



Cochlear Implants: How Do I Go About Getting a Cochlear Implant?

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Once you feel (or have been told by an audiologist or physician) that you are at the point where you need a cochlear implant and in all likelihood meet the criteria for candidacy, your next question is likely to be “How do I go about getting an implant?” Here are some steps to take:

1. Find out which cochlear implant clinics are nearest you.

At this time, there are three manufacturers who are approved by the U.S. Food and Drug Administration (FDA) to sell cochlear implants in the U.S. They are Advanced Bionics, Cochlear Americas and MED-EL. Each of them has a website which provides a list of clinics that implant their devices:

Advanced Bionics:

www.bionicear.com / 1-800-678-2575

Cochlear Americas:

www.cochlearamericas.com / 1-800-523-5798

[This list also includes clinics handling their bone-anchored hearing aids]

MED-EL:

www.medel.com / 1-888-633-3524

2. Check the clinics for features that could be important to you.

- Is the center close enough to your home?
- Who is on the cochlear implant team and how much experience do they have? (This is especially important when the implant is for a child).
- Does the center provide (re)habilitation services?
- If you have an HMO as your insurance carrier, is this center included in its coverage for CI surgery?.

3. Talk to cochlear implant users of each brand to learn their experiences.

- Do they like their implant?
- How has their implant improved their hearing and in what ways—personal life, family life, friendships, school, workplace, worship, entertainment?

- What kinds of listening situations remain difficult for them, such as communicating in noisy places and phone use?
- How does their implant work, what does it look like, what features does it have, and what limitations does it have?

4. Talk to cochlear implant users to learn their views about the clinic they go to and its cochlear implant team (surgeon, audiologist, others).

- Are they satisfied with the services they are getting?
- Are they able to get appointments in a timely manner, especially in an emergency?
- Does the clinic provide all three brands or just one or two?
- Does the staff have a high turnover rate?
- Is the audiologist able to troubleshoot when there is a problem with adjusting the implant processor?



Some ways to find cochlear implant users if you don't know any

- Ask your current audiologist where you can meet local implant users, or have the audiologist contact those implant users on your behalf and to encourage the implant users to contact you.
- Call the nearest cochlear implant clinic and ask them if they could have a patient or two contact you.
- Contact a chapter of HLAA (Hearing Loss Association of America) in your area; you are likely to find at least several implant users at chapter meetings. To find a chapter of Hearing Loss Association of America and chapter contact person: www.hearingloss.org or 301-657-2248; 301-913-9413 Fax.
- If you do not have an HLAA chapter nearby, join HLAA's Online Community to connect with community members who have cochlear implants: www.hear4life.org
- Connect with other national organizations which have chapters:
 - Association of Late-Deafened Adults: www.alda.org
 - Alexander Graham Bell Association: www.agbell.org
 - National Association of the Deaf: www.nad.org

- Attend a convention of one of these national organizations. Many of these conventions have workshops about cochlear implants, including presentations by each of the three main manufacturers. This is a wonderful way to acquire information as well as meet and talk with implant users. For convention dates, check the organization's websites.
 - Join one of the online cochlear implant forums such as York, and ask who in the group has a cochlear implant and lives in your geographical area. This is an excellent way to start becoming acquainted with other implant users, nearly all of whom will be happy to answer your questions and share their experiences with you. See the list of forums at the end of this section.
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5. Go through the candidate evaluation process:

Once you have selected your cochlear implant center, the center will obtain your history to determine whether an evaluation is appropriate. The history can include hearing aid use, history of speech therapy/training, the existence of other medical conditions, and records of audiograms and other hearing tests. If the history indicates you become a candidate for an implant and the evaluation process begins.

As a candidate you will undergo some or all of the following tests to make certain there are no underlying causes that would screen you out. The evaluation process helps to minimize the risks associated with cochlear implant surgery and ensure that you are an appropriate candidate.

