



# **Living with Deafness**

Joyce Sutton O'Brien

## **Dedication**

In memory of Colin Kingsbury, with thanks for the encouragement he gave me for this project.

## **Foreword**

Joyce O'Brien, formerly Joyce Sutton, is a retired teacher of the deaf who worked all her professional life with profoundly deaf and partially hearing children and with hard of hearing adults.

Latterly she became Head of the largest post-16 service for the hearing-impaired in the state system outside London, which was based in Sheffield. The Service supported deaf students in Further and Higher Education and advised the lecturers involved. It also ran adult classes in lipreading and sign language and a course to train volunteers, afterwards assigned to the Audiology Department at the Royal Hallamshire Hospital, to help patients in their homes who were newly issued with hearing aids.

In 1989 she was awarded an Honorary Fellowship by Sheffield City Polytechnic (now Sheffield Hallam University) for her work in deaf education.

As a result of a talk to members of Bakewell U3A on "Living with Deafness", Colin Kingsbury, then chairman, asked Joyce to write this booklet.

# **1. Introduction**

This booklet is aimed at the partners, relatives and friends of deaf people but I hope that some parts of it will also be a help to deaf people themselves.

I use the word "deaf" rather than "hard of hearing", "partially deaf", "profoundly deaf" or "hearing impaired", to cover the whole problem. Also I usually refer to the deaf person as "he" rather than "he or she" or "s/he". Both are to avoid unnecessary repetition.

# **2. Introducing some misunderstandings**

When a survey was done in Sheffield some years ago it was found that 40% of all old-age pensioners had a hearing loss. There are a lot more people with a hearing loss, severe enough to be a problem, than there are people with a visual disability, yet charities for the blind receive far more money than charities for the deaf.

Why is this?

If you close your eyes, you cannot see but it is virtually impossible for a hearing person to make themselves deaf. So a deaf person does not receive much sympathy or understanding.

It is said that deafness is the least understood and the most misunderstood of human disabilities. My aim in this booklet is to help you to understand more about deafness, to clear up some of the misunderstandings and to suggest possible ways to overcome or partially overcome the problems.

Many of us from about the age of 40 may need glasses, at least for reading. Our eyesight deteriorates with age so why cannot we accept that our hearing is likely doing the same? If I am waiting for a bus and I cannot read the number on the front or the destination, I know that I need

glasses. However, if a person cannot hear what another is saying, it is so easy to blame the speaker. He or she must be mumbling!

"It isn't my fault, it's you. You're not speaking clearly!"

Or, if I'm going deaf, I might say, "Speak up, I can't hear you".

And when you speak up, I say, "All right, don't shout. I'm not deaf!"

So you think that I am being difficult but this is not really the case. When a person has a hearing loss, his ears can no longer adjust to a change in volume as can normal ears. One moment, a deaf person cannot hear you so you speak up. Then, immediately, the added volume is too loud. Very loud noise causes pain: hence the reaction. If a person has a hearing loss, noise will still become painful at 120 decibels as with hearing people, yet there is a smaller range of hearing left, so sound becomes painful much sooner for a deaf person.

There seems to be a stigma attached to being deaf. People do not laugh at a blind person; they usually go to help. Whereas a deaf person who makes what seem to be silly mistakes is often a figure of fun. It is no wonder that a person who no longer hears clearly is reluctant to admit that he has a problem.

