are blue and labeled as Implant Plus 675.

Keep hearing aids and implants dry

- Most hearing aids and cochlear implant processors are water resistant. Water resistant does not mean
 waterproof. Water resistant means the equipment can handle some water. Check with your child's audiologist to
 find out if your child can wear their hearing aid or cochlear implant in the pool, sprinkler and bathtub.
- Store your child's hearing aid or cochlear implant processor in a waterproof case if they are near water.
- If your child has hearing aids or bone conduction hearing aids:
 - Dry off the outside of the equipment with a clean, dry cloth if it gets wet.
 - Remove the battery. Leave the battery door open if possible.
 - Let the hearing aid dry for several hours in a dry aid kit. Do this overnight if possible. This will absorb water from the hearing aid.
 - Call your child's audiologist if you do not have a dry aid kit.
 - You can also buy one online (such as Hal-Hen Dri Aid Kit).
- If your child has cochlear implants:
 - Dry off the outside of the device with a clean, dry cloth if it gets wet.
 - Separate the battery, headpiece and processor.
 - Shake out any water.
 - Remove the battery. Throw out any disposable batteries.
 - Replace the microphone cover if possible.
 - Place the cochlear implant in a dry aid kit overnight. This will absorb water from the cochlear implant.
 - Call your child's audiologist if you do not have a dry aid kit.
 - You can also buy one online (such as Hal-Hen Dri Aid Kit).

Connecting to technology

Bluetooth technology

Many hearing devices have access to Bluetooth connectivity. Some require extra accessories to access Bluetooth. Talk with your child's audiologist about these options.

Tele-coil or looping technology

Some hearing devices have induction loops (tele-coil) to help your child hear more clearly in places like movie theaters, concert halls and churches. Not all places have loop technology. You can ask about it if your child's device has this technology.

The telecoil can also be used with phones and other assistive devices. Talk with your child's audiologist for more information about tele-coil options.

Assistive devices

There are tools to help your child thrive and become independent. Some tools include:

- FM systems.
- Remote microphones.
- Amplified or captioned phones.
- Captioning services.
- Alarm clocks with lights or bed shakers.
- Safety alarms and smoke detectors.

School Tips

Individualized Education Plan (IEP)

Your child will be introduced to new things when the school year starts: teachers, classmates and an Individualized Education Plan (IEP).

- An IEP is required for every student with a disability that meets specific needs. It is a written document that includes your child's educational program.
- You have the right to be at your child's IEP meeting.
- You can and should give suggestions for your child's IEP.
- The IEP should:
 - Assess your child in all areas of learning.
 - Consider how hearing loss affects your child's learning.
 - Develop goals for your child.
 - Determine classroom placement and adjustments for your child.
- You can find information about IEP requirements and processes from the Department of Education at https://www2.ed.gov/parents/needs/speced/iepguide/index.html.

Preschool and elementary school

- Give your child's teacher this information at the start of the school year:
 - The best way to communicate with your child.
 - How to troubleshoot your child's hearing aid or cochlear implant.
 - Appropriate expectations for your child
- Make hearing aids and cochlear implants fun for your child. Hearing aids, earmolds, and cochlear implants come
 in different colors and patterns. Have your child decorate their hearing equipment with stickers or accessories.
- Teach your child how to speak up for themselves. Practice with role play.
- Have a show and tell with the class to talk about your child's hearing aids and cochlear implants.
- Teach other students in the class. Ask the teacher if you can read a book about hearing loss to the class.

Children's books about hearing loss

- Abby Gets a Cochlear Implant by Maureen Cassidy Riski
- Elana's Ears by Gloria Roth Lowell
- Having Hearing Aids by Peter Augustine

- Herbie Hears the Horn by Susan Chorost with Susan Stock
- Leo Gets Hearing Aids and Leo Gets a Roger System (available in English and Spanish; also available as an eBook on the Phonak Leo App)
- Mellie and Her Cochlear Implants (available online at https://s3.medel.com/pdf/US/bridge/21538.pdf)

Middle and high school

The teen years have their own challenges. Build a positive attitude about hearing aids and cochlear implants at home.

