NATIONAL INSTITUTE FOR HEALTH & CLINICAL EXCELLENCE
HEALTH TECHNOLOGY APPRAISAL

COCHLEAR IMPLANTS IN DEAFENED ADULTS

PATIENT INTEREST SUBMISSION
MARCH 2007

THE LINK CENTRE FOR DEAFENED PEOPLE
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Executive summary

CICS, NCIUA, RNID, NDCS, LINK and the Ear Foundation have discussed and shared submissions to NICE in order to avoid duplication. While sending separate submissions, we would like to make it clear that we are broadly supportive of the submissions made by the afore-mentioned groups made to NICE about cochlear implantation.

The LINK Centre for Deafened People
LINK works with and on behalf of deafened men and women and their families. Deafened people, including those with cochlear implants, play a crucial role at all levels activities of the organisation – as service users, volunteers, staff and trustees.

The deafened population
There are over 150,000 people in the UK who have become profoundly deafened as adults. After growing up with normal hearing and developing speech and language, these people lose all or most of their hearing through illness, injury, and other causes.

The effects of deafness
Becoming deafened in adult life is a life-changing event with far-reaching consequences, not only for the deafened person, but also for their partners and families. Difficulties are manifest in the following areas:

- Communication: frustration, fatigue and poor concentration.
- Family relationships: separation, divorce and family breakdown.
- Employment: low employment levels, limited job opportunities, loss of financial autonomy.
- Attitudes of other people: intolerance, stigma, discrimination.
- Mental health and quality of life: anxiety, depression, post traumatic stress disorder.

The benefits of cochlear implants
A cochlear implant confers huge benefits to a deafened adult and those they live with. It fits in well with a person’s life and is easy to maintain and use. It impacts positively on family, friends and employers. The benefits extend into all areas of daily life:

- Communication: improves concentration and energy levels, reduces negative impact of tinnitus.
- Family relationships: reduces family stress and tension, facilitates a return to normal role relationships, reduces dependency on partner and children.
- Attitudes of other people: increases tolerance, reduces stigma, reduces social exclusion, reduces the effort required by other people.
- Employment: improves work relationships, reduces discrimination, increases career opportunities.
- Mental health and quality of life: improves confidence and self-esteem, reduces anxiety and depression.

Cochlear implants are enormously effective and have changed the deafened experience completely. A cochlear implant is not just a piece of technology that restores sound and hearing. It improves a person’s ability to interact with others, enhances their sense of connectedness to the world, and helps them in the process of resuming their lives. Implantation is the only health technology intervention currently available to people with acquired profound hearing loss: the alternative is to remain profoundly deafened.
The LINK Centre for Deafened People

The LINK Centre for Deafened People is the leading organisation in the UK working with deafened men and women and their families to raise awareness of Acquired Profound Hearing Loss, to ensure appropriate support is widely available, and to facilitate networking.

Deafened people, including those with cochlear implants, play a central role at all levels of the organisation – as trustees, staff, tutors, peer educators, outreach volunteers, and as service users. The information presented here is derived from over 30 years experience, and from published texts and literature.

Acquired Profound Hearing Loss

Over 150,000 men and women in the UK live with the effects of acquired profound hearing loss. People with acquired profound hearing loss often refer to themselves as ‘deafened’.

An adult can lose all their hearing as a result of illness (meningitis, Menieres disease, viral infection), or accident (head injury, noise/drug induced), but often the cause cannot be identified (sensori-neural loss of unknown origin). The loss can occur suddenly, but it can also develop progressively over a period of months or years.

1. Effects of APHL on communication

Hearing lies at the heart of every human interaction. When hearing is lost or severely impaired, it disrupts communication between the person who has the hearing loss and anyone with whom they come into contact.

To follow conversation, deafened people have to learn a new set of communication skills - lip-reading, asking for words to be repeated or written down, and interpreting the visual clues people present with their gestures and expressions. A few deafened people become proficient in lipreading, but even when a person is speaking clearly, it is estimated that only one third of the sounds of English are visible on the lips.

Difficult as one to one conversations are, even with familiar speakers, full participation in group discussions is impossible. All conversations lose spontaneity, and are slow, laborious and painstaking.

Problems monitoring speech articulation and voice volume may further hamper communication because the ear no longer serves as a monitor when the deafened person talks. Deafened people commonly experience a degeneration of speech, a disintegration of sharpness and precision of articulation, and a loss of intonation and voice quality; the person may also speak too loudly or too softly. Speech degeneration exacerbates communication problems as the deafened person is not only unable to hear others, but may themselves be difficult to understand. An unusual or peculiar-sounding voice adds to the social stigma of deafness.