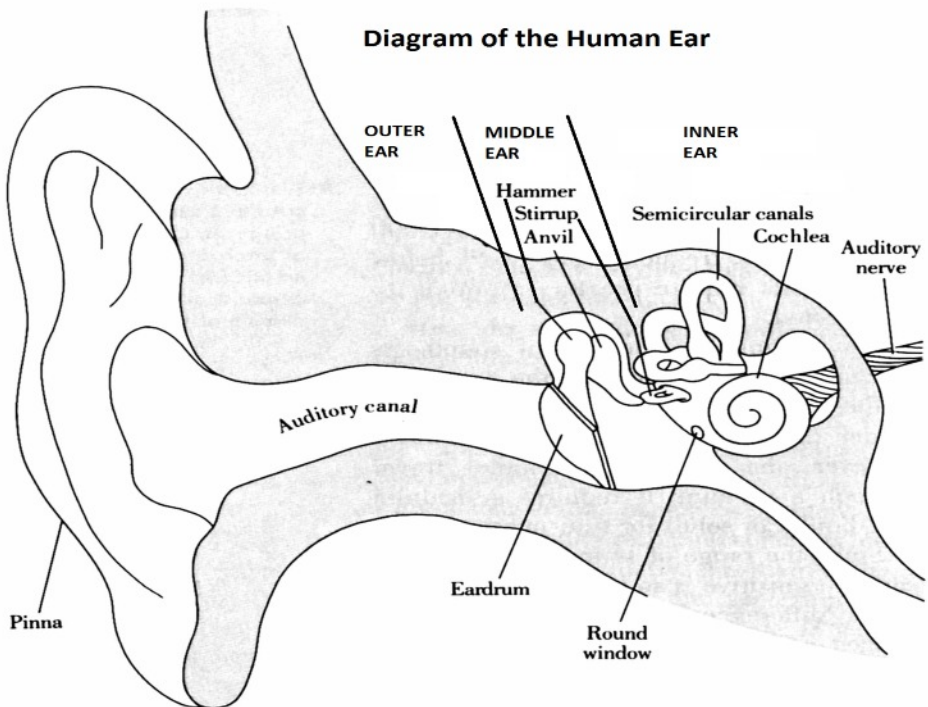
### **3. How we hear**

Now, what do I mean by deaf? Here is another misunderstanding. First let us look at how we hear. (This is a layman's explanation).

Sounds are carried on sound waves. They enter the outer ear, travel along the ear canal, knock on the eardrum, are transmitted to the small bones of the middle ear and then travel to the inner ear and to the cochlea. The cochlea is minute, shaped like a snail's shell and located right inside

the head near the brain. All along the cochlea are minute nerve fibres, each one picking up a different frequency of sound and transmitting it to the brain.

To understand speech you need to hear consonants. Each consonant in English has two frequency components, one high and one low, so two nerve fibres are involved. (Nasal consonants, m,n, ng have three). The nerve fibres that pick up high frequencies are situated on the outside of the cochlea and with age deterioration they are affected first. Therefore consonants become difficult to distinguish and the sounds that a deaf person hears may be completely different from those being spoken.



When giving a talk I like to demonstrate this by playing lists of 10 words each. They have been recorded at Manchester University through a machine that filters out bands of frequencies starting at the highest. The hearing people listening are asked to write down the words they think they hear and are amazed by the mistakes they make.

I should like to give you an example of a word that is *never* heard correctly. It is on List Three where the frequencies above 2000 Hz have been filtered out and listeners are not being made very deaf at all.

Most people score 8 out of 10 on this list but they never get this particular word right. It is "tie". Now the consonant "t" has a very high frequency component and without this you do not hear "t", you hear "k". This word fascinates me and I listen very carefully to the word while reading it again on my paper. The speaker definitely appears to be saying "kie". As there is no such word, the brain fills in with something it can recognize and most people write down "kite".

A silly mistake? Not really.

The majority think that deafness means that the person is not hearing sounds loudly enough. That is only part of the problem. There is also this difficulty with distortion.

