

Should my child have a second cochlear implant?

A decision aid to discuss options with your health care team

This decision aid is for you if:

- Your child has a cochlear implant.
- You are wondering about a cochlear implant for your child's other ear.

What is a cochlear implant?

- A cochlear implant is a surgically implanted electronic device that provides a sense of sound to a person who is profoundly deaf or severely hard of hearing. The internal component works by directly stimulating the auditory nerves inside the cochlea with electrical impulses. External components include a microphone, speech processor and transmitter.

What are your options?



Accept a second cochlear implant. The procedure is the same as the first. After a general anaesthetic, the device is implanted by surgery. Your child will stay in the hospital for about 2 days. Healing takes about a month and then the device is activated. Your child will have continuing auditory-verbal or other type of therapy. The second implant provides auditory stimulation to your child's second ear. The second implant can also act as a "back-up" in case of damage or malfunction of the first implant.



Decline a second cochlear implant. You continue with the current implant and follow-up therapy. You may wish to consider an implant at a later date. Some research indicates that when children receive the second implant within a shorter period after the first one they see greater benefits than when they receive the implant later.

What other health factors may affect your choice?

Check any that apply and discuss your concerns with your doctor.

Your child may not be a candidate for a second implant if he or she has the following:

- Absent auditory nerve in second ear
- Medical reasons for not having surgery

Working through the 4 steps of this decision aid may prepare you for decision making.

Step 1: What are the benefits and risks of each option?

Step 2: Which reasons to choose each option matter most to you?

Step 3: What else do you need to prepare for decision-making?

Step 4: What are the next steps?

Step 1: What are the benefits and risks of each option?

What does the research show?

- Blocks of 100 faces show a 'best estimate' of what happens to **100 children who already have one cochlear implant** who make different choices over 1 year. Each face (☺) stands for one child. The shaded areas show the number of children affected. The numbers are averaged from more than one study.
- There is no way of knowing in advance if your child will be the one who is affected.
- Because this is a new procedure, there is not a lot of research on the long-term effects of bilateral implants. The numbers presented here are based on the literature. Your cochlear implant centre may have different rates. Please talk to your clinician about the rates at your centre.

| |  1 cochlear implant Decline 2nd implant |  2 cochlear implants Accept 2nd implant | Comments from CHEO clinic |
|--|---|--|--|
| Benefits | | | |
| <p>✦ More children will be able to locate sounds in their environment with a second implant. For example, a child could hear the direction of a parent's voice more easily.</p> | <p>14 improve 86 don't improve</p>  | <p>46 improve 54 don't improve</p>  | Our clinic has not measured sound localization in our patients. |
| <p>✦ More children will be able to understand speech in a noisy environment at normal levels with a second implant. For example, being able to understand people talking in a group setting.</p> | <p>0 improve 100 don't improve</p>  | <p>13 improve 87 don't improve</p>  | Our clinic has measured some improvements in understanding of speech in noise for most children with two implants |
| <p>✦ The same number of children will have normal receptive vocabulary with a second implant as those with one implant.</p> | <p>67 have normal receptive vocabulary 33 are still working on this</p>  | <p>67 have normal receptive vocabulary 33 are still working on this</p>  | Our clinic's experience is that children who have had more challenges in developing speech and language with one implant will continue to do so with two implants. |
| Risks | | | |
| <p>✦ There is a risk of surgical complications with a second cochlear implant just like the first surgery.</p> <p>Surgical complications may include ear draining or skin infections, or infections in the head area behind the middle ear.</p> | <p>0 get complications 100 avoid this</p>  | <p>12 get complications 88 avoid this</p>  | Our clinic has similar rates. |
| <p>✦ There is a risk of a permanent facial palsy with a second cochlear implant just like the first surgery.</p> <p>A facial palsy is an inability to control some muscles in the face.</p> | <p>0 of 1000 have this 1000 of 1000 avoid this</p> | <p>1 of 1000 have this 999 of 1000 avoid this</p> | Our clinic has not had a child experience this. There is a risk of this in the future. |
| <p>✦ There is a risk of meningitis with a second cochlear implant surgery just like the first surgery.</p> <p>Meningitis is an infection in the fluid around the brain and spinal cord.</p> | <p>2 of 1000 have this 998 of 1000 avoid this</p> | <p>2 of 1000 have this 998 of 1000 avoid this</p> | Our clinic has similar rates |
| Risks over a FIVE YEAR period | | | |
| <p>✦ There is a risk of a damaged or defective implant with a second cochlear implant just like the first implant.</p> <p>Damage to the implant can happen from falling and hitting the implant, or from a problem with the implant itself. The device needs to be replaced in this case.</p> | <p>7 have a damaged implant 93 avoid this</p>  | <p>14 have a damaged implant 86 avoid this</p>  | The rate at our clinic is slightly better. About 4 of 100 children with one implant experience a damaged or defective implant. |

Step 2. Which reasons to choose each option matter most to you?