Deafened adults commonly experience tinnitus as a result of inner ear damage. Tinnitus may be as mild as a distant hum, or as loud as a pneumatic drill; it can be intermittent or occasional, persistent or unrelenting. Many people report their tinnitus to
be a continuous and debilitating condition from which they have no respite. It often has a severe impact on the person’s ability to lipread and concentrate.

Whatever the situation, communication demands continuous concentration, conscious effort, and tremendous physical and emotional energy - far beyond that which is required by a hearing person. The effort can be so onerous that the deafened person is reluctant to communicate with anybody, and may avoid social contact altogether. It is also the case that their conversation partners with full hearing experience fatigue, frustration and the need to modify their communication behaviour.

**Impact of a cochlear implant**

A cochlear implant has a huge beneficial effect on communication, best experienced in one to one situations, but still useful to some extent in groups, and with strangers. A minority of implant users say they can follow what is being said, even when the speaker’s back is turned.

The majority, however, find that although communication continues to require concentration and focused attention, this is to a much lesser degree than before the implant. Even though the person is now able to use sound and hearing, they will need to use communication strategies and skills they learnt as a deafened person (having to face the speaker, asking for repetition or rephrasing, reading lip patterns and expressions and so on). An implant makes a person more confident about talking and listening, and also more relaxed and tolerant of their own communication mistakes and errors. The person may start to initiate conversations again, with shop assistants, bus drivers or parents at the school gate.

The physical environment continues to play a large part in determining whether the implant user can follow a conversation or not. For instance in quiet well-lit surroundings, with carpets and curtains, the implant user may be able to communicate very well. However, in noisy places with poor lighting and bare floorboards, the same individual may struggle to keep up.

An implant provides the person with the ability to monitor their own voice articulation and volume. As a result they feel more self-confident about their speech and less hesitant about initiating a conversation.

Many people say their tinnitus becomes less intrusive after implantation. The relief that people feel is enormous, helping them to concentrate and communicate far more effectively. Now that they are spending less time coping with the stress of internal noises, they have higher energy levels and feel more relaxed.

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**2. Effects of APHL on family relationships**

Acquired profound hearing loss has an impact on everyone closely associated with the deafened person – partner, children, relatives and friends.

The whole family must make adjustments, and finding the right balance of independence and support is difficult. Some of the major stresses come from an
uncomprehending or even hostile family environment, not to mention the impact on family income.

The family often have to change their social and leisure activities and in some cases their entire lifestyle. The cinema, theatre and pubs are no longer accessible, and the deafened person or couple may prefer not to socialise. The partner may have to take on extra burdens — interpreting, making telephone calls, taking on extra family responsibilities. They may feel embarrassed in social situations or feel humiliated on the deafened person’s behalf.

Doing this over a long period of time takes its toll, and partners commonly experience poor mental health as a result (anxiety and depression). Children sometimes take on adult roles in mediating with the hearing world for their deafened parent. Or a child may take advantage of the parent’s inability to hear (pretending to have said something) or not bring friends home because they are embarrassed.

Being in a relationship with a deafened person is unlike living with someone with an acquired physical disability. An impairment of communication hinders the mutual expression of love and affection. It also strikes at the basis of relationship repair — the necessary process of discussion and negotiation around everyday affairs.

**Impact of a cochlear implant**

For many partners, a cochlear implant is a liberating experience. It significantly lessens the amount of time the partner needs to spend on interpreting, assisting, taking messages, holding telephone conversations on behalf of the deafened person and so on.

While the implant user grows in confidence and independence, the partner may have to take a step back. This will affect the delicate balance that exists between couples, and may take some time to reach a new equilibrium.

There is often a return to normal role relationships now that the support or involvement of the partner is not necessary. The person may start to build a new life - socialise with friends again, enjoy the cinema and theatre, or take up studying. An implant user is able to do much more now what they previously took for granted - chat to people at the toddlers group, listen out for the sound of the baby crying in another room, socialise with friends and colleagues, and so on.

Overall, an implant reduces family stress and tension, facilitates a return to normal role relationships and assists parent-child and spouse/spouse relationships.

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3. Effects of APHL on employment

The impact of acquired profound hearing loss on employment is extensive. People commonly experience problems holding down a job, many giving up work altogether, or working with severe limitations, and losing opportunities for promotion. When support is provided (such as STTR communication support for meetings, a text telephone), the picture is often one of grudging accommodation to the needs of the deafened person.
rather than positive action undertaken willingly to retain a valued employee. Discrimination, both overt and covert, is ever present.