### **An Audiogram or Graph of Hearing Loss**

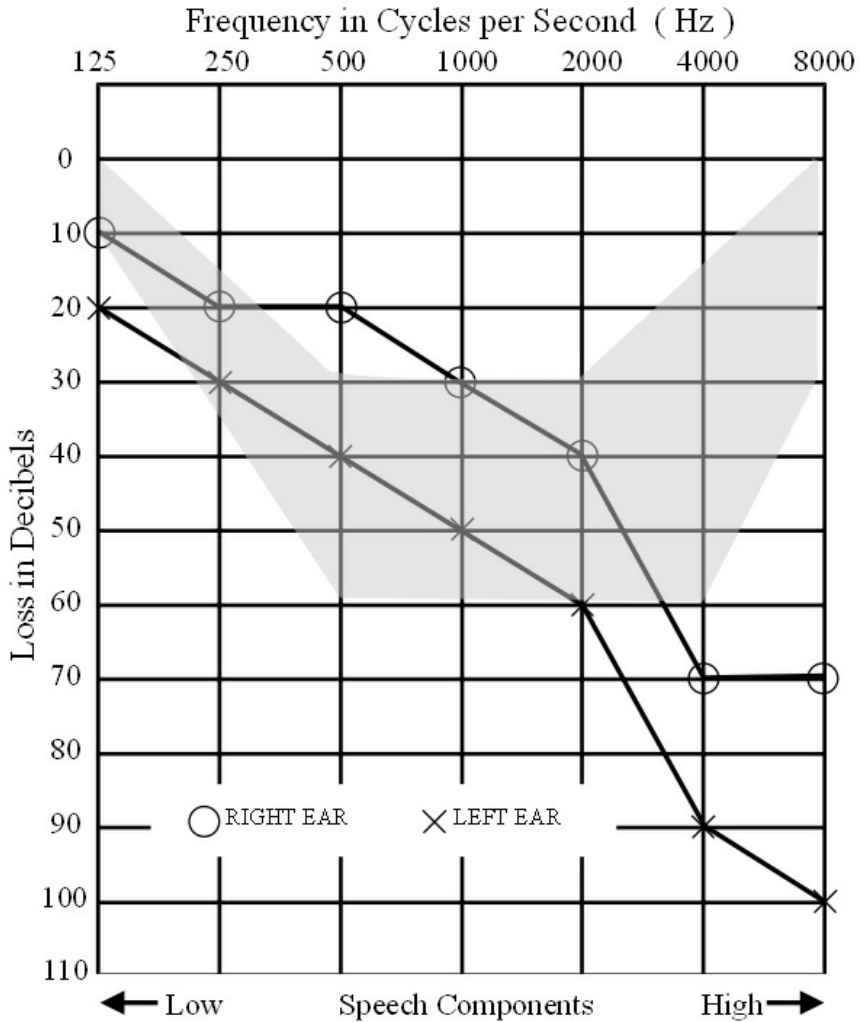
When a deaf person goes for a hearing test, the audiologist produces an audiogram or a graph showing that hearing loss.

A person with normal hearing will have an audiogram showing a loss of less than 20 decibels. Problems begin with a greater loss than this.

An audiogram shows the patient's threshold of hearing measured in decibels at a number of given frequencies. This threshold has to fall within the shaded area in order

for the patient to receive the pattern of speech correctly. A hearing aid therefore needs to amplify sounds effectively to bring all the components of speech within this "speech area". This may not be possible, remembering that most speech sounds have more than one component at different frequencies.

**A typical audiogram for a person with nerve deafness**



Presbycusis or the deafness of old age, sometimes referred to as nerve deafness, will most likely continue to get worse. Loud noise is a factor that can trigger the problem at a younger age either from industry, explosions or very loud music. It is sensible to wear ear protection in these conditions. For older people this graph usually drops down in the high frequencies. As well as not hearing sounds loudly enough, they receive distorted messages so often make what seem to be silly mistakes. Deafness is so often linked with stupidity. No wonder when people become deaf they lose their self confidence.

Some deaf people take over conversations which saves them the embarrassment of trying to understand others. Similarly some deaf people shout when they speak because they do not realise how loud they are. The way to help them is not to say "sh!, be quiet!", and look annoyed but be positive and explain to them calmly in private that they often shout, suggest that they try to speak more quietly and that you will tell them when they are getting it *right*. If at first they look to you for confirmation, a smile, a nod and a small thumbs up sign is all that is required. Gradually they will learn to monitor the volume for themselves and will no longer need your help.

## **4. Using hearing aids**

In the last few years there has been a tremendous improvement in hearing aid technology with the advent of digital aids. The older or analogue aids amplify all sounds including background noise and many people are still having to use them because of the long waiting lists for digital ones.

It is very difficult for a person to manage in noisy surroundings, such as in a pub or at a coffee morning, wearing an analogue aid. In a quiet room he will hear much more easily so will *try* to listen to conversation.



However he knows from bitter experience that he will not hear in noisy surroundings so it is a waste of time to make the effort to listen. This leads to the comment from friends who do not understand,

"He can, hear if he wants to!"

This is not true. He may always want to, but from experience knows that some situations are impossible.

In contrast, digital hearing aids can identify patterns of continuous noise in lower frequency bands and cut these out leaving clearer voice signals. The very latest digital aids also have directional microphones that not only channel the sounds of the person you are facing directly but also pick up the frequencies of the predominant voice in a conversation and filter these out.

