

How Does One Plan for a Cochlear Implant?

I. The process of being evaluated for a Cochlear Implant is multidirectional/multi-involvement. One must see both an audiologist and a CI Surgeon. Sometimes an ENT and sometimes the audiologist make the original suggestion. The process takes a lot of work—a lot of homework. Although the audiologist and doctor will make suggestions regarding the implant, you as an individual need to make the decision as to which brand/company you will select. Understand this is a decision that you will be with for the rest of your life. Like a tattoo, some things might be changed in the future, but changes are difficult, and expensive. It is easy to say, “whatever the audiologist or doctor suggests” is what I will choose.” If that is your thinking, then give me \$30,000 and I will choose a car that I think will fit your needs for the rest of your life. Your homework and decision making process is very important.

- a) What do I know about the CI companies?
- b) How does the implant fit my lifestyle?
- c) What features are available on each that I might want/need?
- d) How old is this implant/processor? Is the company about ready to market a new implant or processor? Which is newest? Is it too new? Is it too old?
- e) How familiar are my audiologist and doctor with this product? (Will my hearing professional need to go to the help section in the programming process multiple times to give me the best programming because s/he has only a few clients that have this product?) Product familiarity is very important.
- f) Will the processor be compatible with my hearing aid? Is it Bluetooth accessible or will I need a streamer? How many microphones does it have? Are these actual microphones or computer directed changes?

II. My pre-implantation evaluation should involve:

- a) My internist/primary care physician/family doctor. (Keep updated throughout)
- b) All other medical people that I have seen in the last year or who prescribes medication for me.
- c) “Undergo pre-admission testing (PAT) with the anesthesiologist prior to surgery to confirm medical candidacy.”
- d) “Psychologically, it's essential that the patient understands the complexity of the post-surgical rehabilitation process and the absolute commitment that's required to maximize one's benefit following surgery. These issues are discussed both by the surgeon and CI audiologist.”
- e) “A third-party evaluation by a social worker or psychologist familiar with cochlear implants and the rehabilitative process can prove helpful in this regard.”

Severtson, M.D.

III. “Figure out how you will effectively give and receive information from all of the people involved in your CI Journey. People will call to access information or to give you information. How will they best communicate.

- a) E-mail
- b) Fax
- c) Text
- d) Call back and leave a message for a family member to interpret.
- e) Caption Phone (save dialogue whenever possible)”
- f) Go to the provider’s office (walk-in) to find out the information needed. Use an assistive listening device.

Convey this need to each provider in advance whenever possible. Record calls if possible to clarify with someone later if needed.

IV. Talk/email your insurance provider. Confirm coverage and eligibility. “Get authorizations in writing.” (CI Hear)

V. From the beginning, keep multiple folders and notebooks:

- 1. For Insurance information. Summarize each conversation, date, time and with whom. Keep all letters, billings, authorizations, contacts and phone numbers. Know who your nurse/case manager is and how to contact.
- 2. All medical information, contacts, phone numbers, fax, e-mail etc.
 - a) all past and present audiograms
 - b) lab reports
 - c) a copy of all medical evaluations
 - d) keep a log of expenses, travel, copying, mailing etc.
 - e) keep originals—make copies if someone needs to see/keep a record.
 - f) authorizations

(CI Hear)

- 3. Memory is the process by which we forget. Keep a diary both of medical, audiological, and insurance discussions. “This is what I heard.”
- 4. Keep a general diary of feelings and experiences to share with others in the future.
- 5. Keep an ongoing contact sheet (phone numbers, fax, e-mail etc.) for quick references.
- 6. Discuss with all involved the sequence of events.

VI. Be sure you have a clear understanding of the surgical and recovery process.

- a) Hair shaved?
- b) How invasive? How much cutting, drilling.
- c) Risk of infection? How will that be controlled?
- d) Residual Hearing?
- e) Outpatient/Inpatient?
- f) Aftercare? Number of visits?
- g) Sequence of events?

VI. **“Making the Choice”**

CI Hear

Fri Mar 31, 2017 5:56 pm (PDT) . Posted by Alice

“Many individuals who are considering a cochlear implant look for help in comparing the different types of implants. They go to various internet groups to find out which implant is best. Comparing or recommending is not the place of CI users. Sharing experiences with what the implant user knows and experiences is. Sharing the websites that site comparisons only creates a false sense of what is true and what is not. Unfortunately, those sites are written by opinionated individuals who are biased toward a particular type of implant thus they are negative towards the others. Herein, we find the very essence of what we know as the brand wars. It’s amazing that you only see this happen with cochlear implant users but this device brings such a degree of passion and loyalty to the users brand that they lose sight of the reality that all of the implants provide amazing sound that brings quality of life. The Cochlear Implant makes miracles happen.

So how does a new implant investigator decide which implant is the one they should choose? The answers are very straight forward. You will realize that these points are my opinion but they are based on over 8 years of activity on various lists and internet chat rooms.”

A. Go to the particular brand website.

www.bionicear.com

www.cochlear.com

www.medel.com

B. Check out the videos, CDs, information packets, and talk with their customer service people. Find out about programs in your area that they may be presenting.

C. Go to you hearing specialist that is CI trained.

1. You need to trust them.
2. Be prepared to ask questions.
3. Share your concerns.
4. Don’t leave the office until your concerns and questions have been adequately addressed.
5. With which implant are they most experienced and enjoy working with.
6. Try their sample models with batteries to see if you are comfortable with the fit and weight.
7. Ask to talk to some of their clients.
8. If children are involved, speak to parents. Talk to other children when possible and appropriate.
9. Who will do your programing and mapping? Are they easily accessible from your home?
What are their office hours? Is travel an issue?
10. Check out internet groups that discuss CI issues. Join them. Read messages and archives.

“Cochlear implants are speech processors. That is the intent of the equipment. Since speech is the important element in life that we need for communications, it is and should be on the top of the list of things accomplished by your CI. Anything beyond that is just a blessing to you and for you to enjoy. The sound is not normal. It is not normal hearing. It is stimulated thru a series of electrodes that generate energy to the auditory nerve which feeds the brain with electronic sound. Over time, this electronic sound becomes more and more normal as you use it daily for your listening needs. Eventually, people sound much like you remember and this is very enjoyable. Always keep in mind that understanding what is being said is the most important feature and remembering that is extremely important - no matter how the sound comes to you.”

“Everyone is different. You may experience understandable sound when you go for your activation. It may take weeks, months and in some cases years. Keeping your expectations low and your hopes in balance will help you thru those days when you might feel as if you have made the worst mistake of your life. It does get better. For some it's faster than others, but very few people report no improvement at all. Patience, patience, patience.”

“Your job is to make the decision of which type you want for yourself or your child. To make this a little easier, after you have been thru all the processes above, take a sheet of paper and write the pros on one side and the cons on the other of each implant type. Be sure that what you have written is what is most important to you. Once this is done, you should have your decision and when you do - stick with it - no matter what it is. Don't look back. Don't let others try to tell you that your decision is wrong. It is your decision and if they sway you in another direction and you end up disappointed, you are going to feel the need to blame them. This is a very important decision, a very happy decision, and a very meaningful decision. Enjoy your right to make it.” (CI Hear, Alice)

Thanks to:

Dr. Mark Severtson

Information is adapted from CIHEar@yahoogroups.com; Digest # 6144; “Successfully Wading Thru a CI Evaluation.”

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