- Talk about your teen's hearing loss and how it may affect their future.
- Help develop a positive attitude and confidence in your teen's hearing loss. This will help prevent negative impact of rude comments from others.
- Teach self-advocacy skills and independence. This will help your teen ask for what they need in school, church and sports.
- Support your child's friendships. It is helpful for them to have friends to share thoughts and feelings.
- Encourage activities so your teen develops friendships.
- Reward your teen's courage, persistence and commitment to their future.

College

There are special services in college for students with disabilities. You and your child must ask for these services and your child must be eligible for them. IEPs are not part of college education. Choose a college that can meet your needs. Visit the school and ask questions about:

- The school's policy for hearing impaired students.
- How to request accommodations.
- How to confirm whether your child is eligible for special services.
- What services they provide.
- What support services are available for students with hearing loss.
- Whether or not the school has been evaluated for ADA compliance.
- The school's grievance policy.

Scholarships for students with hearing loss

There are scholarships for students with hearing loss. You can search for scholarships at collegescholarships.org.

Know strengths and weaknesses

Your child should know their strengths and weaknesses with speech, language and hearing.

- Schedule a speech and language evaluation before starting college.
- Have these tested:
 - Vocabulary level
 - Reading level
 - Speech clarity (in noisy and quiet spaces)
 - Pronunciation
 - Voice quality
 - Listening comprehension with and without visual cues
 - Auditory memory
- Compare test results to normal results.
- Schedule a hearing aid check or cochlear implant mapping with your audiologist before classes start.
- Learn strengths and weaknesses when listening in noise, in poor acoustics and with poor visual cues.
- Learn about hearing loss so you can explain it to others.
- Learn how to troubleshoot equipment.
- Learn which assistive devices work with your equipment.

Learning tips

- Lower noise and use more light.
- Get to classes and events early. Sit close to the speaker.
- Pay close attention and watch the speaker.
- Tell others about your hearing loss.
- Write down important details like phone numbers, key words, dates, times and amounts.
- Find an audiologist near your college who is familiar with your type of hearing aids or cochlear implants. Schedule a visit with them. Know how to contact the office in case you have a problem. You can find a list of audiologists at audiology.org.
- Save your hearing aid and cochlear implants customer service information in a place where you can easily find it.

Special accommodations

Plan ahead. Meet with the person in charge of accommodations before you get to college. Register as a student with a disability. Provide recent notes of your hearing loss and how it affects your learning and daily life.

The person in charge of accommodation will decide if you are eligible. They will give you a letter with a list of accommodations. Show the letter to your professors (college teachers) when classes start. The list may include:

Early registration.

- Preferred seating in the classroom.
- Note-taking by another student.
- Tutoring.
- Live voice or extra time during tests.
- Hearing assistive technology.
- Oral interpreters or cued speech.
- Waivers and substitutions for specific classes.
- Sign language interpreters.
- Copies of the lecture.
- Headset amplifiers.
- Visual information from the professor.
- Voice to text options such as:
 - Video relay (<u>sorensonvrs.com</u>)
 - Voice carry over in which a hearing-impaired person speaks into a phone and the responses are sent by text messages
 - TTY (teletypewriters) and TDD (telecommunication device for the deaf)
 - Speech-to-text system
 - C-Print speech to text (captioning) technology (ntid.rit.edu/cprint)
 - Communications access real-time translation (CART) (https://captionfirst.com)
 - CapTel (<u>captel.com</u>)

Seasonal Tips

Travel

- Travel with extra batteries and hearing aid or cochlear implant processor parts.
- Put the parts in a case to keep them from getting lost or damaged when your child takes off their device.
- If your child is flying:
 - Do not put hearing aids or cochlear implants on the conveyor belt in airport security. Put them in a bowl or tray instead.
 - Your child does not have to remove their hearing aid or cochlear implant processor for security scans. They may hear a distorted sound near the security scanner or the handheld wand.
 - Your child does not need to turn off hearing aids and cochlear implants during a flight.
- The U.S. Department of Transportation outlines passengers' rights during travel: transportation.gov/airconsumer/passengers-disabilities.