Unfortunately many deaf people are routinely waiting one or two years or more to receive digital aids on the NHS. These aids cost thousands of pounds and some elderly people, not having the time to wait, are using their savings to buy them privately, while many others on low incomes have no choice but to keep waiting and to continue to use the analogue aids. I must emphasise that they can still be a great help in one-to-one conversation and in quiet situations. The main aim of using any hearing aid is to assist in hearing speech.

Whichever type is used it is always better to wear two hearing aids rather than one, as this balances the sound and you know better the direction from where it is coming.

If a person is not appearing to benefit from a hearing aid, do not accept the situation but return to the provider and insist on help. I have been told by several deaf friends that the digital aid sometimes seems over enthusiastic and cuts out the voice they are trying to hear as well as the background noise! These cases have been helped by the provider and even a change of aid has been arranged. I must emphasise that any hearing aid can only amplify the sound that the wearer can receive. If a nerve fibre on the cochlea is severely damaged, the sound linked to it cannot be amplified. Listening with a hearing aid is

not the same as it was listening with normal hearing and at first a deaf person may be disappointed. He must be encouraged to persevere and wear the aid, perhaps for a longer time each day, until he gets used to it. He will gradually find it easier to manage and usually a great help.

Please try to understand the difficulties that a deaf person is coping with and be as encouraging and helpful as possible. If you are in the unfortunate position of waiting a long time for a digital aid, I suggest you write to your MP. Unfortunately it is due to the limited funding provided to the NHS and the provision varies between different health trusts and the priorities they choose.

## 5. Lipreading

Even if a deaf person has good hearing aids, it is sensible to consider learning to lipread. Hearing may deteriorate further over time so the sooner a deaf person starts to learn while some hearing remains the better.

Lipreading is not easy: it is estimated that lipreading is only 30% knowledge, which you can get from going to a lipreading class, and 70% guesswork. A person with good language skills who is fairly extrovert may find it easier than some others.

I must emphasise that some sounds look the same and other are invisible; I will explain more about these later. I must also stress that the deaf person's ability to lipread depends largely *on the speaker*. So, if you are speaking to a deaf person who is trying to lipread you:

- don't speak too quickly
- keep your head still so your mouth is not moving up and down

- don't cover your mouth with hands, cigarettes, pencils, pipes, whatever - or a long moustache or bushy beard
- try to speak clearly and don't over-exaggerate words
- try to keep the normal rhythm of speech
- put the light on in the room sooner than you might otherwise do
- you need good light on the mouth and face, so don't stand or sit with your back to the window as your mouth is then in shadow - although you may have a halo of light!
- try to avoid using single words. Some words with entirely different meanings look identical on the lips. Words always need to be put into the context of a sentence.
- don't keep repeating the same thing if he does not understand. Change the words or add other clues. For example "Have you seen John lately?".  
No response.  
Change to: "You know, your brother John. He lives in Rotherham. Have you seen him this week?"
- help with gestures, pointing and visual clues. But be careful not to distract with the wrong visual clue. For example, the hearing husband comes into the room holding a mobile phone. On his feet he is wearing socks and slippers. He asks his deaf wife,  
"Where are my clean socks?"  
No response.  
She is thinking he is talking about the mobile phone. It is better to come into the room, not holding anything, with bare feet and point at them and ask, "Where are my clean socks?"
- remember he will also be face-reading to help his lipreading, so if you are pleased about something, don't

offer a deadpan face - look pleased: For example, "What a lovely dinner you made!"

Or, if you are annoyed, look annoyed. For example, "You've put mud all over my clean floor!" - and point. Remember what I said about gestures and visual clues.

- never say, "Oh, never mind. It doesn't matter". If it didn't matter, why were you telling him in the first place? It is very important that you give him the impression that you want to communicate and that it does matter to you and to him.
- don't wear clothes with stripes or spots on the top half. It dazzles and puts the lipreader off.
- never shout. It doesn't help.

Earlier I mentioned face-reading. It is said that deafness is a disability that makes other people feel disabled. Let me explain. You are trying to tell something to a deaf person. He does not understand you so you try again, but he still does not understand. You are now feeling frustrated and resentful because he is making you feel disabled as well. You must not feel guilty about feeling resentful as that is the normal reaction. The strange thing about deafness is that you feel resentment towards the person whereas you should feel resentment towards the deafness. Your feelings are showing on your face. He reads your expression and gets more tense so is even less likely to be able to lipread you. It is very important, though very difficult, to try not to let your frustration show. Try to keep calm, take a deep breath and explain again in a different way.