Team meetings are often a problem since it is impossible for the deafened person to keep up with the rapid change of topic and speaker in a group. It is likely that work colleagues are not deaf aware, and do not make the effort to include the deafened person. Or they may try, but give up after a while because it is too much effort or time consuming. The deafened person is often excluded from office banter and social chit chat.

Using the telephone at work is another source of frustration and dissatisfaction. Since the voice telephone is not accessible to deafened people, they must use an operator service, called Typetalk, or the text telephone. Some deafened people themselves are unwilling to use these methods as they require time (conversations using Typetalk or the text telephone are about 60% longer than a spoken conversation) and effort, for both the deafened person and the person they are calling. In many work situations Typetalk and text calls just do not fit in. As a result, many deafened people rely on work colleagues to make telephone calls on their behalf, or do not make telephone calls at all.

**Impact of a cochlear implant**

*Having a cochlear implant markedly improves the users’ work life. They are able to communicate much more effectively with colleagues, and many will be able to use the voice telephone. The implant makes life easier for everyone.*

*M*eetings will still present problems. The major advantage the implant confers is that if the meeting is well chaired, the user will be able to follow the discussions with much greater ease than before. At work where accuracy or involvement in free-flowing discussions is necessary over several hours, communication support such as STTR will still be required.

*The ability to pick up the voice telephone and have a spoken conversation at work is a massive bonus for many implant users (as well as for family and social purposes). Some implant users are able to talk to anybody on the telephone. Others, however, say that the voice telephone is restricted only to family and friends with familiar voices, where it does not matter if there are misunderstandings. At work these people will continue to rely on Typetalk operator service or the text telephone.*

*It is important to manage people’s expectations in the workplace so that, for example, one’s employer and colleagues do not think the implant will cure all the communication difficulties that used to exist.*

4. Effects of APHL on attitudes of other people

Deafness still carries a strongly negative stigma in our society. There is a great deal of discrimination and prejudice towards people with a hearing loss, not necessarily overt or malicious, but subtle and implied. Examples include people being reluctant to change their communication behaviours, and finding ways of excluding and marginalising deafened people by deliberately avoiding them, cutting short any conversation and talking to their (hearing) partner instead.
Hearing people quickly become irritated when normal conversation does not flow smoothly, and can be patronising, even when the intention is intended to be supportive or complimentary. Deafened people often say it is acceptable in our society to laugh at deaf people even though such behaviour is considered offensive, insulting and entirely inappropriate with other disabilities.

Furthermore, deafened people who experience balance disorders may also bear the brunt of being thought of as old (decreased mobility, slower movements), or inebriated (staggering as if drunk).

**Impact of a cochlear implant**

An implant often changes peoples’ perception of deafness and of the deafened individual. This may be due to the fact that an implant can very often be seen, and its very visibility gives the deafened person a recognised mark that he or she has a disability (and is not just pretending to have a hearing loss or being rude).

Since the implant user now makes use of sound and hearing, the effort required by the other person to communicate is considerably lessened compared with what was required before the implant. In addition, rather than irritation or hostility, many other people show a polite curiosity in the new gadget, and their interest has a positive knock-on effect on communication – a willingness to make a bit more of an effort, and to be a little more patient if mistakes occur.

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**5. Effects of APHL on mental health and quality of life**

Becoming deafened in adult life is a severely life-challenging event with consequences not only for the deafened person, but also their partner and anyone else they live with.

In the acute stage, there is usually a period of shock and numbness. Confusion and bewilderment is often replaced by alternating depression, anxiety about the future, and a sense of hopelessness. The deafened person faces, especially at first, a complete inability to communicate with family, work colleagues and friends. This is coupled with a lack of knowledge or understanding from others. Deafened people often talk about feelings of imprisonment or being shut off from people and the world around them.

They also remark that losing their hearing is like a bereavement, and commonly they grieve for things they had always taken for granted: birds singing, children’s voices, intimate conversations in the dark, the reassurance and security of environmental sounds.

Self-esteem and self-confidence is always affected, and this adds to the experience of intense loneliness and social isolation. Deafened people frequently become reliant or dependent on their partners, and avoid social situations or new situations that require communicating with people. They can not face the humiliation of making mistakes and the embarrassment of communicating in a way that is different to most other people.

It is not surprising therefore that the rates of depression and anxiety for both the deafened person and their partner are far higher than the national average. Sometimes the symptoms of post traumatic stress disorder are present.
While deafness may not be ‘life threatening’ in the usual sense of the term, it is ‘lifestyle threatening’ and implies the need for huge adjustments.