Camps and sports

- If your child is going to camp, label each piece of their hearing aid or cochlear implant with their name. Send extra cables, batteries and backup equipment.
- Talk to your child about water and sand precautions.
- Meet with the camp leader.
 - Set goals for your child's involvement in activities.
 - Review the best way the leader can communicate with your child.
 - Teach the leader about your child's hearing aids or cochlear implant and its care.
- Think about getting an adjustable helmet so the hearing aid or cochlear implant processor will fit underneath. Do not remove any of the existing foam inside the helmet
- It is important that your child wears the hearing device as much as possible. Create plans for water time and for wear time in the summer.
- Keep the hearing aids and cochlear implant in a safe place when your child is not wearing it. Decide who is responsible for the equipment.
- Your child can wear glasses and sunglasses with hearing aids and cochlear implants.
- Your child can wear disposable swim earplugs to keep water out of their ears when swimming.
 - Most pharmacies sell different sizes.
 - Your child may need custom-made swim molds if they have had ear surgery. Your child's audiologist can make them.

Winter use

The most common issues during winter are extreme temperatures and moisture. Keep these things in mind when your child enjoys winter activities:

- Cold temperatures can drain battery life. Bring extra batteries or your charger.
- Moisture from sweat, rain or snow can damage the hearing aid. Have your child wear a hat or head covering.
 Use your drying kit if it gets wet.
- Use a retention cord to help prevent the device from getting lost. This is most often included in new hearing aid fitting. See the resources section for more options.

Frequently Asked Questions (FAQs)

How can I get my child to use their hearing device more?

Some children wear their hearing devices without issue. Other children do not like things in their ears. This is like when children do not want to wear hats or shoes. Some children go through phases of wearing their devices and not wearing them.

The goal is to work up to wearing the hearing aid whenever your child is awake. Make the hearing device a part of their daily routine. It is hard to start and keep a regular schedule for hearing devices. Keep trying every day. Focus on times of the day when hearing is important and your child is rested and happy.

Here are some tips to help your child wear their hearing devices more often:

- Put in hearing aids during times when you are close to your child and talking, signing, singing or playing with them.
- Put in hearing aids when your child is distracted with a toy or food they enjoy. They may not notice you putting them in.
- Some parents use a hat or headband that covers the ears to stop their child from pulling off devices. This may be needed for a short time to stop the habit of pulling or playing with the devices. It is important to check that the hat does not change how the hearing aid works or cause the hearing aids to whistle. Ask your child's audiologist for suggestions.
- Some parents use rewards like a sticker chart to help toddlers wear their hearing devices.
- A routine time to put in hearing aids can help your child form habits. Some families put them in while getting dressed.

How can I stop my child from pulling their device out of their ears?

You may find that your child will not leave the devices alone. They may constantly pull them out or take them off. Some children may get attention by pulling them out and running away. These behaviors can be challenging and frustrating for families. It may make you wonder if your child will ever get used to them.

You may feel guilty because you know the importance of wearing the device as much as possible. You may also worry about the risk if your child puts the device or its parts in their mouth. **You are not alone**. Many young children go through phases like this. We offer some tips below for the many families in this situation.

It is important to know if there are any problems with the hearing aids that may cause your baby to pull them out. Some earmolds do not fit well or hearing aid volume is too loud or too soft. You can do a listening check to make sure the hearing aids work. Your child's audiologist can change the earmold or adjust the hearing aids.

How can I stop my child from pulling their device off when I look away?

Children spend a lot of time exploring. That means they will explore their ears and their hearing devices. Here are some tips for staying calm when your child constantly removes their device:

- Try distracting your child with things they enjoy like toys, a snack or a book. Put in the hearing device while they are distracted. This keeps their hands busy so that they are less likely to bother the devices.
- Calmly put the devices back on. A child will sense if you are frustrated. Staying calm will help your child cooperate.
- Be persistent and positive. Try not to let your feelings get the best of you.
- Some children are more persistent than others. They may repeatedly remove the devices. Trust that this is a phase. It may help to start with short periods when you can pay full attention to your child. You can lengthen the time slowly.
- Remember that these behaviors are also good. Your child may be showing their independence or curiosity. This is part of development even though they can create barriers.
- Take a break if needed. You know your child best. It may not work to put devices back in when your child is upset or having a tantrum. Trust your judgment and wait for your child to calm down. Give your child positive attention when the devices are back in.