As I said at the start of this section, lipreading is very, very difficult. Your deaf person needs every possible help, encouragement and understanding but also, if you are trying your best to help, he needs to understand how difficult this communication is for you and you are learning too. If you can sometimes laugh together about it all, it will help you both to relax. After all you are in this together!

## 6. Learning to lipread

As a teacher of lipreading I found it useful to explain to the class the shape of the mouth for each consonant on first meeting it and then to give masses of practice in sentences.

You might like to try these consonants, looking in the mirror. Try not to exaggerate

**p, b** and **m** look the same. The lips meet and part.

**f** and **v** look the same. The upper teeth meet the lower lip and then part.

**sh, ch, j** and soft **g** all look the same. The lips are pushed forward.

**s, soft c** and **z** all look the same. The lips are slightly apart and stretched sideways.

**t, d** and **n** all look the same. The tip of the tongue touches the back of the front teeth. This is difficult to see.

**th** - The tongue just shows between the teeth.

**l** - The tongue flashes behind the teeth. It should not protrude .

**w** - Lips are puckered almost as for a whistle and it is fairly easy to recognize. It is used in most initial question words e.g. when, where, why, what, which - so the lip reader needs to fasten on to it quickly to get the right meaning of the question.

**r** - Lips come together and are pushed forwards.

**y** - Teeth meet, lips push forward and then the mouth opens. It is hard to describe but fairly easy to recognize.

**k, hard c, hard g** and **ng** are all invisible as they are formed further back in the mouth.

**h** is also invisible and takes the shape of the vowel that follows it.

I will now give you a few examples of these consonants, in words that look alike in sentences. Each of you could try them in a mirror and then try them on each other. Remember not to exaggerate and try to keep the normal rhythm of speech.

**b**, **p** and **m** look the same. Compare **ban**, **pan** and **man**.

There is a **ban** on smoking in public places.  
Put the vegetables in the **pan**.  
The old **man** walks very slowly.

**f** and **v** look the same. Compare **fail** with **veil**.

The boy did not want to **fail** the examination  
The bride wore a **veil** over her face.

**sh**, **ch** and **j** all look the same. Compare **shops**, **chops** and **jobs**.

Mother went to the **shops** for some bread.  
She bought some **chops** for dinner.  
The boy had a lot of **jobs** after he left school.

**s** and **z** look the same. Compare **Sue** with **zoo**.

My best friend is called **Sue**.  
We saw an elephant at the **zoo**.

Let us now look at the invisible consonants:

**k**, hard **c** and hard **g** look the same. For interest, let us compare the final **k**, which is invisible with a final **th** which is not: **pack** with **path** (northern pronunciation).

Please **pack** your clothes carefully.  
Please walk on the **path**, not on the grass.

**h** is also invisible. Compare **Harwich** with **carriage** and **garage**.

They boarded the ferry at **Harwich**.  
The seat in the railway **carriage** was damaged.  
The **garage** gave me a car while they repaired mine.

Note that the choice of words for the speaker is important. For example "boarded the ferry" is easier than "caught the ferry".

Also using "railway carriage" and not just "carriage" gives a valuable clue. Trying to think of adjusting your words like this is a challenge but improves with practice! As I said before, doing this together will help you both and can be quite enjoyable.

Here are some pairs of words with totally different meanings that look the same. This illustrates again how easy it is to make what seem to be silly mistakes. They must be put in the context of the sentence.

fashionable	vegetable
fishes	vicious
church	judge
shyness	Chinese
baby	paper

The two of you could try these words in sentences and think of some other pairs. You could make it into a game! Remember, speaker, to try to follow all those rules I gave you!

These are just a few examples but I think they will give you some idea of how difficult lipreading is and how tiring it must be for a deaf person who is relying on it.

It is a very good idea to encourage a deaf person to join a lipreading class. This is usually a happy, friendly place with a patient teacher who understands the problems. It is also helpful to meet other people in the same situation and it will boost self confidence. There should be a number of classes locally at different levels so contact your local authority for information.