Audiological examination – An extensive audiologic exam is done with and without your hearing aids. It includes pure-tone audiograms, sentence discrimination in quiet and in noise, and multi-syllable and single-syllable words.

Balance function tests – Not everyone is put through balance function testing, but some people who have a history of balance problems will undergo these tests. The physician wants to make sure that if you are one of these candidates you will not be at risk of losing whatever remaining balance you have after cochlear implant surgery. The vestibular system is right next to the cochlea and can be affected by cochlear implant surgery.

Psychological evaluation – When this is ordered, you will meet with a psychologist, who then gives his/her assessment of your expectations regarding hearing with a cochlear implant.

Physical examination – The implant surgeon will examine your ears, nose, and throat.

CT or MRI – These tests are done to determine the condition (size and shape) and health of the cochleas. Results of the scan can rule out a candidate. For example, one candidate was found to have a craniopharyngioma when she had a CT scan, and was

not able to go forward with getting a cochlear implant.

Promontory stimulation test – Some centers do this test, but it is no longer routinely done. It involves numbing your ear drum and inserting an electrode through it, then performing pure-tone testing to see how you respond.

Vaccination - Cochlear implant surgery, like any surgical procedure, is not risk-free. According to the FDA, cochlear implant recipients may be at higher risk for pneumococcal meningitis. Some centers require prospective implant recipients to be vaccinated against this; for full protection, it should be done at least two weeks prior to the surgery. If your insurance company does not cover the cost of your vaccination, the manufacturer of the brand you have chosen may be willing to do so.

Cochlear Implant Forums

Some of these online forums are private and open by invitation only, while others are open to any implant user or future implant user. Some forums are “controlled,” while others are open to all devices, all views. You need to determine which is suitable for your own particular needs. Here is a sampling of forums to get you started.

1. Nucleus (Cochlear Americas brand) Forum:

This is a private list for users of the Cochlear Corp. brand (Nucleus 24 and Freedom, for example) and those planning to get that brand. Send an email to help@nucleusci.com

2. Clarion CI Forum:

This private list is limited to users of the Advanced Bionics device (Clarion, Harmony, for example) or those planning to get that brand. Send an email to mbrownen@flash.net or someone whom you know is a member of this list.

3. CI Circle:

This list is for parents of children with implants, and suitable if you are a parent considering whether your child should have an implant.
<http://groups.yahoo.com/group/cicircle>

4. CI Hear:

This is a forum for adults that is open to users of all brands and persons considering getting an implant. <http://groups.yahoo.com/group/CIHear/>

5. Cmaillist:

This forum is for members only but welcomes users of all brands and other interested persons. <http://groups.yahoo.com/group/ci/>

6. York U CI List:

This is open to all brands and to persons who are interested in implants. To sign up, send a message to listserv@yorku.ca and in the text put "subscribe ci firstname lastname [insert yours], for example **subscribe ci Joe Smith**"); do not put anything in the subject line.

For More Information:

- The National Institution on Deafness and Other Communication Disorders (NIDCD), which is part of the National Institutes of Health: www.nidcd.nih.gov/health/hearing/coch.asp
- NIDCD's directory of organizations that provide information (in print and online) on cochlear implants: www.nidcd.nih.gov/directory (select "Search by Keyword" on this page and click on "cochlear implants")
- Cochlear Implant Education Center, within The Laurent Clerc National Deaf Education Center at Gallaudet University: clerccenter.gallaudet.edu

A Cautionary Note:

As you search the Internet for information about cochlear implants and clinics where you might get an implant, keep in mind that this is a vast and very fluid resource. You will need to be very careful to separate the wheat from the chaff. There is a lot of misinformation among the nuggets you will uncover. Be especially wary of blogs, which reflect personal opinions more than factual information that you can rely on. If you find a statement or passage that puzzles you or appears to be propaganda, print it out and consult a physician or audiologist about it, or do further research in an attempt to determine the accuracy of the statement, opinion, or claim.

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