How do I know if the hearing aids are working?

Keep in mind that children may not respond right away. You may not see clear signs that they are hearing or see changes in speech and language right away. You may wonder if the devices are working. Your child's audiologist uses special techniques to make sure the hearing aids are set to your child's needs. Hearing aids can break or not work like they are supposed to at times, but this is not common.

You can check the sound of your child's hearing aids at home by doing a listening check every day (see Maintenance and Listening Checks section for instructions). It is important to check that hearing aids are amplifying the sounds in a safe way.

- There are indicator lights on the hearing devices that tell you if they are working.
- The light does not mean the sound is the way it should be. Check with the manufacturer on what the specific patterns or colors of light mean.

You will see many behavior responses from your child over time. Some parents notice that their child responds to sounds without their hearing aids. They may wonder whether their child needs the device. This can be confusing. Some children hear enough without hearing aids to respond to some sounds in their environment. This does not mean that they can hear all the sounds that are important for learning speech and language

If you wonder whether your child is benefiting from hearing aids, remember what speech sounds like with and without hearing aids. Talk with your child's audiologist if you have questions about why your child wears or does not wear hearing aids.

How can I help prevent the loss of their devices?

Hearing devices can cost a lot of money. Many families worry about losing them. There are accessories like clips, headbands and hats that can help keep hearing devices on ears. Many hearing devices also have phone applications that can help locate lost devices. There are still options if a device is lost.

For hearing aids:

New hearing aids often come with loss, damage and repair warranties from the company that makes the hearing aids. Families can also insure hearing aids in these ways:

- Buy extended warranties for loss or damage from the hearing aid manufacturer.
- Hearing aid insurance companies offer yearly warranties for loss and damage after the manufacturer's warranty
 expires.
- Some **homeowner's insurance policies** will cover the cost of lost hearing aids. You may ask your insurance agent about coverage and adding the hearing aids to your policy.

Talk with your child's audiologist for more information about warranties and policies to help protect your child's hearing aids.

For cochlear implants:

Cochlear implant processors, parts and accessories can cost a lot of money. Many families worry about damaging or losing these devices. The manufacturer warranties can help ease those concerns.

- Processors, headpieces and cables often come with a 5-year repair warranty with the first kit. They can be fixed
 for free if problems happen within the first 5 years of owning them.
- These devices also have a 1 time loss-and-damage warranty during the first 5 years. This means they can be replaced 1 time within the first 5 years if they are lost or damaged.

You will get a new warranty when you buy an upgraded processor. The upgraded processor, headpiece and cable often come with a 3-year repair warranty. Families can insure the devices in these ways when manufacturer warranties are over:

- Buy extended warranties for loss or damage from the device manufacturer.
- Some **homeowner's insurance policies** will cover the cost of lost hearing devices. You may ask your insurance agent about coverage and adding the devices to your policy.

Not all parts and accessories are covered by warranties. Talk with your child's audiologist to understand your warranties. Ask them what steps to take to ensure safe keeping and long-life of the equipment.

What causes the whistling? How can I stop it?

The whistling is called feedback. You may have heard a louder version at concerts or other public events. It happens when sound comes out of a speaker and moves to the microphone. Pointing the microphone away from the speaker will stop the whistling or feedback in these cases.

The speaker and microphone in a hearing aid are close together. This makes it easy for sound from the speaker to go back to the microphone. There is no way to redirect the microphone. Here are some ways to reduce feedback:

- Deep insertion of earmolds or domes
- New earmold tubing
- New earmolds
- Remove earwax from the ear canals or earmolds
- Feedback management from hearing aid programming by your child's audiologist
- Hearing aid adjustments by the audiologist

Call your child's audiologist if whistling or feedback continues. They can provide troubleshooting tips.

How can I help my child be independent with their hearing devices?

A feeling of ownership and responsibility for their hearing aids is an important goal for children.