**Impact of a cochlear implant**

For many people having an implant means they can get their life back on track again – as spouse, parent, friend, professional and so on.

People with implants generally feel more connected to their environment, now that they can hear birds singing, the doorbell and telephone ringing, doors closing and cars rushing past. They are more able to participate in everyday activities in unexceptional ways i.e. they do not have to constantly anticipate or second guess what people are saying to them, or ask for things to be repeated or written down so often. They feel less of a social burden since an implant reduces the isolating effects of deafness.

Whereas previously the person may have avoided social situations or relied on a partner, the implant user can carry on a conversation, or even initiate a conversation, confident that they will be able to follow the majority of what is said. Since other people do not have to work so hard to make themselves understood, the occasional (or less frequent) communication error is not such a problem. The reduction in social anxiety enhances a person’s sense of independence, confidence and self-esteem.

Having an implant can mean a chance to make up for time and opportunities lost because of deafness. People can rise to challenges they had once thought impossible - a relationship, parenthood, changing job, studying at University. Some resume their lives as they were, albeit in a slightly different way.

A cochlear implant confers many improvements in a person’s mental health and quality of life. There is a reduction in isolation and less anxiety about social situations. There is greater independence, confidence and trust in one’s own abilities. There is often renewed hope and a sense of optimism for the future.

**Conclusion**

Becoming deafened can be a catastrophic, alienating and terrifying life event. Deafened people cannot communicate in the way they used to, so the most basic conversation becomes a fraught experience. Couple and family relationships are inevitably affected, often resulting in separation, divorce and family breakdown. Friendships and social life can be severely curtailed. The inability to hear has a dramatic effect on every aspect of every day living.

An implant can make a huge difference to a person’s life, and the benefits will be experienced by all, including the implant user’s family, friends and work colleagues - even the shop assistant or dental receptionist. An implant will never restore hearing to normal, but it will reduce or lessen many of the difficulties deafened people face.
Having an implant restores sound and hearing so enhances communication per se. It also decreases fatigue and frustration levels, and restores energy and concentration. It improves the confidence someone has in their own communication ability, and allows the person to express themselves to the world in the way they wish, just as hearing people do.

Implants usually have an extremely positive impact on family and partner relationships, primarily because through the effect of releasing time previously spent supporting, interpreting or performing tasks on behalf of, or for, the person with the hearing loss. The implant user may feel more in touch with their family, and in turn, the family may feel less isolated from each other and other people.

Working life with an implant may be less stressful; employment opportunities and career paths may open up. Discrimination may decrease or cease altogether.

Looking after the implant is straightforward. People usually put it on when they get up in the morning, and take it off when undressing at night. The only other regular attention needed is to change batteries. There are regular tests to maintain or upgrade the technology, and users obtain immediate help from the hospital if problems arise. Sometimes the implant gets sweaty in the summer and causes chaffing, but apart from that there is no down-side to the implant. The side effects are negligible, apart from cost and the risks attached to surgery.

One implant user summed it up. “My implant has had a huge impact on my life. I still operate as a deafened person in a hearing world, rather than someone who now sees themselves as hearing. But it was not until I had the implant that I realised how many areas of my life I had slowly pruned away when I lost my hearing. My wife’s life had been cut back too. Now we have got back to doing most of what we did before – life is still different from when I could hear normally, but it is so much richer than it was before the implant.”
Case histories

Case history 1

A was 21 when she first noticed her hearing loss, and 28 when she became profoundly deafened. Here, she describes the effect of deafness and her implant on her role as mother of two young children.

I was already profoundly deafened when I fell pregnant with my first child. It was very scary when I started to get labour pains in hospital. I was on my own in the delivery room for long periods and the baby was starting to come. I was shouting for someone to come, and I didn't know if anyone had heard me.

I found it difficult to join the mums and baby groups because I was totally reliant on lipreading. And of course, the other mums were not deaf aware. I could not expect them to speak clearly, look at me, and look after their babies. So I stopped going and missed out on the support and sharing of information parents tend to get from these groups.

There were other problems too - not being able to hear my children's voices, not being able to rest myself because I couldn't hear the baby's waking cry, making telephone calls to the GP with a text telephone while holding two ill children. Once my son had got his fingers trapped in the video recorder, and was stuck for sometime before I found him – distressed with two squashed fingers.

The children were two and four when I had the implant. Suddenly I could hear them speak. I could understand their words without even having to lipread.

