BIAP recommendation n° 07/1 : Information on Cochlear Implants for hearing-impaired children

CT 07 recommends care-taking by professionals of the multidisciplinary audio-phonological team (cf. CT 14) for the severe or very severe hearing-impaired infant, if possible before the age of six month.

Consequently, it recommends :

Precise diagnosis of the hearing impairment and possible related disorders together with the necessary complementary screening.
Close contact with parents or parental guidance.
Optimum development of the chosen mode or modes of communication according to parental choice.
Early hearing-aid adaptation.
Continuous assessment of the child’s development prior to any implantation decision.

1. FAMILY INFORMATION

Two parts :

- for children presenting a congenital or pre-lingual hearing impairment
- for children presenting a post-lingual impairment : acquired or developing deafness.

1.1. For children presenting a congenital or pre-lingual hearing impairment

1.1.1. Information during the diagnosis procedure

Straightforward information on cochlear implants can be given from the start of this process, within the general information framework. This information should not diminish commitment to care process and in particular to the hearing-aid.

Consequently, the following points must be stressed :

- the placing of a cochlear implant is not a « miracle » operation. It does not restore the ear or re-establish normal hearing capacity.
- it has precise and limited indications. It can only be proposed after a period of observation long enough to assess benefit of hearing-aids and the child’s development.

During this period, it is essential, with parental participation :

- to pursue prosthetic adaptation while stressing the patience necessary for assessing results.
- to practice well-adapted and continuous hearing and perception education.
- to develop the child’s powers of communication and to create language access conditions.

This care-process is, in all its aspects, a pre-requisite for any future cochlear implantation.

During this period, families must be helped in considering :
- hearing impairment and its repercussions
- the choice of communication mode
- the psychological, linguistic and pedagogic implications of this choice.

1.1.2. Information given by the audio-phonological team during the care-process

1.1.2.1. Collective information

This information can come in several forms and be part of the general information given to families : interviews, conferences, parent meetings, contacts with hearing-impaired individuals.

This information must be widely pluri-disciplinary.

Documents and videos may be used as long as they present an objective view of potential results.

Above all, this information must be coherent and distance itself from - even maintain a critical attitude towards - media-diffused information.

Finally, within the cochlear implant general information framework, the commission requires an approach to the problem of hearing impairment-related disability. The presence of related disability does not constitute a counter-indication for the cochlear implant. In taking the decision, however, the child’s potentialities, the existence of a communication strategy and the family’s motivation will all have to be taken into account. The indication thus depends chiefly on the benefit to be derived from the implant in the context of this related pathology.

1.1.2.2. Personalised information (when the possibility of a cochlear implant is being considered).

A possible implant may be under consideration either for the audio-phonological team caring for the child, or by the family trying to make a decision about this possibility. It is necessary for the different members of the team to have been in consultation before giving any answer to the plan.

The role of the doctor (ENT, phoniatrists or audio-phonologist) is important for this information but it must be given in close collaboration with the professionals concerned (cf. recommendations CT-25 Annex : doctor’s role in parental guidance).

The information must be wide-ranging, repetitive, personalised :

- information on the implant itself

· its principle, benefits, limits and different types of implant
· how can it benefit the child as compared with the present situation ?

- Information on the pre-implantation period
- Parents must be informed :
· on the necessity for complementary examinations
· on the possibility of a counter-indication to the operation
· on the importance of the parental decision. This decision requires a commitment :
- to oral language development
- to assiduity in the post-implantation rehabilitation programme

Parents must be allowed time to reformulate their questions and to meet with :
- hearing-impaired individuals
- families of hearing-impaired children with or without implant
- members of associations for parents of hearing-impaired children with or without cochlear implant.

The family may go through a difficult period before making a decision. The obligation of choice and the heavy responsibility it represents may require psychological help, to be adapted to this particular situation (cf. recommendation CT-25 - Parental guidance).

1.1.3. The family approaches or is approached by the implantation team

This team must make contact with the caring team. It must ask for the child's multidisciplinary file and study it.

Initial questioning and examinations shall aim at assessing the feasibility of implantation and any possible counter-indication.

1.1.3.1. Observation period with implantation in view

Except in special cases, the implantation decision may only be made after a minimum six-month observation period. This time-lag is necessary for the infant in order to assess the child's development, making sure beforehand of the quality of care and hearing-aid adaptation during this period. Prosthetic hearing perception must be checked and this examination repeated if necessary. Finally, this time-lapse will allow families to come to a considered decision.

1.1.3.2. Feasibility study

This requires the participation of the entire pluridisciplinary implantation team. There must exist a consensus on the implantation indication between the implantation team and the team taking charge of the child.
The feasibility study requires :
- an ENT examination
- a complete audiometric examination
- a language assessment
- a prosthetic assessment
- a psychological assessment
- an aetiological investigation
- an investigation of related disorders.

Complementary examinations :
- electro-physiological examinations
- radiological examinations (scanner, MRI, etc.)

1.1.3.3. The implantation team must keep the family informed

It should maintain permanent contact with the care-taking team in order to assess the child's development.

It should provide all necessary information

- on whatever benefit can be obtained with an implant and the possible use of residual hearing capacity
- on the surgical operation, including risks and cost.
- on the time-lag between the operation and activating the implant
- on the post-implantation follow-up, the modalities, duration and cost.
- on possible technical progress in the future and possible technical failure, which may both justify the replacement of all or part of the device, with or without surgical intervention.

It shall organise meetings with implanted children and their families.

The commission stresses the fact that the final decision always rests with the family.

1.2. For children presenting a post-lingual hearing impairment

This may be an acquired or a developing hearing impairment.

Information recommendations will be the same as those for children presenting congenital or pre-lingual deafness.

However, the commission wishes to point out that :
· the diagnosis and assessment of benefit will be easier.
· the possibility of a cochlear implant can be explored early, especially for post-meningitis deafness.
· Post-implant re-education can be shortened but depends on how long the deafness has existed.
· Oral communication must be preserved and stimulated but other forms of communication, adapted to the child's specific needs, may be necessary.
· There must exist a consensus on the implantation indication between the implantation team and the team taking charge of the child.

2. INFORMATION GIVEN TO THE CHILD TO BE FITTED WITH A COCHLEAR IMPLANT

The commission wishes to stress the need to also provide the child himself/herself with as much information as possible. This information shall be adapted to the child's comprehension and language level, in order to allow him or her to take part as far as possible in the implantation decision process.

Information should be given using every available means of transmission of a message, depending on the hearing-impaired child's age. For example, the external implant apparatus can be presented : the child can also meet with other children fitted with an implant.

This information should be given immediately before the operation, during the post-operative period and later at the time of the settings.

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