- Let your older toddler or preschooler choose colors of earmolds or hearing devices. This can help them be part of the process. There are many different earmold color choices and stickers.
- Help your child become their own advocate when they start school.
 - Teach your child to tell an adult when the hearing aid battery needs to be changed. Or teach them how to change the battery themselves.
 - Encourage your child to ask their teacher and others to speak more clearly or rephrase if they did not hear them.
- Younger children can share books at daycare or preschool to help other children understand about hearing
 loss and hearing devices. Older children can share about their hearing loss and hearing aids during a show and
 tell. This can help them take ownership of their hearing loss and help other children understand.
- Children may feel empowered to advocate for themselves if they know they are not alone. Connect them with other children who are deaf or hard of hearing through parent groups or support groups.

This timeline is helpful for children developing independence with their devices:

heartolearn.org/research/infographics/Teaching%20HA%20Care Final.pdf

Resources

Batteries

Some places to buy batteries are:

- <u>hearingshop.com</u>
- cochlearbatteries.com
- hearingplanet.com
- adcohearing.com
- amazon.com

Accessories

You can buy accessories from the device manufacturer or choose from the places listed here.

Retention

- gearforears.com
- mybigcommerce.com
- https://hearinghenry.com
- silkawear.com
- etsy.com
 - Ear Suspenders
 - EarSavers
 - Thebebopshop
 - AnchorYouHearing
 - LilNells
 - EARSfashion
 - TheBAHABowtique (for bone conduction hearing aids)

Decorate or personalize

- <u>hayleighscherishedcharms.com</u>
- etsy.com
 - PurpleCatAidCharms
 - HearlamDesigns

- JaaCreations
- DHHdesignstudio
- BAHABeautiful

Moisture control (dry aid kits)

- hearingaidsweatband.com
- gearforears.com
- dryandstore.com

Earplugs

- etymotic.com
- https://www.earplugstore.com
- Ask your child's audiologist about custom earplugs and swim molds.

Assistive listening devices

- audex.com
- adcohearing.com
- harriscomm.com
- <u>hitec.com</u>
- weitbrecht.com

Special needs laws

- wrightslaw.com
- listen-up.org
- hearingloss.org
- letgeorgiahear.org

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources throughout this handbook and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these Sites. Use of the links provided on this or other sites is at your sole risk.

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Children's Healthcare of Atlanta:

Provides people with disabilities reasonable modifications and free appropriate auxiliary aids and services to communicate effectively with us, such as:

- Qualified sign language interpreters.
- Written information in other formats (large print, audio, accessible electronic formats).

Provides free language assistance services to people whose primary language is not English, including:

- Qualified interpreters.
- Information written in other languages.

If you need any of these services, contact Children's Civil Rights Coordinator at 404-785-4545.

If you believe that Children's has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance with:

Children's Civil Rights Coordinator 1575 Northeast Expressway NE Atlanta, GA 30329 404-785-4545 section1557coordinator@choa.org

If you need help filing a grievance, Children's Civil Rights Coordinator is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services Office for Civil Rights electronically through the Office for Civil Rights complaint portal, available at ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

U.S. Department of Health and Human Services 200 Independence Ave. SW Room 509F, HHH Building Washington, DC 20201 800-368-1019 800-537-7697 (TDD)

Complaint forms are available at:

http://www.hhs.gov/ocr/office/file/index.html

This notice is available at **choa.org**.

Language Assistance Services and Auxiliary Aid Services

English

ATTENTION: If you speak English, free language assistance services are available to you. Appropriate auxiliary aids and services to provide information in accessible formats are also available free of charge. Call 404-785-4545 or speak to your provider.

Spanish

ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. También están disponibles de forma gratuita ayuda y servicios auxiliares apropiados para proporcionar información en formatos accesibles. Llame al 404-785-4545 o hable con su proveedor.

Vietnamese

LƯU Ý: Nếu quý vị nói tiếng Việt, chúng tôi cung cấp miễn phí các dịch vụ hỗ trợ ngôn ngữ. Các dịch vụ và phương tiện hỗ trợ phù hợp để cung cấp thông tin theo các định dạng dễ sử dụng cũng được cung cấp miễn phí. Vui lòng gọi theo số 404-785-4545 hoặc trao đổi với người cung cấp dịch vụ của quý vị.