Common reasons to choose each option are listed below.

Check ✓ how much each reason matters to you on a scale from 0 to 5.

'0' means it is **not** important to you. '5' means it is **very** important to you.



Reasons to **Accept a second cochlear implant**

| | Not Important | | | | | Very Important | | | | |
|--|---------------|--|--|--|--|----------------|--|--|--|--|
|--|---------------|--|--|--|--|----------------|--|--|--|--|

How important is it to improve your child's ability to locate sounds in their environment such as being able to determine the direction of a person's voice?

① ① ② ③ ④ ⑤

How important is it to improve your child's ability to understand people talking in a noisy setting such as a classroom or restaurant?

① ① ② ③ ④ ⑤

How important is it to expose your child's second ear to early speech and language stimulation?

① ① ② ③ ④ ⑤

List other reasons to accept a second cochlear implant:

① ① ② ③ ④ ⑤



Reasons to **Decline a second cochlear implant**

| | Not Important | | | | | Very Important | | | | |
|--|---------------|--|--|--|--|----------------|--|--|--|--|
|--|---------------|--|--|--|--|----------------|--|--|--|--|

How important is it to avoid the risks of surgery such as ear draining, skin infections, or infections in the head area behind the middle ear?

① ① ② ③ ④ ⑤

How important is it to wait until there is more scientific evidence on the effects of a second cochlear implant?

① ① ② ③ ④ ⑤

List other reasons to decline a second cochlear implant:

① ① ② ③ ④ ⑤

Now, think about which option has the reasons that are most important to you.

Which option do you prefer? Check one

- 2 cochlear implants / Accept a second cochlear implant
 - 1 cochlear implant / Decline a second cochlear implant
 - I don't know
-

Step 3: What else do you need to prepare for decision making?



Knowledge

Find out how well this decision aid helped you learn the key facts.

Check the best answer.

| | 2 cochlear implants | 1 cochlear implant | Both are equal | Don't know |
|---|--------------------------------|---------------------------------|--------------------------|--------------------------|
| | Accept 2 nd implant | Decline 2 nd implant | | |
| 1. Which option has the <u>highest</u> chance of your child being able to locate sounds in the environment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Which option has the <u>highest</u> chance of your child being able to understand speech in a noisy environment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Which option has an <u>increased</u> chance of ear draining, skin infections, or infections in the head area behind the middle ear? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Which option <u>improves</u> receptive vocabulary? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Which option has the <u>most</u> scientific evidence on long term outcomes? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Check your answers at the bottom of the page.

Do you know the current evidence on benefits and risks of each option? Yes No



Values

Are you clear about which benefits and risks **matter most** to you? Yes No



Support

Do you have enough support and advice from others to make a choice? Yes No



Uncertainty

Do you feel sure about the best choice? Yes No

Step 4: What are the next steps?

List your plans: (for example, discuss the options with your health care team and/or learn more about the options)

This information is not intended to replace the advice of a health care provider.

Answers for the key facts: 1. 2 implants, accept 2nd implant 2. 2 implants, accept 2nd implant 3. 2 implants, accept 2nd implant, 4. Both equal 5. 1 implant, decline 2nd implant.

Content Editors: C. Johnston, A. Durieux-Smith, L. Moran, Dr. D. Schramm, E. Fitzpatrick.

Funded in part by: Canadian Language and Literacy Research Network, Ontario Graduate Scholarship in Science and Technology. Dr. D. Schramm and E. Fitzpatrick have both received funding from cochlear implant companies in conducting research on cochlear implantation.

Format is based on the Ottawa Decision Guide © 2000, A. O'Connor, D. Stacey, University of Ottawa, Canada.

Publication date © 2009.