## **7. A further need for understanding**

Losing your hearing later in life exaggerates all the problems of old age. Along with a loss of confidence, a deaf person may withdraw from company and become lonely and isolated. He feels very insecure and all this may lead to becoming depressed.

Going deaf can be a particular problem for a man especially if he has always been in charge. If the husband goes deaf, the wife is having to take over much more and manage situations for him. This is quite an affront to his manhood and may lead to dissension between you. Try to realise this and devise ways whereby he can still be in charge as much as possible.

It is essential that you do not take over and speak and answer for the deaf person. Never follow the "Does he take sugar?" syndrome. If somebody asks you a question like this, politely refuse to answer. Say, "I don't know. Ask him yourself". And with a smile, indicate your husband. This is most important and well worth trying to do. Encourage and allow him to speak for himself, if you can, wherever possible. And this applies from hearing husbands to deaf wives as well! The more a companion of a deaf person understands about these difficulties, the easier it will be for them both.

## **8. Some suggestions for deaf people**

Finally I should like to offer some ideas which may help deaf people themselves.

- It is a good habit to carry a small notebook and pen in your pocket or handbag. Then, if you cannot communicate with someone, for example if you need to ask your way or book a train journey at the ticket office or you just find communication with this particular person impossible, you can write down the odd word and



offer the notebook to the other person to write their reply.

- It's important to find out who your real friends are. Unhappily you may find that some people you thought of as friends may now be avoiding you. Try not to worry about this. Concentrate on your real friends. Casual acquaintances and small talk is not easy; you need understanding friends and don't be afraid to explain to them how best they can help you.
- Don't be afraid to tell any new people you meet that you are deaf. Don't try to hide it. They may then be more helpful. It is nothing to be ashamed of. It is not your fault.
- If you don't understand what a person is asking you, say so and ask them to say it again. Don't just agree or say "Yes", thinking this will make things easier, as you never know what you might have let yourself in for!
- In a public meeting, when using a loop system during a question and answer session, there is a potential problem for deaf people because they may not hear the question from the floor. Before the meeting starts, it is a good idea to approach the chair and ask if the speaker will repeat the question into the microphone before answering it. This procedure is likely to help others as well as the deaf person.
- Look for a constructive way to spend some of your leisure time which does not involve much talking and trying to listen and understand. A hobby involving your hands is more restful, such as sewing, knitting, crochet, flower arranging, gardening, car maintenance and DIY. Also there is walking, driving in the country, reading and listening to orchestral or other music. Some of my profoundly deaf friends enjoy music. As one says, "It is different from before, as there is a preponderance of low notes, but still enjoyable!" Try it.
- Deaf people should be encouraged to move outside themselves, not to lose themselves in self-pity but to try

to help others if at all possible. Some deaf people I know have been willing to give talks to local groups or the church explaining the problems that deaf people have and how they can be helped. One of my old pupils, who won the National Lipreading Competition, had done some public speaking before going totally deaf from meningitis. She decided, with a change of theme, to carry on and talked very successfully to many organisations about the problems of being deaf.

- Lastly I should like to emphasise that it is most important for a deaf person to face the problem and not try to hide it. It won't go away. It may get worse. So trying to accept your deafness rather than being bitter about it, using your strength and energy to be positive about your life, rather than negative, is more likely to lead to overcoming the disability and living a happy and fulfilled life in spite of it.

## **9. Useful contacts**

### ***National***

#### **Action on Hearing Loss (former know as RNID)**

19-23 Featherstone Street, London. EC1Y 8SL Telephone:

020 7296 8264

Textphone: 020 7296 8246

Fax: 02072968129

"Action on Hearing Loss provide quality equipment at affordable prices to improve the lives of the UK's 9 million deaf and hard of hearing people".

It is possible to get doorbells, alarm and travel clocks, baby and smoke alarms and various aids to the telephone, usually with flashing lights or vibrators. There are also aids to help a deaf person listen to the television, radio or hi-fi without the other people in the room having to suffer from the very loud volume.

There are other aids and it is worth contacting Action on Hearing Loss for information.

## ***Local*** **Lipreading classes**

There are a number of classes at different levels provided by most local authorities. It is important to start in a beginners class at the start of a course. Classes usually start in September, January or after Easter.

I suggest you telephone your local authority. Ask for lipreading classes to get up-to-date information on local classes available at the time of asking.