Korean

주의: 한국어를 사용하시는 경우 무료 언어 지원 서비스를 이용하실 수 있습니다. 이용 가능한 방식으로 정보를 제공하는 적절한 보조 기구 및 서비스도 무료로 제공됩니다. 404-785-4545 번으로 전화하거나 서비스 제공업체에 문의하십시오.

Chinese

注意:如果您说[中文],我们将免费为您提供语言协助服务。我们还免费提供适当的辅助工具和服务,以无障碍格式提供信息。请致电 404-785-4545 或咨询您的服务提供商。

Gujarati

ધ્યાન આપો: જો તમે ગુજરાતી બોલતા હો તો મફત ભાષાકીય સહાયતા સેવાઓ તમારા માટે ઉપલબ્ધ છે. સુલભ ફૉર્મેટમાં માહિતી પૂરી પાડવા માટે યોગ્ય સહાયક સાધનો અને સેવાઓ પણ વિના મૂલ્યે ઉપલબ્ધ છે. 404-785-4545 પર કૉલ કરો અથવા તમારા પ્રદાતા સાથે વાત કરો.

Language Assistance Services and Auxiliary Aid Services

French

ATTENTION : Si vous parlez français, des services d'assistance linguistique gratuits sont à votre disposition. Des aides et des services auxiliaires appropriés pour fournir des informations dans des formats accessibles sont également disponibles gratuitement. Appelez le 404-785-4545 ou parlez à votre fournisseur de services.

Amharic

Hindi

ध्यान दें: यदि आप हिंदी बोलते हैं, तो आपके लिए निःशुल्क भाषा सहायता सेवाएँ उपलब्ध हैं। सुलभ प्रारूपों में जानकारी प्रदान करने के लिए उपयुक्त सहायक साधन और सेवाएँ भी निःशुल्क उपलब्ध हैं। 404-785-4545 पर कॉल करें या अपने प्रदाता से बात करें।

Haitian

ATANSYON: Si'w pale Kreyòl, sèvis assistans lang ou disponib pou ou gratis. Èd ak sèvis oksilyè apwopriye pou bay enfòmasyon nan fòma aksesib yo disponib gratis tou. Rele nan 404-785-4545 oswa pale avèk founisè ou.

Russian

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Arabic

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Language Assistance Services and Auxiliary Aid Services

Brazilian Portuguese

ATENÇÃO: Se você fala português do Brasil, serviços gratuitos de assistência linguística estão disponíveis para você. Auxílios e serviços auxiliares, apropriados para fornecer informações em formatos acessíveis, também estão disponíveis gratuitamente. Ligue para 404-785-4545 ou fale com o seu provedor.

Telugu

గమనించండి: మీరు తెలుగు మాట్లాడితే, మీకు ఉచిత భాషా సహాయ సేవలు అందుబాటులో ఉంటాయి. యాక్సెస్ చేయగల ఫార్మాట్లలో సమాచారాన్ని అందించడానికి తగిన సహాయక చర్యలు మరియు సేవలు కూడా ఉచితంగా అందుబాటులో ఉంటాయి. 404-785-4545 కి కాల్ చేయండి లేదా మీ ప్రొసైడర్తో మాట్లాడండి.

German

ACHTUNG: Sie haben Anspruch auf kostenlose Sprachdienste, wenn Sie Englisch sprechen können. Kostenlose Dienstleistungen und Hilfsmittel, die geeignet sind, Informationen in zugänglicher Form zu vermitteln, werden ebenfalls angeboten. Sprechen Sie mit Ihrem Anbieter oder rufen Sie die Nummer 404-785-4545 an.

Tamil

கவனிக்க: நீங்கள் ஆங்கிலம் பேசுபவராக இருப்பின், இலவச மொழி உதவி சேவைகள் உங்களுக்கு வழங்கப்படும். எளிதில் அணுகக்கூடிய வகையில் தகவல்களை வழங்குவதற்கான பொருத்தமான துணை உதவிகளும் சேவைகளும் இலவசமாகக் கிடைக்கின்றன. இந்த சேவையை பெற 404-785-4545 என்ற எண்ணிற்கு அழைக்கவும் அல்லது உங்கள் வழங்குநரிடம் கலந்துரையாடவும்.