Initially, the implant gave all of us as a family more space and more flexibility. I didn't need to be in the same room as the children all the time so I could make sure they were safe. I could do two things at once - make the dinner for the children and chat to them at the same time. Conversation is more free-flowing with the implant and not as hard work.

My own voice improved with the implant so it is easier for the children to understand me. With the implant I have been able to help them to read. I never thought this would be possible, and this has brought me immense pleasure.

Now the children are getting older they do argue with each other, but I can hear if things are getting heated, even if I am in a different room. I am much more involved with their life now. I talk to the mums and dads at the school gates, and have joined the school PTA. I am much more relaxed about inviting the children's friends around for tea.

Case history 2

B lost all his hearing suddenly when he was 41, and was implanted five years later. Here he describes the impact on his working life, before, and with an implant.

Before I had the implant I worked for a bank. I changed roles many times ‘to accommodate’ my deteriorating level of hearing. Each time, the move was to a lesser
post which made me feel very negative and frustrated that I was not progressing as well as the others around me.

I relied heavily on colleagues, but I felt they only told me what I really needed to know and the rest they didn’t bother with as it was too much effort. Meetings were hopeless as I missed out nearly all that was said. If there was a mistake at work I always assumed it was me, and that I had got the wrong end of the stick.

I always declined work social invitations for a lunchtime drink or outings in the evenings. Often I was left out of small things - like the run to a shop. Someone in the office would shout they were going and people would say what they wanted. It wasn’t until the person came back with the bacon butties or whatever, that I realised I had missed out – again!

My work life is completely different now as I run my own business – and that, for the most part, is because of my cochlear implant.

I can use the voice telephone which is essential in my job. I make fewer mistakes when communicating with other people and this has had a big effect on my confidence levels. I can also relax enough to have a sense of humour and enjoy banter with colleagues and customers – I really missed this when I was deaf.

The implant has helped me regain my energy levels as I don’t feel drained from the constant stress and frustration of relying on lipreading and second guessing what people are going to say or have said.

The positive aspects of implantation for a deafened person cannot be underestimated. I have benefited in every areas of my life and continue to do so. I have a lot more energy and better concentration skills now than ever before, and I feel very positive and optimistic about the future.

Case history 3

C was 50 years old when she first noticed hearing problems. By the time she was 65 her hearing had deteriorated to nothing. She obtained an implant at the age of 72.

The effects on deafness on my life were profound. What could I do, where I could go, why had it happened to me? I felt angry and frustrated. I wasn't Deaf, I wasn't hard of hearing. I didn’t belong anywhere.

So, I learnt how to lie well and to keep my true feelings inside. I just smiled and bluffed my way through. I cried a lot. My loss of confidence and my progressive hearing loss always went hand in hand so by the time I became deafened I was at a very low ebb.

I lost all my independence and became completely reliant on my husband. He had to come shopping with me and talk to the shop assistants on my behalf. He had to make all my telephone calls to the dentist, optician and with friends and family. He had to interpret what people said to me. I even had to drag him to the GP so he could interpret what the doctor was saying to me. It was hard work for us both. I hated being
like this, and hated the effect my deafness was having on our lives and our relationship.

As a deafened person, I always had to face the person who was speaking to me, and get quite close to them. This used to upset people because they found it intimidating, an invasion of their personal space. I avoided groups like the plague, and I stopped using buses and trains as I couldn’t handle other people talking to me. I ignored strangers if they spoke to me, or said ‘I’m deaf’ and walked off quickly.

I was 72 years old when I obtained my cochlear implant and it changed my life.

I have regained my independence and now go out by myself. I can shop on my own and enjoy it. I can use the voice telephone to speak to my family and friends. My husband does not have to spend so much time looking after me. He can devote more time and energy to his work and to other things. Our relationship has changed, and it took a while for both of us to settle into a new way of doing things and being with each other (and with others).

With the implant I still need to look at a person’s face to lipread them, even though I can hear what is being said. I am not good with accents, people who mumble, fast talkers, and men who have beards that cover their lips. Noisy groups are still a problem, and I still bluff on odd occasions. But this does not make me feel embarrassed or humiliated as it used to. I now have the confidence to know that I will be able to follow what someone says, so I feel much more relaxed and easy about it. I’m sure people pick up on that.

People used to patronise me when I had no hearing, and treated me as if I was thick. They thought I was rude when I didn’t reply to them. They ignored me as it was hard work to talk to me. They raised their eyes when things had to be repeated. They talked to my husband instead of me. This has completely changed since my implant. I find now that people don’t talk down to me, or talk to my husband instead. They are interested in my cochlear implant and want to know what it is. In general people are more positive towards me.